TO WHAT EXTENT SHOULD THE PUBLIC BE INVOLVED IN HEALTH DISINVESTMENT DECISION MAKING: A MIXED METHODS INVESTIGATION INTO THE VIEWS OF HEALTH PROFESSIONALS IN THE ENGLISH NHS

by

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Abstract

Demand for health services is growing, but funding is often failing to keep pace. To ensure that budgets are balanced and that delivered services continue to be high quality, decision makers are having to set priorities, removing funding from some services- this is disinvestment.

This thesis details research incorporating a literature review followed by a two stage empirical investigation into the way that disinvestment decisions are made and whether or not the public should be involved. The first stage is a Q-Methodology study, the second is in-depth interviews. The population for the study is NHS health professionals (including managers and clinicians). 55 participants took part in the Q-study, and of these, 20 took part in follow-up interviews.

The study highlighted three distinct perspectives, all of which supported public involvement. One was unequivocal in its support, another highlighted some potential disadvantages to involving the public and the third suggested that the public should have the freedom to choose whether they became involved. The follow up interviews re-iterated participants' support for involvement but suggested that the public should become involved earlier and to a greater extent in those disinvestment decisions which affected more patients and/or resulted in a tangible loss of services.

<u>Preface</u>

This thesis is original, unpublished, independent work by the author, T. A. Daniels. All of the research presented was conducted by the author at the Health Services Management Centre, University of Birmingham and was written up there and at the School of Population and Public Health, University of British Columbia. Full ethical approval for this project was granted by the University of Birmingham Humanities and Social Sciences Ethical Review Committee on 15th October 2012 (application number: ERN_12 -0873). The parameters of the study were approved by the University of British Columbia Research Ethics Board on 15th November 2013 (certificate number: H13-02827).

Table of Contents

List of Tables

List of Figures

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The NHS would be nothing without its talented and committed staff. During the course of this research I had the pleasure of interacting with a small proportion of this group and I would like to thank each and every participant for giving up their time freely and for participating so whole-heartedly in the study. I would also like to thank the members of the public who gave up their time to take part in the early stages of the research.

Lastly I would like to thank my family and friends for their encouragement over

the last three years, and for maintaining faith that I would get the thesis finished even when I wasn't convinced myself! In particular I would like to thank my partner Lindsey for embarking on this adventure with me and believing in me and my research. I would also like to thank Lindsey's parents, Sue and Paul, for their generosity in putting up with me and providing a roof, an office and catering whilst I was writing up.

<u>Dedication</u>

For Lindsey, thank you for all of your encouragement, support and love

<div align="center">**Chapter 1 - Introduction**</div>

1.1 Introduction

This chapter sets the context within which the research into public involvement in health disinvestment decision making detailed in the rest of the thesis was planned and carried out. It gives a brief introduction to the current state of global health funding, then pays specific attention to the situation within the English National Health Service (NHS), detailing its historical development and recent financial problems in order to explain why it was an ideal setting within which to base the research. In addition to setting the research context at the outset of the data collection, the chapter also gives updates as to how the context changed over the course of the project and how the relevance of the research and its findings have increased since the project commenced. The introductory chapter concludes by defining a number of key terms used throughout the study and setting the parameters of the research before briefly introducing the contents of the rest of the thesis and providing an overview of the following nine chapters.

1.2 The Global Health Context

According to the United Nations (2012) the global population grew by almost 4.5bn between 1950 and 2010, almost tripling in size to reach the 7bn level. This increase in population is in large part due to improvements and advances in health care and public health which have seen average life expectancy across the world increase from 48 years in 1955 up to 70 years in 2012 (World Health Organization, 1998, 2012a). Indeed the global population has aged to such an extent that by 2025

it is predicted that over-65s will make up 10% of the total population, with the proportion of these older people requiring support from working age adults predicted to rise to 17.2% in 2025 from 10.5% in 1955 (World Health Organization, 1998).

Where previously the majority of people died from conditions such as pneumonia, influenza or gastric infections, those in the developed world are now much more likely to die from heart disease or cancer (Jones et al., 2012). These are conditions which can be treated and managed, if not cured, and where, in the past, patients may have died a painful but relatively quick death from an infectious condition, they are now able to live with these long-term conditions for extended periods. Across the developed world, those patients living with multiple co-morbidities are becoming 'the norm rather than the exception' (Department of Health, 2014, p.3).

Similarly, as the developed world has become wealthier there has been a marked increase in 'lifestyle' conditions or 'diseases of affluence' such as Type 2 Diabetes, Asthma, Coronary Heart Disease and Peripheral Vascular Disease (Ezzati *et al.*, 2005). Whilst taking millions of people out of poverty, seeing deaths through nutritional deficiencies, perinatal and maternal conditions, respiratory infections and infectious and parasitic diseases all but wiped out in the West (Stevens, 2004), this increase in wealth has given them increased access to alcohol, tobacco and richer processed foods and precipitated a dramatic rise in preventable, costly long-term conditions.

As conditions affecting populations have developed, so have the technologies available to treat these conditions- diseases such as cancer, for instance, can now be contained and beaten with the right course of treatment, and survival rates have improved greatly in recent years (Jemal et al., 2008). These technologies have not come cheaply, however, and this, in addition to the rapidly expanding population, is another key factor in the rising cost of delivering health care in the 21st century (Barbash and Glied, 2010). With the availability of new treatments capable of diagnosing conditions more quickly and accurately, and the availability of state of the art drugs able to treat previously incurable conditions, patients' expectations of the treatments available, and of clinicians, have risen sharply. It is reported that this has also increased costs (Sabbatini et al., 2014) as clinicians potentially try to meet these increased demands by over-prescribing or continuing to allow patients access to unproven or unnecessary treatments (Campbell et al., 2007).

In addition, health spending is being driven up by a global shortage of qualified staff. With highly qualified professionals in such short supply, health care providers have been forced to offer increasing wages in order to be able to meet patient demands, and staff have increasingly been drawn to wealthier countries (Kuehn, 2007). To further understand the current global health funding position, in 2012 the World Health Organisation estimated that global spending on health was worth $6.5trn (World Health Organization, 2012b). A recent report by Deloitte (2014) suggested that spending over the period 2014-2017 could rise by 5.6% per year; this would see global health spending topping $8trn per year by the end of

the decade.

Whilst a significant proportion of this health care inflation is due to spending in the US (estimated to be around $9000 per capita per year (World Bank, 2014)), the rest of the world has not been immune from rising prices. Regardless of health system organisation and public/ private funding and delivery models, many health economies across the globe have been squeezed by a combination of rising demand and health inflation, and have been forced into taking tough decisions regarding provision.

These decisions have entailed the setting of priorities and deciding how and where limited resources should be used. According to many health economists and commentators, an unavoidable aspect of this process of prioritisation is disinvestment (Mitton and Donaldson, 2004b). Disinvestment is a contested term, but within this study it refers to the act of removing funding from services, treatments and technologies, affecting their accessibility to patients. Within the literature different authors highlight different drivers for disinvestment, with some suggesting that it can be used to optimise service quality (Elshaug *et al.*, 2007) and others foregrounding the need to disinvest in order to balance budgets and invest in alternative services (Donaldson *et al.*, 2010b). Disinvestment decisions taken for both of these purposes are incorporated into this thesis, although the global economic climate dictated that financial drivers for disinvestment took precedence in the eyes of the majority of respondents.

Whilst it is recognised that some academics dispute the need for disinvestment on the grounds that further funding could be assigned to health services by governments, and that projections of the effects of population aging and health inflation could be overstated (Russell and Greenhalgh, 2012), the assumption that disinvestment is unavoidable is a premise of the study. Throughout this thesis disinvestment is defined as the removal of funding from services, treatments and technologies, affecting their accessibility to patients.

The thesis is written from a normative standpoint, whereby the researcher has an underlying view on how disinvestment decision making should be carried out and the principles that should guide this (Olsen and Richardson, 2013). The researcher takes the view that an explicit approach to the making of priority setting and disinvestment decisions is the most equitable, although it is recognised that this approach is not always taken in practice. One system faced with disinvestment decisions is the English National Health Service (NHS), within which the research reported in this thesis was carried out.

1.3 The National Health Service

The English NHS was founded in 1948 with the purpose of providing medical care which was free at the point of delivery and accessible to all regardless of their ability to pay[1]. Pulling together hospital care, primary care, mental health and a whole range of community services under one umbrella for the first time, the NHS

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[1] Similar 'NHS' structures with similar principles exist in Scotland, Wales and Northern Ireland but they are all administered separately. This research focuses solely on the NHS in England. Where the term 'NHS' is used in this thesis it refers to the English NHS unless otherwise stated.

revolutionised the lives of millions of Britons providing care from cradle to grave (Warden, 1995). Although having altered slightly over the intervening 65+ years (e.g. introducing prescription charges and charges for dental treatment in 1952) the founding principles of the NHS remain in place to this day and it is still funded through general taxation.

Once described by Lord Lawson, the former Chancellor of the Exchequer, as 'the closest thing the English have to a religion'(Brown, 2012, p.256), the NHS holds a unique place in the hearts of many of the country's citizens. As a result of this, and the fact that, as a publicly run and funded service, it had come to be seen as politician led (Klein, 2007), the National Health Service has become increasingly politicised and has become a key battleground over which elections are fought (Webster, 2002). Given this, the NHS has come to attract substantial media attention with decisions around funding, funding gaps and the use of public money coming under particular scrutiny (Dixon and Harrison, 1997). The design of decision-making processes therefore holds particular significance, and this seems only likely to increase in the future.

1.4 Historical NHS Finances

When it was first founded the NHS was overwhelmed by unmet need as a generation of people who had lived through two World Wars came to recognise the difference that the new health service could make to their lives (Digby, 1998). Many people had lived and worked in poor conditions for years and had never previously been able to afford to seek treatment. Within a matter of years the NHS

was beginning to cost significantly more than its founder Nye Bevan or Prime Minister Clement Atlee's government had originally bargained for.

By 1960 the UK was spending 3.9% of its GDP on health care and this proportion has only grown since, with 9.3% of the nation's wealth committed to health spending in 2012 (OECD, 2014). Whilst this rise is substantial, it is less steep than the rises in a number of other countries, indeed of the 11 OECD countries with health spending figures published for 1960 and 2012 it is the smallest increase. France, for instance increased their proportion of health spending from 3.8% to 11.6% during that period, Canada went from 5.4% to 10.9% and Switzerland from 4.9% to 11.4% (OECD, 2014). The UK government has certainly committed significant sums to the English NHS- in 2014/15 the NHS budget had reached £133bn (Campbell, 2014) - but given the increases elsewhere, the argument that the government could and should be willing to commit more funds does bear some consideration (Appleby, 2013).

1.5 NHS (Re) Organisation

The way in which health services are organised in England has changed markedly since the formation of the NHS; one of the most fundamental changes was the formation of the internal market in 1991. Described by Le Grand (1999, p.28) as a 'massive social experiment', this reform separated out the purchaser and provider roles within the NHS and, instead of continuing to provide hospitals and other health care providers with block funding contracts, encouraged them to compete for work in order to secure funding. Under the new system purchasers, or

commissioners, were charged with contracting providers to deliver the most cost-effective care for their local population (Rosen and Mays, 1998); it was hoped that competition between providers would improve quality and efficiency.

The purchaser/ provider split remains in place today and, as is described within the methods chapter, representatives from both sides of the divide took part in this research. Despite the retention of the internal market, much has changed in the NHS since Prime Minister Margaret Thatcher's reforms and, in 2012, the NHS in England underwent what has been described as its biggest re-organisation to date (Jowit, 2012) when the 'Health and Social Care Act' (Health and Social Care Act, 2012) was passed. The passing of this act handed responsibility for commissioning (and de-commissioning) services over to groups of General Practitioners known as Clinical Commissioning Groups (CCGs); this responsibility had previously been held by Primary Care Trusts (PCTs). The act also encouraged greater involvement of the private sector within health care provision in England by requiring that more services be put out to tender, and attempted to remove layers of bureaucracy by disbanding Strategic Health Authorities who had previously acted to broker deals between commissioners and providers within the English regions.

The timing of this act is significant as far as the research is concerned because many of the changes were being enacted at the time that the empirical data collection was carried out, and all of the participants will have been affected in one way or another by the Health and Social Care Act. Some participants may have been given additional commissioning responsibility as a result of the act, some

may have lost a previous job or moved organisation as a result of it, and some may have been forced to compete with a wider range of private sector competitors following the act's ascension. Although the research does not seek to draw any conclusions about the rationale behind the Health and Social Care Act, or whether or not it has achieved its objectives, its potential impact on the participants and their views should be borne in mind, particularly given the qualitative nature of the research.

1.6 <u>Current NHS Finances</u>

The UK, like much of the rest of the developed world, suffered a severe recession beginning in 2008 and extending well into 2009 (Frankel and Saravelos, 2012). In attempting to stabilise the economy the UK government of the time invested £100bn's into the banking sector, reduced Value Added Tax to stimulate demand, and embarked on a programme of quantitative easing. Whilst averting the possibility of a catastrophic banking collapse, the government's actions did leave the country with a significant national debt (Ping Chan and Oliver, 2013); the Conservative/ Liberal Democrat coalition government formed in May 2010 have been attempting to reduce this through public spending cuts ever since.

One of the aims of the Health and Social Care Act (2012) was to reduce management costs within the NHS. Although the NHS budget had been protected by the government from the spending cuts that affected many other departments (Hunter, 2010) the small annual increases that it was granted were not sufficient to meet the increasing demand. Health Secretary Andrew Lansley's reorganisation

was seen as one possible way to make savings, as was the efficiency drive launched by then NHS Chief Executive Sir David Nicholson in May 2009. The 'Nicholson Challenge' asked NHS organisations to release £15bn to £20bn of efficiency savings between 2011 and 2014 (Hawkes, 2012); both this and Lansley's mission to reduce bureaucracy were fresh in the minds of participants when data collection began in early 2013.

Sir David Nicholson's challenge was made to NHS organisations before the general election of 2010, and without full knowledge of what the future health funding settlement would be, but it set the tone for austerity within the NHS and began to detail how cold the climate could become (Appleby et al., 2009). Following the general election the coalition settled on NHS funding which amounted to a real terms increase of around 0.1% per year[2] to 2015/16; during that time demand is expected to have risen by between 3% and 6% per year (Appleby et al., 2014).

A recent report by current NHS Chief Executive Simon Stevens entitled the 'Five Year Forward View' (2014) challenged NHS organisations to work more collaboratively to deliver care and challenged the public to take more responsibility for their own health. The report set a demanding target for the NHS to deliver £22bn of recurring efficiency savings by 2020/21 and challenged a future government to deliver a further £8bn of annual funding in addition to this. It

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[2] higher than anticipated inflation in 2010/11 actually resulted in a real terms fall in health spending in that year

is difficult to say how close to meeting the 'Nicholson Challenge' the NHS came (evidence suggests that it was not delivered in full (Torjesen, 2012)) but, regardless of this, Simon Stevens latest offering suggests that it is still facing a £30bn a year shortfall. Stevens' report (2014) serves as a further indication of the timeliness of this research into disinvestment decision making in the NHS.

1.7 <u>Disinvestment in the NHS</u>

The Stevens report makes a clear call for the integration of services, with, where appropriate, hospitals being encouraged to offer GP services and GPs being encouraged to provide hospital services in the community. There is also a call for NHS organisations to seek to share back office and management functions as well as a suggestion that the traditional barriers between health and social care should be broken down. The report (2014) stops short of suggesting that large scale disinvestment could be required to close the funding gap but, in order for the proposed re-organisations and integration to come close to bridging the £22bn gap (around 16.5% of the current NHS budget) it seems inevitable that some disinvestment will be needed (Harrison, 2014). As Donaldson et al. (2010b) suggested in the wake of the 'Nicholson Challenge', traditional approaches to efficiency such as lean thinking and quality improvement initiatives will not deliver the desired levels of savings. In order to deliver savings on the scale outlined by Stevens some level of disinvestment must be carried out. What is of interest in this thesis is the way in which these disinvestment decisions are taken and, in particular the extent to which the public could, or should, be involved.

As was suggested earlier, the Health and Social Care Act (2012) precipitated some of the biggest changes to health care purchasing and provision since the formation of the NHS but the more recent Care Act (Care Act, 2014) is arguably more relevant to the context of this research. The general purpose of the Care Act was to set out roles and responsibilities relating to social care in England but one late addition (clause 119) made by Health Secretary Jeremy Hunt and Health Minister Earl Howe has particular significance in the debate around public involvement in disinvestment decision making.

The amendment made by Mr Hunt and Earl Howe sought to extend the powers of the 'Trust Special Administrator' (TSA). A TSA is an individual appointed by the Secretary of State or 'Monitor' to take over the day to day running of Trusts or Foundation Trusts which are deemed to be financially unsustainable in their current form, or are deemed to be at serious risk of failing to provide high quality services (UK Government, 2013). In returning organisations to financial balance and/or improving the quality of services the TSA's role must, by definition, include some elements of disinvestment.

Clause 119 aimed to extend the TSA's remit beyond the trust within which they had been appointed so as to give them powers to re-configure services across a health economy, potentially making disinvestment decisions incorporating neighbouring organisations which are delivering high quality, sustainable services (O'Dowd, 2014). Crucially the clause aimed to make it possible for the TSA to take these decisions at just 40 days' notice with agreement from the Secretary of

State for Health but only minimal opportunity for stakeholder (including the public, staff and patients) involvement (Eaton, 2014).

Prior to Clause 119 the TSA at South London Health Care Trust had sought to relieve some of the financial pressure on the organisation by downgrading Emergency Department and Maternity Services at the neighbouring Lewisham Hospital (Pollock et al., 2013). Lewisham Hospital was part of the Lewisham and Greenwich NHS Trust which was financially solvent in its own right and deemed to be providing good quality care. Despite local outcry the TSA moved to enact his decision with minimal stakeholder involvement. Jeremy Hunt backed the decision to push forward with the disinvestment at Lewisham (despite the fact that it was part of a separate organisation) but he, and the TSA, were eventually defeated in two court cases which ruled the TSAs actions to be unlawful (Dyer, 2013). The disinvestment decisions taken at South London Health care and Lewisham were making national news headlines at the time when the empirical research was conducted. The decisions were mentioned regularly by participants during data collection and are therefore an important part of the context within which the research was carried out.

Having been defeated in court twice, Mr Hunt added Clause 119 as an amendment to the Care Act (2014) in an attempt to ensure that future decisions made by the TSA would be legally binding and to put the Health secretary's powers to act across organisations beyond doubt (Dyer and Torjesen, 2013). In essence, Clause 119 would enable disinvestment decisions to be made across organisational

boundaries in the future without the requirement for significant stakeholder engagement. The Care Act was eventually passed in June 2014 but Clause 119 was 'watered down' somewhat following a Coalition rebellion and lobbying by campaign groups. The proposal passed into law made provision for Clinical Commissioning Groups to veto decisions which would require disinvestment in successful organisations in order to stabilise failing trusts (O'Dowd, 2014).

The strength of the clause that was ascended as part of the act has yet to be tested in court but it seems unlikely to have resolved the fundamental questions over the extent of powers that the TSA should have in terms of disinvestment and the requirement (or otherwise) for them to involve local stakeholders in decision making. The fact that Clause 119 was inserted by the Secretary of State for Health after the empirical data for this research was collected goes to show that there is a need for further clarity over the ways in which disinvestment decisions should be taken and, in particular, what the role of local communities should be within that decision making process; the research detailed in this thesis directly addresses this theme.

1.8 Thesis Contents and Structure

This thesis details the background to, methods and results of an in-depth literature review and two-stage empirical data collection seeking to answer the research questions;

- Should the public be involved in disinvestment decision making? Why?

- To what extent should the public be involved?

- At what stage should they become involved?

- What types of decision should the public be involved in?

Empirical data collection took the form of a Q-Methodology study followed by a series of in-depth interviews. The participants in the research were health professionals working in front line clinical or middle-management roles within provider, commissioner or 'other' e.g. public health organisations in England. The initial research plan had been to compare and contrast the views of a random sample of the public with those health professionals that took part in the study, but the design was modified shortly after data collection for the Q-Methodology study had commenced. This alteration of the sampling and research design came about because of severe difficulties in recruiting a sufficiently large, representative sample of the public to participate. Representativeness was assessed with reference to the extent to which the sample of participants reflected the age, gender, ethnic background, socio-economic status and level of education of the wider local community (the city of Birmingham).

After several months of unsuccessful public recruitment attempts, the researcher opted to focus efforts on increasing the size and breadth of the NHS professional sample and to make this group the sole focus of the research. Analysis of the Q-Methodology data after 45 participants had taken part, and then again after 55 participants, showed that data saturation had been reached and that further

sampling would not enable additional significant factors to be uncovered; this demonstrated that a sufficiently diverse range of views and experiences had been accounted for in the sample. The decision to make NHS professionals the focus of the study is borne out by the findings presented later in the thesis.

The research focuses on disinvestment decisions i.e. decisions to remove funding from services, treatments and technologies, affecting their accessibility to patients, taken at either the service level or at the wider health economy level- there is less focus on patient level decision making or bedside rationing. The research is concerned with the role of the public as taxpayers (i.e. the funders of the NHS) and community decision makers (i.e. local citizens who take a view on the services that should and should not be provided in their area). The role of the patient does arise in the research findings but, as is discussed later in the thesis, patients are distinct members of the public with a distinct perspective on disinvestment and are not the key focus of this research.

This thesis consists of a further nine chapters following this introductory chapter. The title and a brief description of the contents of each of the chapters is given below.

1.8.1 Chapter Two- Disinvestment Decision Making

Having outlined the global and UK national health contexts in the first chapter and detailed the requirement for priority setting and disinvestment, chapter two gives an introduction to some of the approaches that are used in practice to make these

decisions. The chapter details and critically evaluates a number of criteria and non-criteria based priority setting decision making processes including economic evaluation and Programme Budgeting and Marginal Analysis (PBMA), and introduces disinvestment as a significant area of research interest in its own right. Kahneman and Tversky's (1979) Prospect Theory is used to conceptualise the key differences between disinvestment and the other aspects of priority setting.

1.8.2 Chapter Three- Stakeholders in Disinvestment Decision Making

This second background chapter aims to build upon the previous chapter by discussing some of the ethical implications of priority setting and disinvestment decision making as well as highlighting the range of different interests amongst stakeholders in the decision making process. The chapter provides an introduction to the public as one of the more significant stakeholders and aims to analyse their role and interest in the decision making process. Several common approaches to public involvement espoused in the literature are critically analysed and are classified against Arnstein's Ladder (1969)

1.8.3 Chapter Four- Literature Review

This chapter details an in-depth review of the literature relating to public involvement in disinvestment and priority setting; its purpose is to uncover and critically analyse the most relevant knowledge, theory and research relating to the research questions. In addition to this, the review also seeks to highlight gaps in the literature and guide the subsequent direction of the study. The chapter begins by detailing the approach taken to identifying the relevant literature, including the

search terms and databases used, before the results/ outcomes of the literature search are detailed and the findings are synthesised. Findings from the literature review are presented in a narrative form with key themes grouped into a series of propositions relating to public involvement in disinvestment decision making.

1.8.4 Chapter Five- Methodology, Research Design and Sampling

This chapter highlights the empirical evidence needed to bridge the knowledge gaps identified by the literature review and then introduces the constructionist/ interpretive research paradigm and the mixed methods approach used to collect the requisite empirical data. The applicability of constructionist/interpretive ontological and epistemological assumptions to the research questions is explored in depth as well as the implications of these assumptions for the data collection phase.

1.8.5 Chapter Six- Research Methods

This chapter gives a detailed account of the steps taken within the data collection process. The chapter begins by introducing Q-Methodology as an approach to research before giving an in-depth description of the way that it was applied as the first stage of this mixed-methods project. The chapter then gives a comprehensive account of the semi-structured interviews that were carried out following the Q-Methodology study as the second stage of the mixed-methods design.

1.8.6 Chapter Seven- Results Part One- Whether and Why the Public Should be Involved in Disinvestment Decision Making

This chapter is the first of two results chapters, it combines the findings from both

stages of the research to provide an answer to research question one- whether or not the public should be involved in disinvestment decision making and why. The first section of the chapter details the results of the Q-Methodology study, including giving details of the final sample of 55 participants, and the factors uncovered through the research. The second section details the make-up of the interview sample before using findings from the qualitative data to explore the motivations behind the perspectives uncovered in the Q-Methodology research.

1.8.7 Chapter Eight- Results Part Two- Extent and Timing of Public Involvement in Different Types of Disinvestment Decision

This chapter builds upon the first findings chapter, using the results from the in-depth interview phase to focus on providing an answer, firstly, to the second research question- the extent to which the public should be involved. The chapter then goes on to consider the findings from the research in relation to the third and fourth research questions- the stage at which the public should become involved and the types of decision that the public should become involved in.

1.8.8 Chapter Nine- Discussion

Chapter Nine draws upon the theory and knowledge presented in the background chapters to contextualise and draw together the findings from both the Q-Methodology study and the in-depth interviews giving more rounded, conclusive answers to the research questions. The discussion then applies the findings of the research to the approaches to public involvement and disinvestment decision making outlined in the background chapters. The chapter also provides an

assessment of the overall approach to research, critically examining any limitations and the role that the researcher played in the research process itself before concluding with recommendations as to the future direction that research in the field should take.

1.8.9 Chapter Ten- Conclusion

This final chapter provides an overall summary of the thesis, pulling together the key points from the previous nine chapters and giving concise answers to the research questions. The conclusion gives consideration to the research context outlined in the introduction and assesses how it changed during the course of the research, how it may develop in the future and what the implications of this may be. The conclusion ends by outlining potential ways in which the research detailed in the thesis could be developed and built upon in the future, and the key implications of the research findings for theory, research, policy and practice.

1.9 <u>Summary</u>

Having examined the context within which the research was carried out, giving a thorough description of the resource shortages faced by health systems and the reasons for these shortages, and detailing why the research is timely, this introductory chapter then provided readers with a preview of each of the remaining chapters of the thesis. After accepting that the need to set priorities is unavoidable and that disinvestment is required, the next chapter examines how these difficult resource allocation decisions are taken in practice and why disinvestment, as a function of the priority setting process, is of particular research interest.

Chapter 2- Disinvestment Decision Making

2.1 Introduction

The purpose of this chapter is to introduce disinvestment decision making and some of the processes that are used to make resource allocation decisions and set priorities in health care. A number of criteria based decision making processes, including economic evaluation and Programme Budgeting and Marginal Analysis (PBMA), are critiqued before disinvestment is introduced as an important research topic in its own right. The distinctions between disinvestment and priority setting are explored fully, with Kahneman and Tversky's (1979) Prospect Theory introduced as a means of conceptualising this difference.

2.2 Priority Setting and Disinvestment

Priority setting is the process of making decisions 'over what health services to provide, how, where and for whom'(Bate and Mitton, 2006, p.275) in the face of limited resources and growing need. As it is not possible to provide funding for all potentially beneficial treatments, limits must be set and difficult decisions must be taken as to how best to use the limited resources (Ubel, 1999). Priority setting activity can take place at three levels within health decision making; macro, meso and micro. The macro or health system level is where priorities are set for the nation and funding is divided accordingly, the meso or programme level is where decisions are taken at a local level as to how to divide resources between competing services, and the micro or patient level is where funding is prioritised between individual patients (Klein, 1993; Litva et al., 2002). Those individuals or

groups charged with taking these decisions are referred to throughout the rest of this thesis as decision makers.

Disinvestment, also known as divestment, decommissioning or de-insurance, is most commonly defined in the literature as 'withdrawing health resources from any existing health care practices, procedures, technologies or pharmaceuticals that are deemed to deliver little or no health gain for their cost, and thus are not efficient health resource allocations' (Elshaug *et al.*, 2007, p.23). Disinvestment is an aspect of the priority setting decision making process, and is often necessary to fund service expansions in other areas (Mitton and Donaldson, 2004b). Despite this, and the researcher's normative stance that disinvestment should be part of a wider priority setting process, it is recognised that disinvestment may, in practice, also take place outside of a formal decision-making framework. In this thesis, disinvestment refers to decisions taken both formally and informally.

The rationale for disinvestment may be cost and clinical effectiveness (Elshaug *et al.*, 2007), it may be freeing up resources for re-allocation (Nuti *et al.*, 2010) or to address budgetary gaps (Donaldson *et al.*, 2010b), or it may be to make wider service and quality improvements in line with an organisation's strategic values and objectives (Garner and Littlejohns, 2011).

An extension of Elshaug et al.'s (2007) definition is provided by Schmidt (2012) who suggests that disinvestment can fall into three categories; absolute disinvestment (Elshaug's definition), relative disinvestment (where resources are

transferred from one service area to another in order to increase the positive benefits provided) and 'category three' where absolute and relative disinvestment are combined. An example of 'category three' disinvestment could be the closure of a GP surgery for one afternoon per week in order to provide increased funding for community nurses. In this case the GP service would only be partially withdrawn (i.e. one afternoon per week) and would continue to provide positive benefits the rest of the time but the community nursing service would be able to expand and deliver increased benefits.

Additional to the categorisation of disinvestment provided by Schmidt is a fourth category, which will be termed 'cost based disinvestment'. In this case, decision makers may disinvest in a service which is clinically effective without re-investing funds elsewhere. In difficult economic times, where traditional approaches to deliver efficiencies will not suffice, decision makers will be forced to consider this type of disinvestment over and above simply 'taking resources from areas of care that provide no added value' (Donaldson *et al.*, 2010b, p.801). Due to the potentially high-profile nature of cost based decisions, however, it is conceivable that decision makers may continue to make the case that disinvested services are not clinically effective rather than offering clarity about their financial motivations. Giacomini et al. (2000), for instance, highlight the de-insurance of IVF treatments in Ontario, Canada as a good example of where unconvincing clinical evidence was used to justify a decision taken on primarily financial grounds.

2.3 <u>Types of Disinvestment Decisions</u>

In practice, disinvestment can take a number of forms ranging from 'substitution' of services through to 'full withdrawal' (Daniels *et al.*, 2013). Full withdrawal or true disinvestment refers to making services or interventions completely unavailable to patients, in many cases this will include removing, reducing or replacing services, also known as decommissioning (Williams *et al.*, 2013). Other approaches to disinvestment identified by Daniels et al. (2013) were contractual variation (agreeing to purchase less of an intervention from a provider- often linked to substitution) and restriction (setting additional constraints as to which patients are eligible to access services).

Examples of all the approaches to disinvestment identified by Daniels et al. (2013) have been reported in the academic and popular literature (Duerden and Hughes, 2010; Ramesh, 2011; Beckford, 2011; Ford-Rojas, 2012), but perhaps the most well-known and highly publicised examples of disinvestment within health services globally have been full withdrawals. See James (1999), Naylor (1999), and Iglehart (2000) for discussion of full withdrawal of short term care beds in Canada in the 1990s, or Campbell (2012) for an example of substitution and full withdrawal of maternity services in the UK.

In the context of this thesis, disinvestment refers to all of the definitions highlighted by Schmidt (2012) as well as cost based disinvestment. In practice, the rationales for disinvestment are not mutually exclusive and a single disinvestment

can achieve a number of objectives e.g. improving service quality and reducing cost. In this thesis, the rationale, and whether or not a formal priority setting process was followed, are secondary concerns. What is most important is the act of removing funding from services, treatments and technologies, affecting their accessibility to patients. It is this outcome that defines disinvestment in the minds of those affected by these decisions and, as such, it will define it for the purposes of this research.

2.4 <u>Non-Criteria Based Approaches to Priority Setting and Disinvestment</u>

A wide range of approaches to priority setting and disinvestment have been identified in the literature. These approaches have previously been categorised as economic and non-economic (Mitton and Donaldson, 2004b; Bate and Mitton, 2006), but this distinction perhaps over-complicates the discussion in this thesis. What is significant is whether or not the process is based on pre-defined criteria, or whether the decisions are taken in a more arbitrary way. For the purposes of this research, where the term priority setting is used it will solely refer to the more transparent, explicit, criteria based approaches described by Rudolf Klein (1995) amongst others.

Whilst the researcher's normative stance displays a preference for criteria-based decision making, the prevalence of non-criteria based approaches makes it important to consider them as part of the decision making context. In light of this, historical allocation, decibels and internal market al.location will be briefly introduced before a number of criteria based approaches are critiqued in more

depth.

Historical allocation entails services or treatments receiving an allocation of funding based on what they received previously and is the most arbitrary means of resource allocation. Depending on economic conditions it may mean a percentage increase or a decrease being applied to budgets across the board; if a decrease is applied then individual departments will be expected to make disinvestment decisions in order to balance their budgets. The lack of a requirement to make decisions on an individual service basis prevents high-level decision makers from having to take tough decisions, and may begin to explain why it has been shown to be highly prevalent within health authorities (Mitton and Donaldson, 2002).

Linked to historical allocation is allocation on the basis of which service 'yells the loudest' (Mitton and Donaldson, 2002, p.47) or makes the most convincing case for funding. Bate and Mitton (2006) refer to this notion as 'decibels' and it could mean that those services supported by interest groups or politicians (Mitton and Donaldson, 2002), or those that are led by charismatic leaders, are treated more favourably than those who are less able to put their point across. Those services receiving less favourable treatment may be forced to make disinvestment decisions in order to remain viable.

Within publicly funded health systems, internal markets can also be used as a means of allocating resources. Where patients have the freedom to choose between service providers (or GPs have the freedom to choose on their behalf) and funding

is linked to activity, as is the case within the English NHS, those services that are not needed, or valued the most by patients will receive less and less funding and will eventually fall by the wayside and be disinvested in (Cooper, 1995b; Goddard *et al.*, 2005). In this case, disinvestment decisions would effectively be taken on the basis of levels of activity, with the numbers of patients using each service being the only criterion for funding.

2.4.1 Criticisms of Non-Criteria Based Approaches

The nature of non-criteria based approaches dictates that they lack transparency (Mitton and Donaldson, 2002), with all three approaches identified open to the criticism that they fail to give an opportunity for adequate stakeholder involvement. Similarly, because historical allocation and decibels, in particular, fail to challenge the status quo, they could result in the perpetuation of existing inequities or inefficiency within the system.

Decibels could act to ensure that historical allocation continued or they could act to challenge it and unduly increase funding for one service area at the expense of another. Decibels could have a similar impact on internal market al.location, either through effective marketing of some services directly to patients or through effective networking with GPs to encourage referral to one service provider over another. In both of these instances, the ability of certain stakeholders within the priority setting process to state their view loudly and clearly could ensure that they receive funding at the expense of others, and that disinvestment takes place in some services regardless of their quality or efficiency, or the merits of their case.

2.5 <u>Criteria-Based Approaches</u>

2.5.1 <u>Needs Assessment</u>

Needs assessment uses epidemiological principles to identify disease priorities and the extent of unmet need within a given population, thus allowing resources to be targeted in a way that benefits the health of that population (Stevens and Gillam, 1998). If there is no prevalence of a particular condition within a population then there is no need to assign budget to tackle that condition and any existing budget may be withdrawn. If needs assessment highlights significant prevalence and/or unmet need then disinvestment can be used to free up resources from other areas which are considered to be lower priority, this funding can then be re-allocated to that area. Whilst needs assessment can offer some transparency and does have the flexibility to change over time (Wright *et al.*, 1998), it is flawed in a number of ways.

First, there is a difficulty in how to measure need i.e. which disease is the most serious? Does mortality or morbidity take precedence? Once priority areas have been identified, little clarity as to how funding should be used within disease groups is offered (Bate and Mitton, 2006). Using needs assessment alone would focus funding on those diseases that cause most deaths e.g. Ischaemic heart disease (Donaldson and Mooney, 1991) without allocating any funding to upstream interventions that may prevent future harm and cost. This may also result in cheaper, more effective treatments for conditions with lower morbidity/ mortality being overlooked, or disinvested in, in order to provide funding for expensive

treatments for the deadliest conditions regardless of their clinical effectiveness (Cohen, 1994).

In addition, just because a particular disease has a high mortality rate it does not necessarily follow that providing additional funding to provide treatment will save more lives- what if there is no effective cure? (Baltussen and Niessen, 2006). Needs assessment may be transparent but, like historical allocation, the opportunity for the incorporation of stakeholder values is variable (Jordan *et al.*, 1998). In disinvestment decisions, needs assessment would promote removal of funding from those areas that met the least immediate needs first.

2.5.2 The 'Core Services' Approach

Identifying core services that will be publicly covered and, by definition, those services that will not be publicly covered, is another commonly used approach to setting priorities and deciding where disinvestment will take place (Sabik and Lie, 2008). Different health systems have used a range of different approaches to identify services that will, and will not, be included in public health plans and have incorporated different values and criteria into the decision making process.

In Oregon, USA, an 11 member Health Services Commission was appointed in 1989 to investigate how Medicaid coverage could be extended to a broader range of recipients. In order to provide publicly funded treatments to more recipients whilst living within existing means it was necessary for Oregon to set priorities as to which services it could and could not continue to fund (Klevit, 1991). The

commission used public values (elicited during a wide ranging consultation) to rank 17 categories of treatments and services- 'acute, fatal conditions where treatment leads to full recovery' were prioritised most highly. Within these categories individual treatments were then ranked in order of clinical effectiveness (as defined by an exercise involving a number of Oregon physicians who were asked decide between 1000 pairs of treatments for different conditions) (Kitzhaber, 1993).

The cost for a 'basic' package of each treatment was then calculated and the commission went through the list of 17 categories assigning funding to each of the treatments until the Medicaid budget had been fully assigned. This process initially produced some anomalous results but after some re-work by the commission, the revised list eventually passed into law in 1994, with 565 out of 696 services/ treatments receiving funding (Ham, 1997). As a result of the process, 141 services/ treatments were not funded and were therefore disinvested in.

In New Zealand, the Core Services Committee, now known as the National Health Committee, was established in 1992 with the intention of limiting government expenditure and ensuring that resources were equitably and efficiently allocated (Cumming, 1994). Initially a series of consensus conferences were held amongst experts to make decisions on the provision of specialised services and treatments for particular conditions. The intention of these meetings was to establish a core list of available services, but decision makers eventually rowed back from this, deciding instead to continue funding all existing services but with stricter clinical

guidelines for access and potential alterations in the levels of funding that each service received (Feek *et al.*, 1999). The Core Services Committee initially made their decisions on the basis of pragmatic reasoning but eventually they devised four principles upon which they felt that priority setting decisions should be made; benefit (effectiveness of the treatment), value for money, fairness (ensuring that the patient who can benefit most is receiving the treatment) and consistency with community values (Ham, 1997). Despite these principles being set at a national level, they were left to local decision makers and clinicians to interpret and relied on implementation at a local level.

2.6 Criticisms of Arbitrary Approaches, Needs Assessment and Core Services

Research has shown that many of the approaches to priority setting and disinvestment outlined above are still prevalent within health care (Miller *et al.*, 1997; Mitton and Donaldson, 2002; Teng *et al.*, 2007). In some cases they may prove to be effective, but there are a number of reasons why, in the majority of cases, an alternative approach could deliver a more efficient and equitable allocation of resources, and a more effective way to make disinvestment decisions.

First, with the majority of these approaches there is no appreciation of the margin, and the benefit that can be derived by allocating each additional unit of funding to a particular treatment or service. The first pound spent on a service may deliver more benefit than subsequent pounds (Cohen, 1994). It cannot simply be assumed that additional funding will continually deliver the same levels of benefit, or that removing funding from a service will continue to come at the same cost. Therefore

allocating resources without taking this into account will always be inefficient in the long run.

Linked to the margin argument is that of opportunity cost whereby a decision to use funding in one area prevents it from being used in another- the opportunity cost is the benefit forgone (Mitton and Donaldson, 2004b). With the core services approach, for instance, increasing levels of funding will continue to be provided to services indefinitely as long as patients meet the clinical criteria. There is no consideration of the marginal benefit of this expenditure and whether or not expenditure in a different area could deliver more benefit- the increase in benefit would be the opportunity cost. Similarly, implicit priority setting through historical allocation and decibels can result in interested parties skewing the argument towards their services or treatments and neglecting to consider the opportunity cost of providing them with funding (Robinson, 1999). In disinvestment decision making, the opportunity cost of a decision would be the difference in marginal cost between a decision to disinvest in one service over another.

Another difficulty with historical allocation, in particular, is its lack of transparency (Bate *et al.*, 2007). Needs assessment and the core services approach apply consistent criteria to priority setting and disinvestment, and provide the opportunity for stakeholder input, but historical allocation is more implicit. This subjectivity can make it difficult to compare service options and result in a failure to maximise the benefits of investment, or minimise the costs of disinvestment (Mitton and Donaldson, 2002). In publicly funded health systems in particular, the

lack of transparency and accountability would also make historical allocation a procedurally unjust way to make priority setting and disinvestment decisions (Daniels, 2000).

The approaches detailed thus far struggle, on the whole, to manage the balance between new technologies and treatments, and those that are already publicly funded and available; this could be resolved if the margin were taken into account (Mitton *et al.*, 2003). The Core Services Commission in New Zealand, for instance, continued to provide funding for all existing services, focusing its attention on clinical guidelines and assessment of new technology, without considering whether existing services actually met their criteria. Similarly, historical allocation seems to promote funding existing services ahead of investing in new ones (Bate *et al.*, 2007). In both of these cases it is possible that new technologies that and approaches could be overlooked in favour of continuing to fund existing treatments that were potentially less clinically or cost effective, and should be disinvested in.

2.7 <u>Applying Health Economics Principles</u>

Many of the limitations of the approaches highlighted earlier can be overcome by employing criteria founded in the principles of health economics. Mitton and Donaldson (2004) highlight three approaches that take some of these principles into account; Economic Evaluation, Quality Adjusted Life Year (QALY) League Tables and PBMA.

2.8 <u>Economic Evaluation</u>

Economic evaluation allows for the simultaneous assessment of costs and outcomes from different treatment options and services, and can enable decision makers to set priorities on the basis of both technical and allocative efficiency. Technical efficiency is concerned with establishing the most efficient way to deliver particular one-dimensional, measurable goals e.g. reduced mortality (Shiell *et al.*, 2002). Allocative efficiency is concerned with establishing the most efficient way to use resources across different service areas or different areas of public spending more generally (Hutubessy *et al.*, 2003).

Cost-Effectiveness analysis (CEA) is best suited to questions of technical efficiency; it compares two or more service or treatment options to establish the extent to which they deliver the desired goal, and the costs associated with delivery. The outcome from CEA is known as the incremental cost-effectiveness ratio (ICER); this summarises the comparison between the cost of an additional unit of health gain from one treatment and the cost from alternative treatments (McCabe *et al.*, 2008). The most technically efficient option would be the one which delivered the same (or better) outcome with less input, or delivered a better outcome with the same level of input (Palmer and Torgerson, 1999). In the case of disinvestment, existing services could be analysed with funding being removed from the least technically efficient option for the treatment of a particular condition. CEA is considered to be one of the most simplistic forms of economic analysis but it is widely used within single service or disease areas; its applicability

across programmes is far more limited (Mitton and Donaldson, 2004b).

Cost benefit analysis (CBA) is ideally suited for establishing allocative efficiency. It compares the value (or benefit) of a particular service or treatment with that of alternative ways of using resources. It is typically used when a new service/ treatment is proposed which is more costly than existing alternatives and funding to cover the difference must be reallocated from other areas (Donaldson, 2002). The purpose is to establish the way in which a limited amount of resources could be used to deliver the most benefit; those that deliver the most benefit are considered to offer the most allocative efficiency. The value (benefit) of the different options is typically measured in financial terms e.g. how much would consumers be willing to pay themselves for a particular service, and do they value that service more than others? By placing a monetary value on the benefits, CBA can ensure consistency between areas where it would otherwise be difficult to make comparisons (Shiell *et al.*, 2002).

Cost benefit analysis is closely linked to the notion of opportunity cost as it can be used to set priorities between disparate services, with those considered to offer less allocative efficiency potentially receiving less funding and becoming candidates for disinvestment. Despite this acknowledgement of opportunity cost, the advantages of using CBA to make disinvestment decisions should, according to Drummond and Jefferson (1996) be considered in light of a key limitation. This limitation is that individual patients from different social classes and backgrounds may, because of their differing means, be willing to pay different amounts for

treatments; those from poorer backgrounds may be willing to pay less for an equivalent health gain. As a result of this, disinvestment decisions could be inequitable, with those diseases which affect the more affluent being more likely to retain funding if the limitation is not taken into account in the calculations.

Cost Utility analysis (CUA) is an approach which can be used to inform decisions made on the basis of both technical and allocative efficiency i.e. decisions between related treatments/ services for similar conditions or decisions across broader programmes of health/ public expenditure (Mitton and Donaldson, 2004b). Cost utility analysis provides a monetary value for each unit of health gain provided by a particular treatment or service. It could be used in technical efficiency calculations to compare the cost per increased year of life expectancy provided by different treatments for a particular condition; decisions around where to provide funding and where to disinvest could then be made in a similar way to CEA.

If broader, multi-dimensional measures of health gain i.e. not measures that are disease specific, are used then CUA can also be applied to wider decisions on funding allocation (Shiell *et al.*, 2002; Drummond *et al.*, 2005). If factors such as quality of life and societal values are taken into account, then CUA can be used to measure allocative efficiency, and decisions on where to prioritise funding and where to disinvest can be made accordingly. Cost per Quality Adjusted Life Year (QALY) is a measure (or ICER) that has become synonymous with CUA (Robinson, 1993; Chumney *et al.*, 2006) and can be used by decision makers to provide guidance as to the allocative efficiency between competing programmes

and choices (Gold *et al.*, 1996).

2.8.1 <u>Incorporating Quality of Life into Disinvestment Decisions</u>

Quality adjusted life years (QALYs) are a means of measuring both the additional life that a patient enjoys because of a particular treatment and the quality of that life; they are commonly used in ICER calculations (McCabe *et al.*, 2008). In simple terms, one single QALY is considered to be an additional healthy year (Mitton and Donaldson, 2004b). QALYs are calculated by taking a measure of a patient's current health state between -0.5 and 1 (-0.5 being a state worse than death e.g. coma, and 1 being optimal health) and an estimate of how much longer the patient will live without treatment (or if their current treatment regime continued). Next an estimate is made of the patient's health state if they were to receive treatment and how much longer they would expect to live for (NICE, 2010). QALYs are then calculated using the following formula:

No treatment/ current treatment: Life remaining with no treatment/ current treatment x Existing Health State= Current QALYs

New treatment: Life remaining with new treatment x Health State if treated= QALYs with new treatment

Change in QALYs= QALYs with new treatment – Current QALYs

The difference in cost between the patient's current treatment regime and their new treatment is calculated and this is divided by the change in QALYs. This cost per

QALY can then either be used to establish whether a new treatment meets a pre-defined cost-effectiveness threshold (Weinstein, 2008) or it can be used to make comparisons between a number of proposed new treatments in the form of a QALY league table (Petrou *et al.*, 1993).

When making disinvestment decisions, existing services could be analysed to assess what their cost per QALY is and those that deliver the least benefit at the highest cost could be considered as candidates for disinvestment. Alternatively, the QALY could be used in a more blunt way, and decision makers could reduce the cost per QALY threshold at which they are willing to fund treatments and make savings by de-listing those treatments with a higher cost per QALY (McCabe *et al.*, 2008).

2.8.2 <u>QALY League Tables- Advantages and Disadvantages</u>

Cost per QALY league tables offer the advantage of allowing comparisons between treatments in different specialties/ programmes, thus incorporating the notion of opportunity cost as well as recognising the importance of quality of life in addition to length of life. Despite this, however, there are a number of disadvantages to using QALYs to set priorities.

First, the opportunity cost considered in league tables considers only length and quality of life, not the wider societal value of different treatments (Gerard and Mooney, 1993). Second, quality of life measurements are subjective and each patient will have their own interpretation of what healthy may be and may attach

different levels of utility to different health states (Mooney, 1989). This links to the argument that evidence used in QALY calculations can be unreliable (Mason, 1994), although this can be mitigated to some extent by rigorous evaluation and ranking of the quality of outcome data before QALY league tables are constructed (Laupacis *et al.*, 1992).

Also, it is difficult to say with certainty that a patient's health and quality of life are only being affected by the condition for which the new treatment is designed; they may be suffering from a number of unrelated conditions. Different methods and approaches to QALY calculation incorporate co-morbidities differently, and it is possible to exclude those patients with co-morbidities from trials all together (Haagsma *et al.*, 2011). In reported studies it can be unclear, however, how, or if, co-morbidities have been taken into account. In their literature review of the 'Time Trade-off' approach to QALY calculation, for example, Arnesen and Trommald (2005) reported that there was no description of co-morbidity for patients within 90% of the diagnostic groups in their review. Failure to consider co-morbidities may mean that a new treatment which treats just one of a patient's conditions may have little impact on their life expectancy or quality of life if their other co-morbidities go untreated.

Setting a cost per QALY limit and using this for rationing/ disinvestment may also fail to deliver the desired savings because a low cost drug may be required by millions of patients whereas an extremely high cost drug may be required by just a few. The cheaper drug may have a much lower cost per QALY, but the overall

cost to the health system could be exactly the same; this difficulty in taking into account the overall resource constraints within which a decision is being made is a criticism of cost effectiveness and cost utility evaluations more generally (Bate and Mitton, 2006).

2.8.3 <u>Health Technology Assessment</u>

In practice, economic evaluations are often considered alongside other evidence by those charged with making decisions on health resource allocation. One example of a multi-disciplinary approach which incorporates economic evaluation into decision making is Health Technology Assessment (HTA). Definitions of HTA vary widely but the Institute of Medicine offer a comprehensive description. HTA is 'any process of examining and reporting properties of a medical technology used in health care, such as safety, efficacy, feasibility, and indications for use, cost, and cost effectiveness, as well as social, economic, and ethical consequences, whether intended or unintended' (Institute of Medicine (U.S.), 1985, p.2).

There is no universally applied process for carrying out HTAs but Goodman (2004) provides a ten-step summary which incorporates the key features;

1. Identify assessment topics

2. Specify the assessment problem

3. Determine locus of assessment

4. Retrieve evidence

5. Collect new primary data (as appropriate)

6. Appraise/interpret evidence

7. Integrate/synthesize evidence

8. Formulate findings and recommendations

9. Disseminate findings and recommendations

10. Monitor impact

The first seven steps of Goodman's process (2004) entail collection of evidence through systematic reviews (this would include collecting evidence from economic evaluations as well as using clinical data); it is not until step 8 that a multi-disciplinary team, including clinicians, economists, ethicists and others will come together to consider all of the evidence as one before beginning to draw conclusions (Esmail, 2013). Whilst HTA lends itself to assessment of new technologies and decisions as to whether to fund clinical developments, it has increasingly been used for re-assessment in recent years. This is where existing technologies have been assessed against HTA criteria to establish whether they meet clinical, ethical and cost-effectiveness thresholds. This re-assessment has been promoted in the literature by Adam Elshaug (2008), Laura Leggett (2012) and Amber Watt (2012a) amongst others, who feel that HTA could offer a means of identifying and disinvesting in technologies that are not considered to be clinically or cost effective.

2.8.4 HTA and Disinvestment

Despite support from a dedicated group of academics, the use of HTA for disinvestment is not universally accepted as a panacea and there is a need to further develop the evidence base (Ibargoyen-Roteta *et al.*, 2009; Leggett *et al.*, 2012). It has been suggested that there is an implementation gap between the identification of technologies for disinvestment and the actual removal of funding (Haas *et al.*, 2012; Henshall *et al.*, 2012). Much of the gap between identification of disinvestment opportunities and the delivery of tangible savings is due to patient and clinician inertia; one possible way to overcome this could be to offer a proportion of the savings made through disinvestment up for re-investment into new technologies and services (Noseworthy and Clement, 2012). Other difficulties in mobilising HTA for disinvestment, or optimisation as Henshall (2012) describes it, include loss aversion amongst stakeholders, heterogeneity of patient outcomes and the difficulty in presenting a convincing argument that there is an absence of benefit.

2.8.5 The Limitations of Economic Evaluation in Practice

Whilst the work of Elshaug and colleagues has advanced the field and helped to highlight the advantages of using HTA in disinvestment decision making, it should be recognised that, in practice, economic evaluation (e.g. CEA or CUA) is still often used in isolation and this approach has a number of limitations. First is the difficulty in incorporating wider factors e.g. politics, and broader health system objectives such as increased equity or social desirability of programmes, into

decision making (Drummond *et al.*, 2005). Also, economic evaluation can be a time-consuming and costly exercise which requires significant amounts of information (Mitton and Donaldson, 2004b; Williams *et al.*, 2008), and is rarely capable of taking into account the full range of cross-programme treatment and service options that are under consideration by decision makers (Birch and Gafni, 1992). Economic evaluation also fails to take into account resource limitations and, as such, may recommend funding treatments on the basis that they are cost-effective without considering the fact that there is no additional budget available to pay for them (Bate and Mitton, 2006). Also, economic evaluation can only assist decision makers in making tough decisions; it cannot make them for them (Phillips, 2005). In order to use economic analysis as a tool, decision makers need the knowledge and expertise to understand and interpret its outputs, but, in practice, these skills have been shown to be lacking (Williams *et al.*, 2008).

2.9 <u>Overcoming the Limitations - Programme Budgeting and Marginal Analysis</u>

The PBMA framework is an approach to priority setting that has the economic principles of opportunity cost and the margin at its core. PBMA is a seven stage process which has the methodological rigour of economic evaluation whilst also being user-friendly and having the flexibility to make allowances for the complex nature of health decisions (Peacock *et al.*, 2007). There have been over 300 examples of PBMA implementation documented in the literature since the first application of programme budgeting in health in the 1970s (Pole, 1974).

Published evaluations of the success of PBMA programmes have shown it to be

particularly effective in promoting procedural justice and fairness (Gibson *et al.*, 2006), changing decision making culture within organisations (Peacock, 1998) and identifying resources for disinvestment and reallocation (Mitton and Donaldson, 2001; Tsourapas and Frew, 2011). These same evaluations have, however, also shown that organisations often fail to adopt the PBMA process for future use (Tsourapas and Frew, 2011) and that decisions taken using PBMA are not always implemented in full (Peacock, 1998). Like other criteria based priority setting and disinvestment decision making processes, it seems, PBMA has both advantages and limitations, but its ability to take account of opportunity cost and the margin make it worthy of consideration.

The PBMA process begins with a decision on the level and extent of the priority setting exercise (e.g. at the macro, meso or micro level) before current activity and expenditure are mapped in a programme budget (Mitton and Donaldson, 2004b). Next an advisory panel is formed; this panel would typically consist of a broad range of senior managers/ clinicians as well as potentially some lay representation. The fourth step is to devise the criteria against which the marginal benefit of the different options will be measured; this may involve input from a range of stakeholders including decision makers and the public (Tsourapas and Frew, 2011).

The fifth step in the process is for senior managers to identify areas for growth, as well as potential options for resource release, from within their services; these are promoted in the form of business cases or proposals to the advisory panel (Dionne

et al., 2009). The penultimate step is for the advisory panel to use the benefit criteria identified in step four to carry out a marginal analysis of each of the options to establish which offers the most marginal benefit; recommendations on how any additional funding should be used will be made on the basis of this analysis. The final stage in the process is for the validity of these recommendations to be checked with stakeholders and for the budget planning process to be informed accordingly (Mitton and Donaldson, 2004b).

Where no additional funding is available, PBMA can be used to identify the existing areas that offer the least marginal benefit and resources can be reallocated to other (new or existing) services that offer more marginal benefit (Nuti *et al.*, 2010). Likewise, where the overall funding envelope has been reduced and expenditure must be cut, PBMA can be used to make decisions around disinvestment and can ensure that marginal losses are minimised (Donaldson *et al.*, 2010b). By considering the opportunity cost of decisions that are taken, PBMA can help to ensure that the mix of services provided is the most technically and/ or allocatively efficient possible, regardless of whether the overall budget is rising or falling.

2.9.1 PBMA- Advantages and Disadvantages

By involving decision makers early in the process and allowing them to suggest their own ideas for expansion and retraction, the PBMA framework offers the potential advantage of ensuring buy-in to the priority setting process. Also, using the common PBMA framework and bringing decision makers from different areas

of an organisation together can help to encourage collaboration and shared learning (Madden *et al.*, 1995). Unlike the economic approaches detailed earlier, PBMA recognises the fixed budget within which decision making takes place (Mooney *et al.*, 1992) and the fact that expansion in one area often necessitates disinvestment, or opportunity cost, in another.

Despite the benefits of PBMA, it is not without limitations and one of the most common criticisms of the process is the amount of information it requires (Mitton and Donaldson, 2004b), not to mention the difficulty in acquiring evidence that is sufficiently reliable (Madden *et al.*, 1995). Similarly to other economic approaches, PBMA has also been criticised in the past for its difficulty in incorporating equity and distributive justice considerations (Madden *et al.*, 1995) although more recent developments focusing on effective stakeholder engagement and ethical considerations within the process have helped to overcome this (Gibson *et al.*, 2006). Lastly, in practice, PBMA has been shown to come up against institutional barriers, whereby priority setting and disinvestment decisions are not enacted by decision makers and/ or there is a reticence for the different programs to suggest areas for resource release (Jan, 2000).

2.9.2 Multi Criteria Decision Analysis (MCDA)

MCDA is an umbrella term which incorporates a number of different formal approaches to the incorporation of different criteria into decision making (Mendoza and Martins, 2006). MCDA allows decision makers to assess numerous different investment or disinvestment options against criteria that they consider to

be important, and to quantify the benefits that they can deliver. The different approaches to MCDA can be categorised into three groupings (Thokala and Duenas, 2012); value measurement models which assign numerical scores to each criterion and allow a series of options to be compared with each other simultaneously, outranking models which assess options in pairs before ranking them against each other and goal, aspiration and reference level models which seek the option which most closely meets a pre-defined standard.

In priority setting and disinvestment decision making practice, MCDA has been used to inform the ranking process of PBMA exercises (Mitton *et al.*, 2014) and to provide evidence for HTA (Thokala and Duenas, 2012). In addition to this it has also been used as a priority setting tool in its own right (Bots and Hulshof, 2000; Robinson *et al.*, 2012) and has, anecdotally, been used to make disinvestment decisions, although there is little published work to support this. Where it has been used for priority setting, it has been preferred to economic evaluation because of its ability to take account of a range of considerations and criteria, including cost effectiveness (Baltussen and Niessen, 2006).

2.10 <u>Distinctive Elements of Disinvestment</u>

In this chapter the more common criteria-based and non-criteria based approaches to priority setting decision making have been discussed and the advantages and disadvantages of each have been highlighted. The question of disinvestment has, thus far, been tackled in and amongst broader priority setting literature and practice but in order to position this study and to introduce disinvestment as a research area

in its own right it is necessary to consider some of the distinctions that exist. To some, the differences between the existing priority setting literature and disinvestment may seem nuanced but they are deeper and more significant, particularly in the context of public involvement, than they appear.

Disinvestment is "a growing area of priority setting in health care that requires national and international perspectives, debate and collaboration" (Elshaug *et al.*, 2007, p.29). Whilst the priority setting tools and literature outlined earlier are well developed, and have been adapted for disinvestment in some cases, it is too simplistic an argument to suggest that disinvestment has been fairly researched and represented within the existing priority setting literature. Gaps still remain (Schmidt, 2012) and there are a number of compelling arguments that make it an important area for further research in its own right.

The priority setting literature differs from the disinvestment literature in that it usually refers to decisions being taken on how to invest additional funding using the kind of models detailed earlier (Robinson *et al.*, 2011). Disinvestment, conversely, is taking resources away and is considered to be a wicked issue with no clear solution and an incompatibility with traditional technical and linear approaches to decision making (Grint, 2005). Dickinson et al. (2011) suggest that priority setting which leads to rationing (or disinvestment) requires a new kind of leadership through soft power and a more collaborative approach. This call is reiterated by Cooper and Starkey (2010) who highlight the need for national champions and suggest that health professionals and managers must develop a

common understanding and narrative around disinvestment.

Disinvestment is an emotive issue affecting numerous stakeholders, and this is another quality that sets it apart from decisions to allocate additional resources (Robinson *et al.*, 2013). As a result of this, organisations tend to restrict disinvestment decision making to times of financial constraint (Mitton *et al.*, 2014). Emotions are amplified by the media who portray disinvestment as indiscriminate cuts, rather than focusing on patient safety or effective use of resources (Ettelt *et al.*, 2010; Robinson *et al.*, 2013), and can create the kind of negative publicity that would rarely, if ever, be associated with priority setting decisions to allocate additional funding to one service and not another. This intense media interest can also have the effect of making disinvestment decision making processes more implicit so as to avoid legal and political challenges (Robinson *et al.*, 2013); this is entirely contrary to the spirit of transparency fostered by explicit approaches to priority setting.

The potential for disinvestment to have a system-wide impact is another key distinction; decisions to increase resources for a particular service or treatment are unlikely to negatively affect related services, and may even reduce demand for these alternatives. Disinvestment, however, can have a wider impact (Giacomini *et al.*, 2000; Robinson *et al.*, 2013) where demand for alternative services rises in an unmanaged way, increasing pressure and overall costs in the system (Smith *et al.*, 2010).

The reactionary nature of disinvestment decision making also distinguishes it from decisions to allocate additional funds. Teng et al. (2007) suggest that priority setting (and disinvestment) should ideally take place as part of a wider strategic planning exercise. In reality, however, this planning is often limited to decisions on how to spend additional funding, with disinvestment concentrated at times of financial hardship (Mitton *et al.*, 2014). Even the word disinvestment has negative connotations, risking association with an un-coordinated approach to cost reduction (Cooper and Starkey, 2010), whilst priority setting sounds more pro-active, planned and aspirational. Indeed, the more positive light within which priority setting can be viewed has previously been highlighted by Dickinson et al. (2011, p.363), who wrote that "'priority-setting' has less starkly negative connotations, referring more to populations than individuals, without directly alluding to punitive resource allocation."

2.11 <u>Prospect Theory</u>

Where disinvestment does feature in the broader priority setting literature it is usually in the context of finding funding to reallocate elsewhere (Wilson *et al.*, 2009; Nuti *et al.*, 2010). Disinvestment for the purposes of this reallocation, however, is usually a partial withdrawal of resources (Mitton and Donaldson, 2004b) rather than a full withdrawal, and the original services usually remain available in some form (Daniels *et al.*, 2013). In the eyes of service users and the public this is a key distinction which is described concisely by Kahneman and Tversky's (1979) Prospect Theory.

Prospect Theory suggests that, when faced with a risky decision, people's attitudes towards risks concerning potential loss will be significantly different from their attitudes concerning possible gains. Where they are faced with the option of accepting a small gain or taking a gamble where there is a chance of a bigger gain or receiving nothing, people are found to be risk averse. When facing a probable loss (i.e. they are offered the option of accepting a small loss, or gambling to either sustain a bigger loss or to maintain their current position), however, they seek risk and are more willing to gamble. This aspect of Prospect Theory goes against Expected Utility Theory, linking to the 'Endowment Effect' under which individuals value goods (or services) in their possession more highly than they value equivalent goods (or services) that they could purchase or gain.

Under the Endowment Effect individuals wish to maintain the status quo and are highly loss averse (Kahneman and Tversky, 1979). Prospect theory provides a lens through which to view priority setting and disinvestment, helping to explain why research into public involvement in disinvestment decision making is of significance. The theory suggests that public (and other stakeholders) feel the loss of services more keenly than they would ever feel the benefit of new or additional services being provided.

Given the choice, the public would not risk the services that they currently have but, if they knew that services were being considered for closure and that, without any action, they were bound to lose out, then their loss aversion may encourage risk-seeking behaviour and they may be more inclined to act. This risk-seeking

behaviour may, in practice, not be so risky, but it may entail members of the public becoming more involved in the decision making process than they would normally feel comfortable in doing. This could, for instance, involve signing petitions, writing to elected representatives, attending public meetings or taking part in demonstrations. Also, priority setting decisions to reallocate small portions of funding from one area to another may not result in a noticeable loss to the public and therefore this loss aversion may not materialise. With full withdrawal the public are more likely to notice and feel the effects of the disinvestment.

One of the strengths of Prospect Theory, when applied to health priority setting and disinvestment, is that it recognises the impact that the current situation may have on public preferences and allows for this to be taken into account. Mooney (1989) uses the example of blindness in QALY calculations and suggests that different individuals may value the health state of losing the sight in one eye differently depending on whether or not they currently have vision in one or two eyes. In this case, individuals that have already lost the sight in one eye may value the sight in their remaining eye more highly than those who still have vision in both eyes. Nord et al. (2009) make a similar argument relating to the ways in which individuals who already have a disease or disability may value the change to a health state brought about by a new technology in comparison to a random sample of the general public.

In terms of disinvestment, the theoretical contributions made by Mooney (1989) and Nord et al. (2009) could be extended to illustrate the different ways that

members of the public would view full withdrawal of services in comparison to proposed marginal changes to service provision. Similarly, the contributions suggest that members of the public that have already witnessed disinvestment in their area and have seen service provision reduced, may value the status quo more highly and be more willing to take action in order to protect services. In light of this the way that the public view the status quo, and therefore what their reference point is with regard to possible future losses or gains, becomes particular important in disinvestment decision making (Levy, 2003).

Prospect theory implies that the public could have an important role to play in highlighting the services that they value most, but their loss averse reaction to disinvestment could also potentially call in to question their ability to view decisions rationally and to consider the wider context (although this could also be true of other interested parties such as service providers). It remains unclear whether or not the public should be involved in disinvestment decision making, and, if they are involved, how their views should influence the process.

2.12 <u>Summary</u>

This chapter began by presenting and critiquing a number of criteria and non-criteria based approaches to health care priority setting and disinvestment decision making. Kahneman and Tversky's Prospect Theory (1979) was then introduced as a framework to differentiate between disinvestment and other functions of the priority setting process and to present it as a topic worthy of research in its own right.

Having considered how priority setting and disinvestment decisions are taken, those affected by the decisions will now be considered. The next chapter will identify who the stakeholders within the decision making process are and what their perspectives and claims may be. The discussion around the involvement of the public, in particular, will then be expanded upon, with methods, levels and advantages and disadvantages of public participation being examined comprehensively.

Chapter 3- Stakeholders and Justice in Disinvestment Decision Making

3.1 Introduction

The previous chapter defined what is meant by the term disinvestment in health services and critically evaluated some of the ways that priority setting and disinvestment decisions are taken. The purpose of this chapter is to build upon this by presenting some of the ethical implications of disinvestment decision making as well as appraising the interests of a range of stakeholders in the decision making process. The chapter concludes with a critical analysis of the role of the public as a stakeholder within disinvestment decision making and introduces Arnstein's ladder as a means of classifying some of the more common public participation approaches.

3.2 Justice and Fairness

The previous chapter focused on disinvestment and priority setting decision making processes, but little attention was paid to ethical considerations and the fairness of the outcomes and the processes themselves. These ethical considerations are important for this thesis because disinvestment decisions should be made in a fair and just way so as to ensure that they do not affect one group or another unduly, and so as to ensure that they are acceptable to those people who pay for, use and work within health services. The following sections present distributive and procedural justice positions and frameworks that can be used to assess the 'fairness' of disinvestment in both the decisions that are taken and how those decisions are made.

3.2.1 Distributive Justice

Distributive, or substantive justice relates to the way that a society distributes scarce resources amongst those with competing needs and is synonymous with the notion of fairness (Roemer, 1998; Rawls, 1999). In health priority setting and disinvestment, a decision would be considered to be just if resources were distributed amongst services or treatments in an equitable, fair and defensible way. Fair allocation of health resources could be defended from a range of ethical standpoints including communitarian, individualist, egalitarian and utilitarian (Olsen, 1997; Williams *et al.*, 2012). Utilitarianism, for instance, would seek to use resources in such a way as to maximise the overall health care benefit for society (Rosenheck, 1999). This benefit could, for example, be measured using QALYs.

3.2.2 Procedural Justice

Whilst distributive justice, and the fairness of the outcomes of priority setting and disinvestment decision making, are important, what is arguably more salient to this discussion is the fairness of the processes themselves. This is known as procedural justice and has been shown in a number of studies to be considered more important, in terms of perceptions of fairness, than distributive justice (Tyler and Caine, 1981; Tyler, 1984; Lind *et al.*, 1993). In other words, in order for decision making to be perceived to be fair, it is most important for the process used to make that decision to be fair. Whilst these findings are countered by Van den Bos et al. (1997), who suggest that substantive and procedural justice are of equal significance, the importance of ensuring the fairness of any disinvestment decision

making process is not disputed.

3.2.2.1   <u>Accountability for Reasonableness (A4R)</u>

In order to assess the procedural justice of a priority setting process, many academics and practitioners have turned to the A4R framework devised by Daniels and Sabin (1997; 2000; 2008). A4R is designed specifically for health priority setting and is able to incorporate considerations from a range of fields without being constrained by their limitations (Martin and Singer, 2003; Gibson et al., 2005). A4R proposes four criteria, or conditions, against which to evaluate a priority setting process and establish whether or not it is fair; these are publicity, relevance, revision and appeals condition and enforcement condition.

The first condition is publicity; this states that all decisions regarding limits to care and the rationale behind these decisions should be made available to stakeholders. The second condition is relevance; this suggests that the rationale used to make the decision should be relevant to the context in which the organisation is operating; it should "appeal to evidence, reasons, and principles that are accepted as relevant by fair-minded people" (Daniels and Sabin, 2002, p.45) who wish to co-operate with others in making a decision. The third condition is the appeals and revisions condition which states that the process should allow for decisions to be challenged and for changes to be made in the light of appeal outcomes or new arguments, evidence or experience. The last of the four criteria is the enforcement condition which stipulates that the process should be regulated either through voluntary or

public arrangements to ensure that the previous three conditions are met.

In addition to the four criteria laid out by Daniels and Sabin in their original work, Gibson et al. (2005b) suggest that a fifth condition should also be considered when evaluating priority setting processes. They entitle this condition the empowerment condition and suggest that efforts should be made to ensure that all groups are able to participate in the priority setting process and to ensure that any differences in power between groups is minimised.

The addition of Gibson et al.'s (2005b) empowerment condition is intriguing because it begins to clarify the role of organisations in stakeholder involvement. The publicity condition implies that there should be a certain level of stakeholder engagement but the amount of influence that they should have remains unclear. For instance, would it be acceptable to simply inform the public of the outcome of a decision making process or should they be involved in actually making the decision? Should they even influence the decision making process itself? In the relevance condition, who are 'fair-minded' people and what happens to the views of those who are not willing to co-operate?

A4R has previously been linked with the Programme Budgeting and Marginal Analysis (PBMA) framework (Gibson *et al.*, 2006) but it can be used to evaluate the fairness of any approach to priority setting. This may include any or all of the approaches discussed earlier, or combinations of these processes, although applications within a strictly disinvestment context remain limited (Polisena *et al.*,

2013). The discussion chapter will return to the criteria based approaches, critically appraising these in light of the study findings and considering the implications of the findings for A4R.

3.3 <u>Stakeholders</u>

Those individuals or groups who are affected by priority setting and disinvestment decisions that are taken and/or can have an influence over these decisions are known as stakeholders (Freeman, 1984). Depending on their position and perspective, these stakeholders will have a range of attributes including power (over decisions/ decision makers), legitimacy (within the decision making process) and urgency (i.e. the degree to which their claims call for immediate attention) (Mitchell et al., 1997). These attributes will give the claims of different groups increased salience and thus impact on the approach taken to engage them; some groups may merit genuine decision making responsibility whilst others may merit simply being informed of the outcome of the decision making process.

The Mitchell et al. (1997) framework has been selected because it takes account of the multi-faceted nature of stakeholder relationships, recognises their complexity and appreciates that different groups have different saliency within decision-making. The framework recognises, for instance, that just because one group has power over a decision, it does not necessarily mean that it has legitimacy. The framework (1997) will be used throughout the following two sections, and in the discussion, to consider the unique view that each of the identified stakeholders has of disinvestment decision making, and how the power, urgency and legitimacy of

their claims may affect the way in which decision makers seek to engage them in the process.

Stakeholders can be divided into two categories- internal (those who operate within the decision making organisation) and external (those who are outside of the organisation). The exact stakeholders within a health decision making process vary depending on the context but all of these groups have the potential to influence disinvestment decision making. In order to understand the role of the public, as one of these stakeholders, and to appreciate the context within which public involvement in decision making takes place, it is necessary to identify the range of stakeholders and consider the nature of their claims. The eight groups identified by Patrick and Erickson (1993) will be used to contextualise the role of the public.

3.4 Internal Stakeholders

Two broad groups of internal stakeholders are identified by Patrick and Erickson (1993); administrators and clinicians. Administrators, who, for clarity, will be referred to as 'managers' throughout the rest of the thesis, have the role of collecting and analysing performance and financial data within the priority setting and disinvestment process. Without this data it would be impossible to complete a thorough decision making process (e.g. PBMA), thus giving them power and influence within decision making (Mitchell *et al.*, 1997; Martin *et al.*, 2002a). Depending on their level within the organisation and their exact role, managers may be responsible for the operational management of a number of service areas or

may have the responsibility for commissioning services i.e. making decisions on how to spend public money. Their knowledge and level of responsibility make their claim for involvement in decision making particularly urgent. In terms of power, senior managers play a key role in the priority setting and disinvestment process, with the final decision on resource allocation often resting with organisational executive teams (Gibson *et al.*, 2004).

Clinicians, including nurses, doctors and allied health professionals, are the other group of internal stakeholders identified by Patrick and Erickson (1993). Similarly to managers their level of legitimacy, urgency and power within the decision making process (Mitchell *et al.*, 1997) depends on their exact role, but their input is hugely important (Sabin, 1998). Clinicians include doctors, nurses and allied health professionals and their role within priority setting is to provide a frontline, clinical perspective on decisions that are being taken; this unique perspective gives them significant legitimacy. Clinicians have first-hand knowledge of how services work and what interventions and changes are effective; their main interest is in delivering optimal care for their patients (Kassirer, 1998), although they may also have personal interest in the process e.g. job security. In addition, clinicians have to work with the decisions that are taken during the priority setting process and are directly impacted by priority setting and disinvestment decision making; this gives their claims urgency and means that they should be addressed quickly. As those delivering the services, clinicians hold significant power within priority setting decision making; if they refused to abide by decisions taken then it would be

extremely difficult for organisations to fully implement them and the priority

setting exercise would fail (Mitton *et al.*, 2003). Similarly to managers, depending

on the design of the process, senior clinicians may hold the final decision making

say on priority setting and disinvestment, or may take on an advisory role.

3.5 <u>External Stakeholders</u>

Patrick and Erickson (1993) list public interest groups and lobbyists as two

separate stakeholders within the decision making process but, in the case of

priority setting and disinvestment, their motivations and interests are very similar

and so they will be conflated as 'interest groups' here. Interest groups exist to

represent particular specific causes, in the case of health care this may be securing

additional funding for a particular condition or group of patients for instance. They

act to promote the interests of their cause by lobbying decision makers and

presenting convincing arguments as to why that cause should be prioritised

(Baltussen and Niessen, 2006). In priority setting and disinvestment decision

making, these groups are seeking to increase or protect funding for their area of

interest. They may have great knowledge of specific aspects of health care and

may be able to back up their arguments with evidence, but their legitimacy in the

process could, potentially be diminished by their focus on one condition or issue.

This may mean that interest groups fail to consider opportunity cost (Robinson,

1999). The power of interest groups comes from those who support them e.g.

politicians or senior decision makers; with wider influence and more convincing

arguments interest groups can wield significant power but they are not necessarily

powerful in their own right. Similarly to power, the urgency with which interest groups claims should be attended to depends on their supporter base; if they have clinician support for instance then early engagement may be prudent.

Linked to interest groups, politicians/ government officials are another significant external stakeholder group. Assuming that these individuals are in elected positions, their role in priority setting and disinvestment is to act in the best interests of their constituents (and, on a personal level, to ensure that they retain the support of the electorate). Their position as elected public representatives gives politicians legitimacy within decision making and their high profile ensures that their claims are given urgent attention by decision makers (Rosen *et al.*, 2014). Politicians can add significant power and weight to campaigns by the public and interest groups and can help to attract media support; this is particularly important in the case of disinvestment.

The stakeholder group most affected by priority setting and disinvestment decision making are patients and service users. Services exist to serve the needs of these groups and they have a unique perspective, not only on what the services mean to them and how much they value them, but also on the effect that disinvestment or service change could have on them (Martin *et al.*, 2002b). This perspective gives patients and service users legitimacy, but it can mean that they become narrowly focussed on the services that directly affect them. Despite services existing for patients and users, as individuals they lack power in the decision making process and rely on support from interest groups and others. Recent years have seen moves

towards a more powerful patient voice (Jones *et al.*, 2004) but because of their lack of influence, there can be less urgency in attending to their claims, no matter how legitimate they may be.

Where patients and service users are unable to express their opinions, the role of their family members becomes more significant. Family members can advocate for their loved ones as well as sharing their experiences of the services provided and influencing how future priorities are set and where disinvestments are made. In their roles as carers, in particular, family members are oft ignored beneficiaries of health service provision and can offer a unique perspective (Stevens and Gillam, 1998). Family members are arguably better able than patients to see the wider context within which a decision is being taken, but their legitimacy within the process could still be challenged by their closeness to the decision. Without the need to rely on services themselves, family members may feel more able to speak freely about decisions that are being taken without the fear of it having a detrimental effect on their treatment. This freedom could increase their power as a stakeholder and make them more willing to challenge the views of health professionals if they feel that they are not being treated as an equal partner in the care giving process (Ward-Griffin and McKeever, 2000). Also, as families band together and form interest groups they become more difficult to ignore; this collective action, if supported by other stakeholders e.g. politicians, could increase the urgency of their claims.

The last external stakeholder identified by Patrick and Erickson (1993) is the

community, or 'public'; it is the role of this group, considered, in theory, to be the most important stakeholder in priority setting (Bruni *et al.*, 2008), that will be explored in depth throughout the rest of this thesis. A broad range of definitions of 'public involvement' have been proposed. For the purposes of this research, Florin and Dixon's (2004, p.159) definition of public participation as "the involvement of members of the public in strategic decisions about health services and policy at local or national level" has been adopted.

3.6 <u>The 'Public'</u>

The term 'public' has a wide range of different meanings depending on how it is interpreted, Lomas (1997) identified three roles that a member of the public can take in a priority setting decision making context. The first of these roles is the taxpayer; in this role the individual funds public spending and takes a view on how much of this spending should be allocated to health against other priorities. The second role is that of the patient (or potential patient); in this role the individual takes into account the kinds of health services that they would want to receive. The third role is that of the collective community decision maker who, as a local citizen, takes a view on how health funding should be used in their local area and what services should and should not be offered.

Any individual can fall into any, or all, of these groups at any one time and, as Lomas (1997) highlights, this can lead to personal dilemmas and a difficulty in reaching a decision on priorities. This thesis will focus on the public in their roles as taxpayers and collective community decision makers. As far as possible the

public and patients will be viewed as separate groups and the research will exclude patient views on disinvestment and priority setting because this group have a vested interest in protecting the services that they use. The taxpayers and collective community decision makers considered in this research will be expected to be able to view priority setting and disinvestment decisions under a 'veil of ignorance' (Rawls, 1971) as far as possible i.e. they will not have any preconceived ideas about how decisions may affect them personally.

The public's legitimacy as a stakeholder in priority setting and disinvestment in public health systems stems from their role as a funder; as they have paid into the system then they have a legitimate, democratic right to have a say in how it runs (Wiseman *et al.*, 2003; Wilmot *et al.*, 2004). This legitimacy is supplemented by their knowledge of local priorities and what their community wants. The public do, however, lack power in the decision making process. Unless they are well organised and have support from other stakeholders e.g. interest groups, patients groups and politicians, their disparate voices can easily be overlooked and ignored. This lack of power can result in a lack of urgency in attending to the needs of the public and addressing their concerns; organisations may view it as preferable to meet the needs of more concentrated and vocal groups of stakeholders first i.e. making decisions on the basis of decibels (Bate and Mitton, 2006). Despite variable levels of power and required urgency there are a number of compelling reasons to involve the public in priority setting and disinvestment decision making. These will now be explored in depth along with any counter arguments.

3.7 <u>Involving the Public</u>

If a decision is taken to involve the public in priority setting decision making then it will usually be taken with ideological or pragmatic motivations in mind (Abelson et al. 2003). Williams et al. (2012) categorise these into three overall groups- instrumental, political and educative. These groupings provide a useful framework within which to discuss these ideas, although the researcher feels that the term democratic motivations better describes those motivations categorised as political by Williams et al. (2012). As such, this term will be used through the rest of the thesis.

3.7.1 <u>Instrumental Motivations</u>

In their original framework, Williams et al. (2012) identify the instrumental motivations for public involvement as those which relate to the ends or outcomes of decision making, specifically the improvement that public involvement can make to the "quality, consistency and appropriateness of resource allocation" (Williams *et al.*, 2012, p.31). For the purposes of this thesis, however, another slight addition will be made to the Williams et al. (2012) framework, and their understanding of instrumental motivations will be extended to also incorporate motivations relating to public acceptance of decisions. This brings the understanding of instrumental motivations for public involvement into line with other published work extension (Litva *et al.*, 2002; Conklin *et al.*, 2010).

The first instrumental motivation is to gain public support for potentially unpopular decisions. As has already been discussed, disinvestment decisions stir

emotions and they are very unlikely to be welcomed by the public, but involving citizens in the decision making process can help decision makers to gain popular support for the tough choices that they are making (Rowe and Frewer 2000; Abelson et al. 2002). Involving the public in decision making can give them a sense of ownership over their services and may enable decisions which rely on a change in service user behaviour to be implemented more effectively; this is particularly important in the case of disinvestment by substitution as discussed in the previous chapter.

Similarly, Goold et al. (2005) suggests that, through involvement in priority setting decision making, the public give consent to the difficult decisions being taken and that, by participating, the decisions are self-imposed by the public. Although perhaps more relevant at a macro level, the consent drawn from public involvement can also make it easier for those in power to govern their people and can make it less likely that they will oppose spending decisions that are taken at a national level (Irvin and Stansbury, 2004).

Involving the public in disinvestment decision making can ensure that the decisions that are taken reflect the wider values and priorities of the community (Ham, 1993) and that they are 'grounded in citizen preferences' (Irvin and Stansbury, 2004, p.55). In this way, involving the public can help to ensure that legitimate decisions are reached and that the process followed is fair (Daniels and Sabin, 2002).

Incorporating the public perspective can contribute significantly to improving the quality of decisions and policies that are made (Bishop and Davis, 2002) and can help to deliver "better informed decisions" (Petts, 2008, p.832). Without proper engagement with the public, decisions that are taken would only be reflective of the opinions of those people who were involved with health services e.g. patients and staff, not the public more widely (Goold, 2005).

Perhaps more negatively, involving the public properly can help to avoid future legal costs if decisions go against interested parties (Irvin and Stansbury, 2004). Failure to involve the public properly could result in decisions being challenged in the courts and potentially overturned, thus adding the cost of re-running the decision making process to the already significant legal bills.

3.7.2 Democratic Motivations

Health care organisations are accused of operating with a democratic deficit (Pratchett, 1999; Williams *et al.*, 2012) whereby decisions are taken centrally without the opportunity for democratic input by those people who pay for and use the services (Tritter and McCallum, 2006). Where health care decision makers are not democratically elected (as is usually the case) they are accountable to their seniors and to parliament, but not necessarily directly to the public (Cooper, 1995a); this lack of democratic accountability is the source of the democratic deficit in health care.

Involving the public in disinvestment decision making can not only make the

process more transparent (Abelson *et al.*, 2007) but can also make clear what the will of the public is and what their preferences are. Involving the public could, in some cases, also give them the opportunity to make decisions directly, thus taking power away from health care organisations and eradicating any democratic deficit. In both of these cases involving the public would have the effect of increasing the democratic accountability of health care organisations (Petts, 2008); they would either be expected to act upon public wishes or to give a clear explanation as to why a different decision had been taken.

3.7.3 Educative Motivations

The educative motivations for public involvement are linked to the learning that can result, on the part of the participants and the organisation, from public participation in decision making. The first educative motivation is that involving the public may enable them to appreciate the nature of the tough health resource allocation decisions that need to be made (Irvin and Stansbury, 2004). Involvement in the process may introduce the public to the notion of opportunity cost and make them fully aware of the constraints within which health systems work and the unavoidable trade-offs that must be made.

Involving the public may also increase their understanding of the need for change (Rowe and Shepherd, 2002). For instance, when disinvestment is proposed on the basis of quality and service improvement, the public involved in the decision making may appreciate the benefits of the decision rather than focusing on the fact that a service is being removed. Involvement may increase the public's

understanding of the rationale behind decisions as well as increasing their knowledge of how those decisions were taken (Irvin and Stansbury, 2004).

Increased knowledge of the decision making processes could help to improve public confidence in the health care system and increase the level of public trust in those charged with making decisions (Traulsen and Almarsdóttir, 2005). This benefit of involvement is based on the assumption that the public approve of the decision making processes used. If, having been involved in the process, the public feel that they have not had the opportunity to contribute effectively then this may actually decrease their trust in the system. In practice, research has shown that regardless of the level of public involvement, decision makers should only ever expect to achieve a level of critical trust from the public, whereby they are trusting of the organisation but maintain a healthy level of scepticism (Petts, 2008).

3.8 <u>Arguments Against Involvement</u>

Given the list of motivations for public involvement in disinvestment it would be easy to agree with those commentators who consider it to be axiomatically desirable (Mullen, 1999), but there are a number of important arguments against public participation that should also be taken into consideration.

Much of the literature around public involvement is either in favour or against it, but there is little recognition of the fact that not all members of the public want to be involved in complex decision making. In addition, few papers consider the type or level of decision when discussing whether or not the public have a desire to be

involved. Litva et al. (2002) are an exception to this; they found that the public wished to be involved in decision making at the system (macro) and programme (meso) levels e.g. in decisions which involved the overall health system or a particular treatment pathway or individual organisation within the system but were unwilling to be involved at an individual level e.g. when the decision concerned access to treatment for a particular patient or group of patients. Lomas (1997) coined the phrase 'reluctant rationers' in also highlighting the public's reticence to become involved in individual priority setting decisions, preferring instead to leave these to professionals.

Whilst appreciating the quality of much of the past writing on public participation, and the intentions with which it was written, Contandriopoulos (2004) makes three main criticisms of the literature. The first two i.e. that the literature is too normative and that it makes too many assumptions about the desirability of public participation, are not wholly relevant to this thesis but his third argument, that the literature is naive and too idealistic, is significant. In practice, disinvestment decisions are often focused around times of economic hardship (Mitton *et al.*, 2014)- times when organisations must act quickly to relieve economic pressure. The wide range of interests and views held by the public can mean that involving them in decision making leads to a protracted process (Lenaghan, 1999), and this may not be conducive with the requirement to make savings quickly.

Also the structure of decision making processes can severely limit the impact that public involvement can have. Often the final decision in priority setting comes

down to a mediating body which considers a wide range of views (Tenbensel, 2002), including those of the public and experts, and they must interpret the evidence before making a decision. Because of this it is difficult to ensure that public views and values hold adequate weight alongside those of experts, and it is difficult to ensure that they are fed into the process in the way that they were initially intended.

Rayner (2003) suggests that interpretation of public views is less of an issue. Because public engagement processes often rely on expert witnesses, and the public base their views on the evidence and information provided by these experts, there is rarely any significant difference between the views of experts and the public anyway. According to Rayner (2003, p.167), "there have been almost no credible outcome-based evaluations that have established that a public participation technique has led to a technically or socially sound outcome that otherwise would not have been reached." This questions the value of public involvement, and suggests limitations to the instrumental motivations for involving the public that were outlined earlier (Williams *et al.*, 2012).

The criticism that the public are not well informed or knowledgeable enough to contribute to disinvestment decision making is a well-established argument (Knox and McAlister, 1995) and it is true to say that, in instances where the public are being asked to reach a decision on a preferred disinvestment or priority setting option, expert evidence and guidance is usually required in order to assist them. Despite this guidance, and the fact that experts and other stakeholders could,

themselves, have a vested interest in disinvestment, the public are still criticised in the literature for being unable to contribute to decision making without their views being prejudiced by latent self-interest (Bruni *et al.*, 2008).

Deliberative approaches to public engagement (see section 3.10.1 and 3.10.2) attempt to overcome self-interest by seeking consensus among disparate public groups and asking participants to make decisions with general interest and the common good in mind (Bohman, 1996). Whilst these methods have been shown to be effective on a number of occasions (Coote *et al.*, 1997; Lenaghan, 1999) it could be suggested that they dilute public opinion and risk 'group think' (Janis, 1972) whereby the participants conform to each other's points of view and lose their individual perspectives. This dilution of views calls into question the value of public involvement, although the alternative, a decision making process dominated by professionals, could also potentially attract the same criticism.

Different stakeholder groups within the priority setting decision making process will view each of the long list of advantages and disadvantages of public involvement differently. As a result of this, there is a lack of clarity over the fundamental question of whether or not to involve the public in disinvestment decision making and why. This will be the first question tackled by the literature review and empirical research presented in this thesis.

3.9 Ladder of Participation

In practice there are a range of understandings as to what public involvement

entails. As such, the extent to which the public could, and should, be involved should be investigated in addition to the more fundamental 'whether' question. In order to consider levels of involvement fully, Arnstein's Ladder of Participation (1969) will be used as a framework to categorise and critique some of the different possible approaches to, and understandings of, public involvement in disinvestment decision making. These questions of the extent to which the public should be involved in disinvestment decision making, and the stage at which they should become involved will be the second and third research questions investigated through the empirical data collection and literature review presented in this thesis.

Arnstein (1969) uses examples of decision making processes in three US social projects; urban renewal, anti-poverty and model cities, to demonstrate different levels of public involvement. In her paper, she stresses the importance of recognising that citizen participation can mean vastly different things to different people. To her it refers to "the redistribution of power that enables the 'have-not' citizens, presently excluded from the political and economic processes to be deliberately included in the future" (Arnstein, 1969, p.216). By equating citizen participation with citizen power, Arnstein suggests that when organisations give citizens the opportunity to participate in decision making without giving them real power this is not real citizen participation at all.

Arnstein's Ladder of Citizen Participation condenses the spectrum of approaches to, and views of, public participation into an eight rung hierarchy. The ladder of

participation is shown in fig. 3.1.
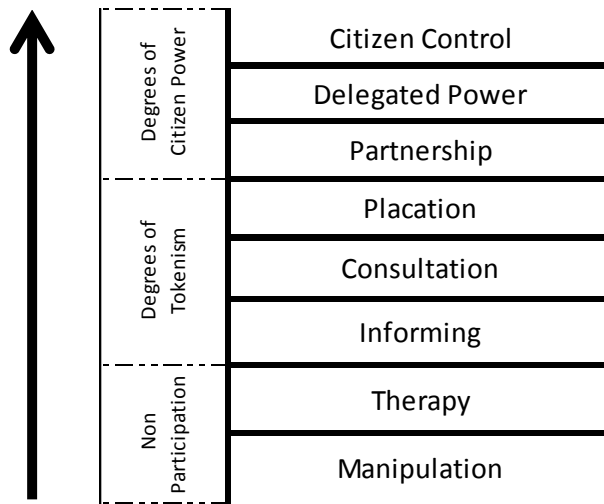
Fig. 3.1: Arnstein's Ladder of Citizen Participation (Arnstein, 1969)

3.9.1 Non-Participation

Manipulation and Therapy entail decision makers (or those in power) making

efforts to change the minds of citizens and to bring them around to agreeing with a

decision that has already been taken. These approaches fall under the heading of

non-participation and, in practice, could entail methods such as appointing a lay

member on to a committee to confirm a disinvestment decision that has already

been made. Alternatively, it could involve presenting a broad, general proposal for

disinvestment to a citizen's advisory board with no real power and asking them to

sign if off before adding detail to the plans and significantly altering the outcome

(maniplulation).

Therapy entails inviting selected public dissenters into group classes and

attempting to educate them and change their ways of thinking so that they come to

agree with society at large or, more correctly, those in power. Therapy does not seem to be much in evidence in the developed world today but Arnstein is clear that, at the time of writing, some decision makers did view it as a legitimate attempt to encourage public involvement.

3.9.2 Tokenism

The next three rungs of the ladder (informing, consultation and placation) represent levels of involvement that are tokenistic. These approaches allow the public to access the decision making process, they can see and hear how decisions are being made and, in some cases, have the opportunity to give feedback to decision makers, but there is no obligation for their opinions to be considered in the final decision.

Informing relates to a one way flow of information from those making a decision to the public. Approaches to informing may include the distribution of pamphlets or leaflets detailing disinvestments or service changes that are planned, and explaining the rights of service users, but without actually giving them the opportunity to influence the outcome of decision making. Providing information through a website or a pre-recorded telephone hotline, or inviting the public to a meeting which takes place too far into a disinvestment decision making process for it to make any difference would also be good examples of informing.

One step above informing is consultation whereby the public are provided with information and their views on disinvestment are sought, but there is no guarantee

that their feedback will be incorporated into decision making. Consultation may take the form of public meetings, surveys or invitations to respond to proposals by post or e-mail. For Arnstein (1969) the main purpose of this type of exercise is not, however, to gather public views but to ensure that the public have had the opportunity to participate in participation. It is this view of participation as an end in itself, without any guarantee that public views will even be considered, that makes consultation a tokenistic form of involvement.

Placation is the act of offering the public a tokenistic level of power within a decision making process. An example of this may be to include a lay person on a disinvestment decision making board amongst a host of professionals and experts from a health organisation. In this case, the lay person would be vastly outnumbered and, even if they were given voting rights, they would still have very little influence over the decision. In practice, organisations may even hand pick lay members to ensure that they were sympathetic to the organisation's perspective and were unlikely to object to the decisions that were being taken.

3.9.3 Citizen Power

The top three rungs of Arnstein's ladder are categorised as citizen power approaches. The first of these is partnership whereby citizens and traditional decision makers are on an equal footing and the two groups work in tandem to make decisions. The examples of this approach used by Arnstein are joint policy boards and planning committees where any recommendations for change must be approved by both the public and decision makers. In practice these partnership

arrangements have often come as a result of previous disagreement between the citizens and decision makers where the public have demanded more say and influence (Arnstein, 1969). In order to work effectively, and to come about in the first place, they rely on strong structures within the citizenry. Apathy and/or disagreement will lead to more tokenistic approaches prevailing.

Delegated power is where officials cede power on certain decisions, or aspects of decisions, to the public. In disinvestment decision making this could take the form of professionals forming the minority on an advisory board and, in a role reversal from placation, being made to explain their perspective in the hope that the public may come round to their way of thinking. Alternatively, public officials could be excluded entirely from aspects of decision making processes, with the public being given the autonomy to take decisions for themselves.

The top rung of Arnstein's ladder is citizen control. This approach seeks to give citizens full decision making control over their services and to allow them to set policy and manage structures. This approach would seek to remove intermediaries between the public and funders/ service providers, and the public themselves would set the conditions under which policies could be altered by others. In citizen control the traditional power holders would work to implement the decisions taken by citizens.

3.9.4 Applying Arnstein to Health Disinvestment

Arnstein's ladder was initially written with housing and planning in mind but over

the last forty years has been applied to a wide variety of fields including business (Cummings, 2001) and tourism (Aas *et al.*, 2005). From the perspective of public involvement in health decision making, Church et al.'s (2002) paper provides a good example of the applicability of Arnstein's ladder and demonstrates its appropriateness to research into health disinvestment decision making.

Church et al. (2002) aim to provide some theoretical guidance to public health organisations in Canada faced with tough resource allocation decisions and a government call to increase public involvement. The article addresses several key questions; one of which is what level of input could the community have in the decision- making process? The authors use Arnstein's ladder as a framework to help to answer this question, linking different approaches taken within Canadian health care to the different rungs.

An example of non-participation was considered to be public attendance at provincial round table meetings. Attendance at these meetings may convince dissenting members of the public that the right decision had been taken in the right way (therapy) or it may simply be an opportunity for the public to 'rubber stamp' the decisions (maniplulation). Either way, attendance at these meetings would give the public no real information about the decision making process and would give them no opportunity to provide input or feedback and, as such, would be hard to consider as anything more than non-participation.

Church et al. (2002) highlight lay membership of elected health boards as an

example of a tokenistic approach to public involvement. In these roles the public could be included simply as a means of sharing decisions that have already been taken (information) or they could be asked for their opinions without any binding commitment on the part of the organisation to act upon them (consultation). Alternatively, lay members of elected health boards could be given the right to vote on decisions but unless they were represented in significant number this would have little impact on the outcome (placation); without the opportunity to impact on the outcome of decisions, this involvement could only ever be tokenism.

Examples of citizen power are more difficult to come by and it is accepted that, within Canada, the majority of public participation activity takes place at the lower rungs of the ladder, rarely moving beyond consultation (Charles and DeMaio, 1993; Church *et al.*, 2002). In their article, Church et al. (2002) highlight hypothetical approaches to citizen power including providing citizens with personalised health budgets (citizen control) and giving the majority of votes on a health board to citizens (delegated power), but real life examples from the literature are lacking. For Church et al. (2002) a move towards partnership in priority setting decision making would be ideal but they accept that any move up the ladder from information and consultation would be hard fought progress.

Church et al.'s work (2002) shows the relevance of the debate about public involvement in disinvestment making and demonstrates the value of Arnstein's framework; the Ladder of Participation should help to provide some theoretical underpinning and explanation for the empirical findings from this study. Despite

the enduring popularity of Arnstein's work, however, it should be recognised that the framework is now over forty years old. In light of changes since 1969, and the ladder's application to new fields, a number of criticisms and proposed additions have emerged.

Alterations put forward by Tritter and McCallum (2006) in relation to Arnstein's Ladder's applicability to health care are particularly pertinent. They suggest that the ladder is too focused on citizens making decisions and the power struggle between public officials and the public themselves. A more complete framework would, in their view have more of a focus on involvement processes, methods and feedback systems.

Tritter and McCallum (2006) suggest that Arnstein's ladder is missing rungs and that it should also take into account the fact that different groups may desire to be involved in decision making in different ways. In addition, they suggest that the public should have a role in framing the problems and deciding what the remit and objectives of public involvement initiatives are in order that evaluation can take place after the event. Lastly, intensity and scale of involvement are also considered to be missing i.e. given the trade-offs between the time it takes to involve the public and the numbers of participants that can be involved, is it preferable for more participants to take part in low intensity involvement or for fewer participants to take part in high intensity involvement?

In addition to their missing rungs criticism, Tritter and McCallum (2006) also

suggest that Arnstein's model ignores a number of 'snakes' or potential pitfalls with public involvement. One of the main pitfalls that they identify is that the model assumes that citizen involvement equals citizen power; this can only be the case if professional groups are willing to cede power to the public, if they are not then involvement will only deliver the changes that the professionals are willing to make. In addition to this, they also suggest that citizen control is likely to lead to services which meet the needs of most but ignore the needs of the few and they suggest that delegated power means the subcontracting of user involvement to voluntary groups which adds further distance between decision makers and the public.

The validity of Tritter and McCallum's (2006) criticisms is recognised, and their work will be incorporated into the discussion of the findings, but the criticisms do not, in the eyes of the researcher, outweigh the vast number of reported successful applications of Arnstein's Ladder. The criticisms are also outweighed by the significant range of fields to which the Ladder has been applied and its intuitive nature. As such, Arnstein's Ladder (1969) will retain a central role in the critical appraisal of the empirical findings presented in the discussion chapter.

3.10 Methods for Involving the Public in Disinvestment Decision Making

As with understandings of public involvement, there are a range of different possible methods and approaches to gathering public feedback, opinions and values, and incorporating these into decision making processes. The method employed could depend on the field within which the decision is being taken, the

type or level of the decision, the purpose of the involvement or on the whim or expertise of those making the decisions. Whichever method is chosen, each has its advantages and limitations; there is no consensus on which is the most effective or successful (Macdonald, 1998). The empirical research presented in this thesis will seek to inform decisions on public involvement methods by establishing whether there are particular types of disinvestment decision in which the public should be involved to a greater or lesser extent; this will be the fourth research question addressed.

Mitton et al. (2009) carried out a scoping review and identified 405 different techniques that had been used to involve the public in priority setting decision making. In many cases these techniques were combinations and variations of existing approaches, so the authors distilled them into 15 broad categories. The findings from this paper will be analysed in more depth in the literature review but in order to start to bridge the gap between public involvement theory and disinvestment decision making, two of the methods identified in the scoping review will be introduced now. The two methods (citizens juries and deliberative polling) have been selected to reflect the assertion in the paper that deliberation is becoming increasingly common in contemporary priority setting, and to demonstrate the complexity and ingenuity of some public involvement processes.

3.10.1 Citizen Juries

Citizens juries, sometimes erroneously referred to as citizens panels (a related but distinct deliberative approach), originated in the USA and were first promoted by

Ned Crosby in the 1970s (Smith and Wales, 2000). Citizens Juries entail the presentation of evidence by experts in a particular field to a stratified, representative, random sample of 12-16 members of the public, known as the jury (Crosby, 1999; Mullen, 1999). Following the presentation of the evidence, the jurors have the opportunity to cross examine the expert witnesses and ask questions to clarify their understanding.

Citizens juries can have one of two purposes; they can either be deliberative in that the jury are asked to consider broad, open-ended questions and to offer guidance to policy makers, or they can be decision-making whereby jurors are asked to consider a number of possible options and to make a recommendation as to their preferred outcome (Lenaghan *et al.*, 1996). Having heard their evidence and cross examined the expert witnesses, the jurors are left to deliberate. Citizens juries usually last four days. As in a criminal trial, the jury consider the evidence that they have heard and, in the case of a decision-making approach, are usually asked to attempt to reach a consensus decision; this discussion and exchanging of views between participants is what makes citizens juries a deliberative approach. If a consensus cannot be reached within the time limit, however, a majority vote can be accepted (Ward *et al.*, 2003).

Mapping citizens juries against Arnstein's framework is not straightforward. It is clear that the approach constitutes far more than non-participation and tokenism but the extent of citizen power depends on the nature and purpose of the jury. If, for instance, a jury was asked a specific priority setting question and decision

makers were bound to act on their recommendation then this could be considered to be delegated power. In practice, what is more likely, however, is that the outcome of the jury would be considered by decision makers alongside other evidence. In some cases this may result in ambiguity over the extent to which the jury has actually influenced the final decision (Pickard, 1998) but in others it could constitute genuine partnership.

As an approach to public participation citizens juries offer a unique combination of advantages (Coote and Lenaghan, 1997). First, the widest possible range of simple and in-depth information from a broad spectrum of perspectives is made available and jurors have the opportunity to check their understanding. Through cross-examination the jurors can scrutinise the testimony of the witnesses and they are not forced to accept the information provided to them at face value. The four day schedule allows more time than most approaches to ensure that all the issues are fully explored and it ensures that there is plenty of opportunity for deliberation through plenary sessions, group work and private meetings before and after the testimony. The purposive sampling approach ensures the independence and representativeness of the members of the jury and the authority given to the jury to make recommendations or decisions means that decision makers are forced to either act on what has been decided or to give detailed explanations as to why they have opted not to.

In addition to the advantages highlighted by Coote et al. (1997) are the educational benefits that participants can glean from cross-examining experts and receiving

high quality data. Also, citizens juries can offer community-wide advantages in bringing together disparate groups of individuals to work together and forcing the participants to take a wider, societal view of the issue through deliberation and the push for consensus (Ward *et al.*, 2003).

Despite the range of advantages citizens juries are not without their limitations. First, as participants are paid to take part and there are associated room hire and travel costs, citizens juries can be an expensive way to involve the public, with the invitation-only nature of the events meaning that many of the benefits are restricted to those within the jury (Rowe and Frewer, 2000). In addition, the small number of participants in the jury means that it is very difficult for a representative sample of the community to be involved and, where consensus is sought, the citizens jury approach can stifle the views of individuals and force compromise (Ward *et al.*, 2003).

Citizens juries (or related consensus conferences) accounted for 18 of the public involvement exercises uncovered by Mitton et al. (2009). Despite their cost and the other limitations highlighted earlier, their popularity amongst decision makers appears to be growing. Further discussion and critical analysis of specific priority setting citizens juries will be included in the literature review chapter.

3.10.2 Deliberative Polling

First conducted in the late 1980's, deliberative polls aim to measure public opinion and increase political equality through education and engagement (Goodin and

Dryzek, 2006; Fishkin *et al.*, 2010). Although sharing many similarities with standard polling, deliberative polls are distinguished by the opportunity that participants have to discuss and consider their views as well as the in-depth range of information that they receive. This distinction is well elucidated by Luskin et al. (2002, p.459);

"An ordinary poll is designed to show what the public actually thinks about some set of issues, however little, irreflective, and changeable that may be, and generally is. A Deliberative Poll is designed to show what the public would think about the issues, if it thought more earnestly and had more information about them." Luskin et al. (2002, p.459)

The process of deliberative polling is to take a random sample of 250-500 individuals and then to measure their opinions on a particular subject or topic using a standard instrument, usually a survey or questionnaire. Having gathered their initial thoughts, the participants are then sent detailed information on the subject about which they have just been surveyed and are given time to read and digest the information before being brought together onto one site (Luskin *et al.*, 2002). When at the single site, the participants are split into pre-assigned groups and asked to discuss the topic at hand; these smaller groups then produce questions which are directed at a carefully selected panel of experts in front of the whole sample (Goodin and Dryzek, 2006).

Following the panel session the participants are then asked to repeat the initial

opinion-measuring exercise. This quasi-experiment allows the convenors of the poll to assess the way that the information and deliberation has changed the opinions of the participants and gives a sense of what the opinions of a hypothetically well-informed broader public would be (Fishkin, 1991).

Similarly to citizens juries, the categorisation of deliberative polls against Arnstein's ladder depends on the purpose of the exercise. Offering such a broad sample of the public the opportunity to have a say in decision making places deliberative polls above non-participation and tokenism but, again, it is unclear whether they represent partnership or delegated power. If the public were asked a specific, clear question, such as 'should the health authority disinvest in hip surgery in order to expand cataract surgery?' then it is conceivable that deliberative polling could be used a means of delegating power from decision makers.

What seems more likely, however, is that deliberative polling could be used to establish changes in public values e.g. by asking 'in order to balance our budget, which of these kinds of services i.e. emergency care, elderly care, or elective surgery should we disinvest in?' This data could then be considered alongside a range of other evidence. The weighting of public values and the scope of the other evidence incorporated would be down to decision makers; in this case deliberative polling would constitute partnership at best and possibly placation if public values were sufficiently outnumbered.

Deliberative polling has two main advantages over other forms of engagement. The first of these advantages is that each individual participant has an opportunity to contribute, and that regardless of the opinions of the rest of the group, they do not have to compromise in order to reach a consensus point of view. Similarly, the second advantage also comes as a result of sampling; due to the large, varied and representative sample (Fung, 2003) deliberative polling highlights a wide range of opinions, demonstrating "the views that the entire country would come to if it had the same experience". (Fishkin, 1995, p.162).

Despite its advantages, deliberative polling also has a number of limitations when compared with other methods. Given its one-off nature, and how far removed the participants can be from the issue, deliberative polling can have limited impact in encouraging further active citizenry amongst the participants beyond the process itself. In addition to this, as deliberative polls are often not attached to any government bodies and state officials are not bound to alter course on the basis of findings through deliberative polling, it can mean that deliberative polls have minimal impact on policy (Fung, 2003).

In addition, the reliance on facilitators, the large sample and the fact that the views of every single individual must be taken into account, not just the group consensus, can make deliberative polling a very expensive method (Abelson et al., 2003b; Williams et al., 2012). This cost has, in some cases, been covered by media companies who make entertainment from the way that participants' opinions change (Goodin and Dryzek, 2006) but it is perhaps not advisable to rely on this

kind of funding when designing a public engagement process. Despite the costs, Mitton et al. (2009) uncovered 23 examples of deliberative polling (or the similar planning cell approach) being applied to priority setting decision making.

3.11 Summary and Research Questions

From the chapters so far it is clear that there are a range of approaches to disinvestment decision making and a wide variety of stakeholders with different requirements and expectations of the process and the outcomes. Of these, the role of the public has been analysed in depth with the arguments for and against involvement having been identified and critiqued, and the breadth of understandings of the term 'public involvement', and methods to gather public values, having been examined using Arnstein's ladder. Despite this examination and analysis, there remains a significant lack of clarity as to whether or not the public should be involved in disinvestment decision making and, assuming that they should, what this involvement should look like and when/how they should be involved. In light of this, empirical research to answer the following questions is proposed:

- Should the public be involved in disinvestment decision making? Why?

- To what extent should the public be involved?

- At what stage should they become involved?

- What types of decision should the public be involved in?

In order to establish what the state of existing knowledge around public involvement in disinvestment decision making is, a comprehensive review of the academic literature was carried out. This review centred around the research questions outlined above and builds upon the previous two chapters. The literature review helps to highlight any gaps in the literature on public involvement in disinvestment decision making and will be used to inform the methodological approach taken to answering the research questions.

Chapter 4- Literature Review

4.1 Introduction

This chapter details an in-depth review of the literature relating to public involvement in disinvestment and priority setting. Its purpose is to uncover and critically analyse the most relevant knowledge, theory and research relating to the research questions. In addition to this, the review also seeks to highlight gaps in the literature and guide the subsequent direction of the study. The chapter begins by outlining the approach taken to identifying the relevant literature, including the search terms and databases used, before the results/ outcomes of the literature search are detailed and the findings are synthesised. Findings from the literature review are presented in a narrative form with key themes grouped into a series of contested propositions relating to public involvement in disinvestment decision making. These propositions represent the key fault lines and areas of debate and disagreement uncovered by the researcher during the review and they were used by the researcher to highlight areas of convergence and conflict within the published empirical and theoretical literature.

4.2 Review Objectives

Having analysed the ways in which priority setting and disinvestment decisions are taken, and considered the strength of claims that different groups of stakeholders have for involvement, a series of research questions focusing on the role of the public was proposed by the researcher- these were stated in the summary of chapter three.

In order to further refine these research questions and problematize the research area by highlighting where the existing literature is incomplete, inadequate or incommensurate, a comprehensive review of the existing literature was carried out (Bryman, 2008). The approach to the review was based on the narrative synthesis process recommended by Popay et al. (2006) (see below), although minor alterations to the steps and the terms used to describe them were made where necessary.

1. Identifying the review focus, searching for and mapping the available evidence

2. Specifying the review question

3. Identifying studies to include in the review- Literature Searching

4. Data extraction

5. Evidence synthesis

6. Reporting the results of the review and dissemination

The purpose of the literature review was to uncover existing knowledge relating to public involvement in disinvestment decision making, to establish whether there were gaps in this knowledge, and to investigate the ways in which further research could help to fill these gaps and contribute to what is already known (Hart, 1998). In the first instance the review was concerned with uncovering existing

knowledge, theory and research around whether or not the public should be involved in disinvestment decision making and why; its focus then shifted to the extent to which the public could/ should be involved, the stage in the process that they could become involved and the types of decision that they could be involved in. In order to ensure that only the most relevant material was included in the review a strict set of inclusion criteria was employed; these were applied to all of the literature uncovered during the broad database search detailed below.

4.3 Literature Review Approach

4.3.1 Searching the Literature

In order to ensure the comprehensiveness and rigour of the literature search a systematic approach was taken to the review. A search strategy was devised to ensure that all relevant academic and grey literature from potentially applicable fields- Management, Social Sciences, Economics, Health, Medicine and Psychology- was subjected to the inclusion criteria. The first stage of this process was to devise comprehensive search terms; the final list is shown below.

| 'Health' or 'Health care' | AND | ('Public' AND 'Participation' or 'Involvement' or 'Engagement') OR ('Citizen' AND 'Participation' or 'Involvement' or 'Engagement') OR ('Community' AND 'Participation' or 'Involvement' or 'Engagement') OR 'Lay' or 'Lay Person' | AND | 'Disinvestment' |

Table 4.1: Initial Literature Review Search Terms

A wide range of health and social policy related databases were searched in order

to identify as much published and unpublished literature as possible. The Medline database, which brings together a range of health related indexes including sources relating to Medicine, Nursing and Allied Health Professions was searched, along with ABI Inform (Health and Medicine) and CINAHL Full text, to ensure that clinical perspectives were represented. The Psycinfo database was searched to incorporate any research into mental health disinvestment as well as aspects of Psychology and Management/ decision making. 'Web of Science', which incorporates the SSCI (Social Sciences Citation Index) was included to ensure that Social Science perspectives, including Economics, were considered. In order to ensure that evidence related to Management and Health Administration was included, the Health Management Information Centre (HMIC) database was also searched; this also provided access to government publications and other grey literature.

Where possible, mesh terms were used to help to target searches and ensure that important sources of evidence were not overlooked. The search terms were entered into the 'keyword' field in most instances but where this was not possible they were searched for in article titles. Search results from the initial string were as follows:

		Cinahl Full Text-	Medline	ABI-Inform (Health and Medicine)	PSYCinfo	HMIC	Social Sciences Citation Index (SSCI)	Web of Science
1	Health care (mesh term)/ 'Health' or 'Health care'	627,884	1,925,870	2,364,558	434,267	174,477	1,120,503	1,178,895
2	consumer participation/ or patient participation/ (mesh term)/ ('Public' AND 'Participation' or 'Involvement' or 'Engagement') OR ('Citizen' AND 'Participation' or 'Involvement' or 'Engagement') OR ('Community' AND 'Participation' or 'Involvement' or 'Engagement') OR 'Lay' or 'Lay Person'	7,559	52,920	90,682	127,958	11,707	136,728	140,142
3	1+2	2,472	32,981	7,722	24763	7,636	4,799	5,141
4	Disinvestment	12	90	51	87	57	128	137
5	3+4	0	4	1	2	5	1	1

Table 4.2: Results from Initial Literature Review Search String

As the table above demonstrates, the initial search string produced only very limited results, with the term disinvestment being the main limiting factor. Whilst the lack of results highlighted the potential contribution of the proposed research, it did, however, mean that search terms had to be broadened in order to ensure that as much relevant theory and research was uncovered as possible.

Whilst disinvestment is a distinct aspect of the priority setting process which, for reasons highlighted in Chapter Two is worthy of research in its own right, there are significant overlaps between the disinvestment and priority setting literatures. In light of this incorporation of the wider priority setting literature was felt to be an important next step. As such, the search terms were broadened to incorporate a wider range of related words and phrases; see table below for details.

'Health' OR 'Health care'	AND	('Public' AND 'Participation' OR 'Involvement' OR 'Engagement') OR ('Citizen' AND 'Participation' or 'Involvement' or 'Engagement') OR ('Community' AND 'Participation' OR 'Involvement' OR 'Engagement') OR 'Lay' OR 'Lay Person'	AND	'Disinvestment' OR 'Cuts' OR 'rationing' OR 'decommissioning' OR 'de-listing' OR 'Health Technology Reassessment' OR 'divestment' OR 'de-insurance' OR 'discontinuance' OR 'service termination' OR 'exnovation' OR 'medical reversal' OR 'priority setting'

Table 4.3: Revised Search Terms

The results of the revised search string are shown in table 4.4 on the following page. Results have been restricted to those from 1990 onwards in line with the inclusion/ exclusion criteria detailed later in the chapter;

		Cinahl Full Text-	Medline	ABI-Inform (Health and Medicine)	PSYCinfo	HMIC	Social Sciences Citation Index (SSCI)	Web of Science
1	Health care (mesh term)/ 'Health' OR 'Health care'	627,884	1,925,870	2,364,558	434,267	174,477	1,120,503	1,178,895
2	consumer participation OR patient participation/ (mesh term)/ ('Public' AND 'Participation' OR 'Involvement' OR 'Engagement') OR ('Citizen' AND 'Participation' OR 'Involvement' OR 'Engagement') OR ('Community' AND 'Participation' OR 'Involvement' OR 'Engagement') OR 'Lay' OR 'Lay Person'	7,559	52,920	90,682	127,958	11,707	136,728	140,142
3	'Disinvestment' OR 'Cuts' OR 'rationing' OR 'decommissioning' OR 'de-listing' OR 'Health Technology Reassessment' OR 'divestment' OR 'de-insurance' OR 'discontinuance' OR 'service termination' OR 'exnovation OR 'medical reversal' OR 'priority setting'	1975	22273	22240	2936	3617	70445	71,993
4	1+2+3 (Limited to 1990-2013)	5	452	16	54	214	25	22

Table 4.4: Results from Revised Search String

As well as using the electronic databases to highlight relevant research, a process of hand searching was also carried out and the reference lists of the literature items identified through electronic searching were scoured to check for any other relevant research and theory. The publication lists of the most cited authors were also searched online to ensure that all relevant work was included, as well as a search using Google Scholar. This additional search increased comprehensiveness and highlighted research that may have been missed during the initial electronic

trawl (Aoki *et al.*, 2013).

4.3.2 <u>Inclusion/ Exclusion Criteria</u>

Following the identification of the broad literature sample any duplicate items were removed from the study. In addition to this, any items that had not been through a peer-review process were also excluded, unless the researcher deemed the circumstances to be exceptional e.g. if the item was a working paper produced by academics from an eminent department with a long history of research and publication in this area. The titles and abstracts of the remaining items were then read and a series of inclusion/ exclusion criteria were applied to identify the work that was most relevant to answering the research questions. A decision tree to demonstrate the inclusion/ exclusion process is detailed in Figure 4.1.

Literature items from around the world were included; the only exception to this rule was the exclusion of literature relating to developing countries. This was excluded because of the difficulty in comparing priority setting processes, characteristics and cultural values in well-funded health systems operating within well-developed democracies with those in countries which may be experiencing extreme scarcity of resources (Kapiriri and Norheim, 2004). Although not providing a clear distinction between developing and developed countries, in order to simplify decision making, only articles relating to Europe, North America or Australasia were included.

Where the literature was originally published in a language other than English a

translation was searched for and, assuming that the article met the other inclusion criteria, it was included in the review. Where no English translations were available, articles were excluded on practical grounds. The same applied where the article was not available electronically, no physical holdings were available at the University of Birmingham or University of British Columbia library and inter-library loans were not possible; only two items were excluded on these grounds.

Only literature relating to publicly funded/ insured health services was considered-literature relating to solely privately funded health services and other publicly funded services e.g. education was excluded. Second, only literature incorporating disinvestment in these health services was included; the definition of disinvestment outlined in Chapter Two was used i.e. the act of removing funding from services, treatments and technologies, affecting their accessibility to patients. Decisions solely regarding the investment of additional funding were excluded.

Fig. 4.1: Literature Review Decision Tree
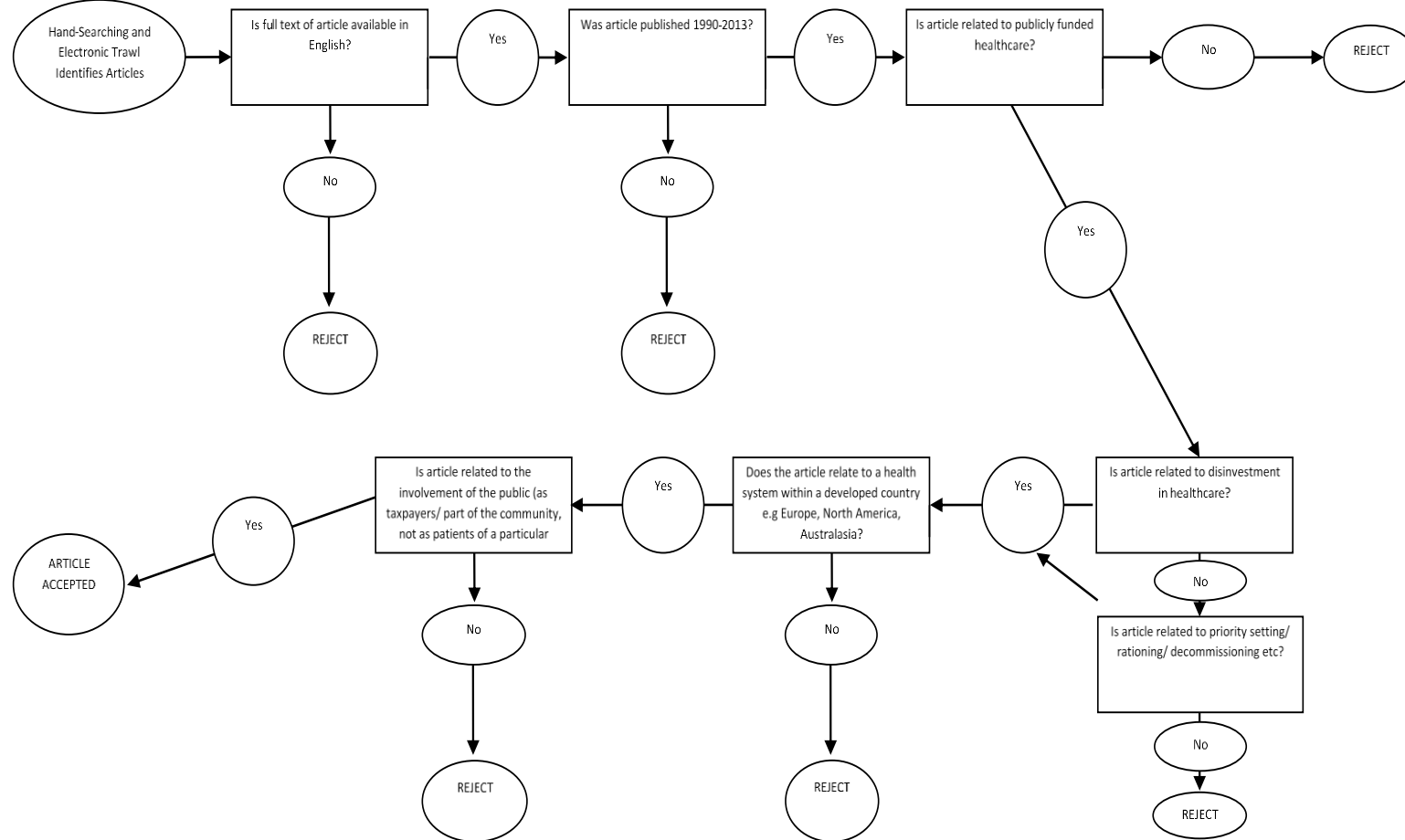
The role of the public, as taxpayers and members of the community, is of particular interest in this research and was pivotal in the literature search strategy. As such, literature which focused on the role of patients (as opposed to the public) in decision making about the services that they received, was excluded. Literature items published before 1990 were also excluded. This decision ensured that all contemporary research was included and ensured that experiences before, during and after the last two UK recessions were incorporated (Elliott, 2012), whilst also helping to manage the numbers of articles included and ensure that the theories and concepts highlighted were as up to date as possible. The abstracts/summaries of all items was read first and where the literature offered no assistance in answering any of the questions it was also automatically excluded from the review.

4.4 Review stages

4.4.1 Data Extraction

In order to extract data from the literature that met the inclusion criteria, each literature item was read in detail and a data extraction form was completed (this is included as Appendix Ten). As well as noting details of the paper and the author, this form allowed the researcher to note the key arguments that were being made by the author, the purpose of the paper, any key theories or concepts that were introduced and any underlying assumptions that the author may have made regarding public involvement in disinvestment decision making.

In addition to this, the form also allowed the researcher to make specific notes on

how the different literature items related to the research questions, for instance whether or not they demonstrated support for public involvement and why. These notes allowed for the researcher to establish the relevance of each of the items in terms of the purposes of the review. Ensuring that only the most relevant literature was incorporated was considered to be vital in producing a complete review (Webster and Watson, 2002). In light of this, only items which gave a view on at least one of the research questions, or were considered by the researcher to provide arguments relating to at least one of the research questions were included in the narrative synthesis.

During data extraction the researcher also noted whether literature items were theoretical or empirical in nature. Where papers reported empirical research, the researcher used the data extraction form to note details of the research methodology including the size of the sample, the research population, and how, where and when data was collected. For the theoretical papers, the researcher noted specific theories and concepts that were advanced, and considered the research traditions from which they emanated, and whether or not these theories had been applied to public involvement in priority setting or disinvestment elsewhere in the literature. Extracting this data allowed the researcher to make an assessment of the transferability of findings to different research contexts and to make a judgement on the extent to which they provided answers to the research questions set out in this thesis. Where literature items reported relevant findings and conclusions, but their transferability was judged by the researcher to be

questionable, they were incorporated into the narrative synthesis with caveats as necessary.

The decision to limit assessment of the included literature to its transferability and relevance, rather than necessarily its quality, stemmed from the challenge of applying quality criteria to such an interdisciplinary evidence base. However, the decision to exclude non-peer reviewed literature (in all but one exceptional case) enabled the researcher to ensure that only empirical studies with explicit methods and which followed a defined research design were included.

The findings from the data extraction process were recorded in a spreadsheet (an abridged version of this table is included in Appendix eight). This spreadsheet gives details of the relevance that each of the included literature items has to each of the questions and, where applicable, provides the researcher's assessment of transferability.

4.4.2 Evidence Synthesis

Following extraction of the relevant data, theory and evidence from the literature items which met the inclusion criteria, a narrative synthesis of the evidence was conducted (Popay *et al.*, 2006). This approach enabled research findings and appropriate theory from a range of fields to be combined and constructed into a convincing story which begins to answer the research questions and highlights the gaps in current knowledge.

Narrative synthesis was chosen over meta-analysis and other approaches more

closely related to systematic reviews because of the wide range of qualitative and quantitative methods that were employed within the reviewed literature (Mays *et al.*, 2005) and the range of different questions that were answered. This heterogeneity made a more aggregative synthesis of the evidence unfeasible (Popay *et al.*, 2006).

The first stage in the synthesis of evidence was to sort the spreadsheet so as to group together literature items with similar conclusions and findings relating to each of the research questions e.g. those showing support for public involvement. These groupings were then further sorted into types (e.g. empirical/ theoretical), academic discipline and country of origin. This sorting enabled the researcher to thematically analyse the data in relation to each of the questions, identifying the "prominent or recurrent themes in the literature, and summarising the findings of different studies under thematic headings" (Dixon-Woods et al., 2005, p.47).

The thematic analysis conducted by the researcher was part theory driven and part data driven (Braun and Clarke, 2006). Prior to conducting the thematic analysis, some of the codes and themes were circumscribed by the research questions, for instance each item was either supportive of public involvement, not supportive of involvement or unclear. For other questions, however, the themes were derived primarily from the data and the researcher was able to interrogate the notes produced during data extraction to devise a set of descriptive codes (Dixon-Woods et al., 2005). A process closely resembling the qualitative data analysis described in Chapter Seven was then followed, and similar codes were merged before being

linked together under overarching themes. These overarching themes represent the 'fault lines' within the literature; they reflect the identification of common themes but which contain divergent perspectives. The researcher considered these 'fault lines' to be the areas of greatest of dispute and discussion within the literature items identified by the search criteria. The coding structure for the thematic analysis is included as Appendix Eleven.

The outcomes of the thematic analysis and the fault lines identified were then considered alongside the characteristics of the data in order to allow the researcher to draw inferences e.g. that literature drawn from one academic field was particularly supportive of one of the arguments, or that one argument was supported in theory but that the empirical data led to different conclusions. The key themes and arguments identified and contested within the literature formed the basis of the contested propositions presented below and are the key output from the narrative synthesis. The results of this literature review are essentially contained within the propositions and the range of perspectives and points of consensus and disagreement in relation to each of them.

4.5 <u>Review Findings</u>

In total 92 literature items which met the inclusion criteria were identified. All of the databases yielded papers which were included but Medline and HMIC were particularly important in identifying literature which was not also available through other sources. Table 4.5 shows the sources of the papers that were included in the review, where papers were identified by more than one database

they have been included in the 'multiple sources' row. After Medline, the second highest contributor of unique literature was hand searching which yielded 21 individual literature items; this demonstrates the importance of hand-searching and the use of non-academic search engines in the identification of literature for this review.

Source*	Initial Search String	Revised Search String	Total
Cinahl	0	0	0
Medline	1	30	31
ABI/ Inform	0	0	0
PSYCinfo	0	3	3
HMIC	1	17	18
SSCI	0	0	0
Web of Science	0	1	1
Hand Searching	1	21	22
Multiple Sources	1	16	17
Total	4	88	92
*Note- only unique 'hits' have been counted against each database. Where literature was identified through searches of more than one source it has been counted under 'multiple sources'			

Table 4.5: Sources of Included Papers

Other than including 'disinvestment' within the title, or as a keyword, there was little to link the four literature items identified in the first search string (see table 4.5) to each other and a separate review would not have proved to be enlightening. As a result of this heterogeneity the disinvestment items (Street et al., 2011; Watt et al., 2012; Henshall et al., 2012; Robinson et al., 2013) are incorporated into the literature review alongside those uncovered by the wider search string.

4.6 <u>Summary of the Literature</u>

Of the 92 items that met the inclusion criteria, 52 reported empirical research, with the majority of the remaining 40 items offering theoretical perspectives/critiques

on the merits of public involvement in priority setting. In addition to these items there were also a small number of descriptive articles, editorials and commentaries- these were either written to compare and contrast existing work or to critique studies/ papers that had already been published.

The majority of items were drawn either from a primarily Health Economics or an Ethics discipline. Some were written for primarily clinical audiences-either Nursing, General Practice or Public Health- and a minority were written by general health services researchers. Many of the items have cross-disciplinary authorship, however, so it is difficult to be too specific and draw clear conclusions about the exact proportions from each of the academic disciplines.

In terms of year of publication, there is representation across every year since 1990 although it is clear that public involvement has become a 'hotter topic' in recent years. Similarly to the temporal spread there was also geographical distribution amongst the identified items, with empirical work hailing from Australia, New Zealand, Canada, Europe and the US included. By far the largest body of empirical work included in the sample, however, was conducted in the UK. Further information about all of the literature included in the review is available in Appendix eight, with methodological details of the more pertinent and relevant studies included in the main body of the review for ease of reading.

4.6.1 Critical Analysis

Amongst the 40 theoretical papers identified during the literature review there was

clear support for public involvement in priority setting and disinvestment, with only four of these literature items categorised by the researcher as being against public involvement (Richardson and Waddington, 1996; Walker and Siegel, 2002; Sabik and Lie, 2008; Stewart, 2013). This suggests a majority view that public involvement in decision making is considered to be a desirable thing, and a number of theories and frameworks were used in the literature to support this position e.g. Deliberative Democratic Theory (Norheim, 1999), Communitarianism (Mooney, 2005), Procedural Justice (Goold, 1996) and Accountability for Reasonableness (Friedman, 2008).

Of the four theoretical papers which displayed some opposition to involving the public in decision making, two were critical analyses of past priority setting exercises (Richardson and Waddington, 1996; Sabik and Lie, 2008), seeking to learn lessons from the ways in which decisions were made. This helps to demonstrate the divide in the theoretical literature uncovered during the review and gives a practical example of the potential difference between the desirability of public involvement in theory and how it is experienced in practice.

Likewise within the empirical literature there was majority support for public involvement, with 32 of the 52 identified items suggesting that the public should be involved. However, in-depth analysis shows that the majority of items were written from a position which was already supportive of public involvement i.e. their preference for engagement was a taken for granted assumption (e.g. Abelson et al., 2003; Goold et al., 2005). However, when the findings from the research

outlined are considered separately there are reasons to question the desirability of involvement e.g. levels of public knowledge/ information (Mitton et al., 2005), public willingness for decision makers to act as agents (Richardson et al., 1992; Coast, 2001) and a lack of consistency in public views (Shickle, 1997).

There was much congruence between the theoretical and empirical literature, with both showing overall support for public involvement in disinvestment decision making. The empirical literature however, contained more critical consideration of the role of the public and there was more acceptance within this literature that there could be some arguments against involvement. The theoretical literature tended to begin with a supportive position and then maintain this throughout- the only exceptions to this rule were the four papers discussed earlier.

In terms of extent of involvement, the theoretical literature describes a range of different roles but it seems to favour the public being involved to the extent that their values are incorporated into decision making (e.g. Kitzhaber, 1993; Mooney, 2005) or to the extent that they set the weights and criteria for others to make decisions (Friedman, 2008). Much of the empirical literature favours a similar role for the public in terms of them having an influence over decision making but not actually being responsible for final decisions (Mitton et al., 2011), but there is more of a focus on the public as one stakeholder amongst many. Whereas in the theoretical literature much of the discussion is around how much responsibility for decision making should be handed to the public by decision makers, the empirical literature contains greater recognition of the roles of other stakeholders and

suggests that these groups are also worthy of involvement in the disinvestment decision making process (Wiseman *et al.*, 2003; Henshall *et al.*, 2012). The stage at which the public should become involved is not investigated or discussed to any significant degree in either the theoretical or the empirical literature.

The empirical literature offers more clarity than the theoretical literature in terms of the types of decision that the public should be involved in. In many cases the theoretical literature makes the case for involving the public in priority setting or disinvestment without recognising the range of different types of decision this may include. The empirical literature makes clearer distinctions between micro, meso and macro level decision making, with public involvement favoured more heavily at the macro and meso levels than at the micro level (Litva et al., 2002; Wiseman et al., 2003; Theodorou et al., 2010).

There are three strands of research within the empirical literature. One focuses on particular methods of eliciting public views and assesses their effectiveness (Lenaghan et al., 1996; Danis et al., 2010; Baker et al., 2014), one focuses on gauging public values and views (Richardson, 1997; Cookson and Dolan, 1999; Dolan *et al.*, 1999), and the other focuses on whether or not the public should be involved in priority setting at all (Litva et al., 2002). The first two of these strands are written with a taken-for-granted assumption that public involvement is desirable and axiomatic (Mullen, 1999).

The third strand of empirical research would suggest that it is too simplistic to

assume that the public should always be involved in disinvestment decision making. The public themselves have differing levels of desire to be involved, preferring to take part in macro and meso level decisions over patient level ones (Litva et al., 2002; Wiseman et al., 2003; Theodorou et al., 2010). Similarly, the public feel that managers and doctors may be better placed than them to make decisions, and they would rather they acted as agents on their behalf (Mossialos and King, 1999; Coast, 2001). Also, if they are to be involved, evidence in the literature suggests that the public support having 'some' influence over decisions, but not 'a lot' of influence (Lees et al., 2002); research into methods and values gives them no opportunity to influence this.

The empirical research into methods and values assumes that all public participants want to be involved in all decision and that they all desire the same level of influence- research into whether or not the public should be involved disputes this. Whilst all three strands of the empirical literature are in agreement that the public should be involved, it is helpful to bear these nuances in mind when assessing the literature. The taken for granted assumption, within some of the literature, that public involvement in priority setting is an inherently good thing should be examined in the specific context of disinvestment decision making.

The following sections synthesise relevant findings from the 92 included literature items (listed in Appendix eight). Empirical and theoretical literature items have been incorporated into the review alongside each other in order to aid the critical assessment of each of the propositions which have been put forward. In addition to

the 92 literature items, reference is also made to material that, although not meeting all of the inclusion criteria, is nevertheless relevant to and/or aids analysis of the themes emerging from the primary review.

4.7 <u>Propositions</u>

In order to present the full range of views expressed and implied, four propositions encompassing the key themes and describing the 'fault lines' within the literature relating to public involvement in priority setting/ disinvestment decision making will be put forward. Propositions one, three and four link to the 'Benefits of Public Involvement' framework- Educative/ Democratic/ Instrumental (Williams et al., 2012) - laid out in Chapter Three, proposition two focuses more on approaches to involvement and the extent of influence that the public could or should have.

The arguments made in the literature, in favour of and against these propositions, will be presented and analysed. In supporting and challenging these propositions, the ways that the research question are approached in the literature will also be addressed. The conclusion to the literature review will aim to give an overall synthesis of the literature in answer to the research questions. Arguments for and against public involvement that were identified in an earlier, more rudimentary, literature review e.g. that public involvement makes decisions more likely to be accepted, have been laid out in full in Chapter Three. This chapter will focus on new insights uncovered through the comprehensive literature review and will, therefore, not repeat the arguments already made earlier in the thesis.

4.8 Proposition one: Health Disinvestment Decisions Affect the Whole Community; Public Involvement in these Decisions can Offer a Number of Benefits to the Community as a Whole

4.8.1 Health as a Conditional Good

A common theme within the literature is that health care is somehow different to other services in the way that it is viewed by individuals and by society as a whole-everyone desires a certain level of health but this cannot be bought or traded, one of the ways it can be delivered is through health care (McGuire *et al.*, 2005). It is argued that good health amongst the population can allow individuals within society to achieve their potential and it can boost the overall economy; this instrumentality has led health to be described by some in the literature as a 'conditional good'(Landwehr, 2013). Because of this, and the view that a certain level of health is a basic human right, there is a suggestion in the literature that it is only proper that society as a whole is involved in decisions to ensure, and define, a minimum allocation of care for all (Fleck, 1994). Clarke and Weale (2012) suggest that the provision of health services is considered to be a vital interest to the country as a whole and, whether one is ill now, has poorly relatives or will be ill in the future, decisions about how health care funding is used are of interest to everyone. This is reflected in the legal duty to consult with the public when reorganisation is being considered (Bowie *et al.*, 1995; Edgar, 1998b; Dolan *et al.*, 1999; Mossialos and King, 1999; Gallego *et al.*, 2007) and why several studies have shown that the public, themselves are keen to participate (Litva *et al.*, 2002; Wiseman *et al.*, 2003;Wiseman, 2005; Theodorou *et al.*, 2010).

This section offers an introduction to views on whether health, or health care, is different, special or conditional and therefore should be considered differently from other services. This review focuses specifically on the impact of these considerations in relation to disinvestment decision making. Further, more wide-ranging detail is provided by a number of authors including Norman Daniels (1993, 2001) and Amy Gutmann (1981) provide excellent starting points.

4.8.2 <u>Societal Benefits</u>

The literature review revealed three perspectives which suggest that, regardless of the outcome of decision making processes, the act of involving the public in priority setting has some value in and of itself. Wiseman et al. (2003) highlight the idea that, because health spending is of community-wide interest, public involvement can help to build and create stronger communities. In a time when modern values reflect a more individualist perspective (Jacobson and Bowling, 1995), it is suggested by some academics that public involvement can encourage the public towards being less self-interested and acting more on behalf of the community (Nelson, 1994).

Mooney (1998) builds on work by Broome (1989) to distinguish between individual claims on health resources and what he refers to as 'communitarian claims.' Under the theory known as 'communitarianism' (Mooney, 1998) the public are not only able to overlook their own self-interest but actually view the benefits of resource allocation from the perspective of the community as a whole. Individuals judge their own wellbeing on the extent to which community goals

have been delivered, not on the extent to which these community goals have had a positive impact on them personally; this is referred to in the literature as realised agency success (Sen, 1992).

This sense of community responsibility is reiterated by Goold et al. (2005) in their introduction to the 'citizen involvement in rationing model', which promotes the incorporation of citizen values into decision making (rather than necessarily asking citizens to make a direct choice) and by Mitton et al. (2011) in their analysis of the ways in which public values can be incorporated into priority setting decision making. Both of these groups of authors refer to public involvement helping to develop an active citizenry and they suggest that, through public involvement, the capacity of individuals to contribute can be enhanced.

In contradiction to the societal view of public involvement in priority setting is the perspective which suggests that involving the public may actually have a detrimental effect on society by giving citizens too much knowledge of how decisions are taken. One example of this highlighted in the literature may be in debunking the social myth that all resources are divided in an egalitarian manner (Nelson, 1994), another may be in the temptation for individuals to prioritise their own needs over the common good of the community (Lomas, 1997) or to take decisions in a utilitarian way, disproportionately affecting minorities within the community (Doyal, 1995, 1998). Systematic knowledge of the ways that decisions are taken and services are rationed, it is suggested, could undermine shared social values and reduce confidence in health professionals' and health services' ability

to provide the best possible care to all as and when it is needed. For the public, the detrimental effects of having too much knowledge of priority setting processes may actually outweigh the benefits of involvement; Obermann and Buck (2001) suggest that there could be a 'utility of ignorance' in not knowing how decisions are taken.

A similarly sceptical view of public involvement expressed in the literature is that it may encourage members of the community to become less scrupulous about the value of life and that, if value judgements are over extrapolated, this could result in moral dilemma for public participants (Nelson, 1994). The example used by Nelson (1994) in his theoretical synthesis of three justice based arguments for and against public involvement ('Just Caring'(Fleck, 1992a, 1992b), 'Just Rationing' (Daniels, 1993) and 'Tragic Choices' (Calabresi and Bobbitt, 1978)) is that of a decision by the public that $1m is too much to spend on a treatment to save a patient's life. This value judgement is then extrapolated to question whether, by the same reasoning, the knowledge of a future saving of $10m would justify taking the life of a patient with a long term condition that was incurable and expensive to treat but not immediately life threatening. Similarly, Zwart (1993) is critical of the Dutch government's attempts to implement communitarian decision-making in health priority setting because of their failure to address the moral dilemma caused by the dichotomy between the liberalist view of life (where each individual strives to live as long as possible regardless of opportunity cost) and the communitarian view (where each individual accepts the notion of a 'fair innings'). These

dilemmas imply that full public involvement in decision making may not always be desirable, and that there are some decisions in which involving the public may have negative consequences and may not offer the societal benefits outlined earlier.

4.8.3 The Risks and Rewards of Shared Responsibility

Despite the preference expressed within some of the literature to remove the public from priority setting decision making all together, it would not prevent difficult decisions, particularly those involving disinvestment, from needing to be taken and would not remove the possibility of moral dilemmas within the decision making process. Precisely because of this, and the size and difficulty of decisions, there are calls in the literature to involve the public in order to reduce the burden of responsibility placed on decision makers (Lees *et al.*, 2002; Wiseman, 2005). In the case of bedside rationing in particular, the moral and ethical burden placed on physicians is, according to Edgar (1998b), too much for them to bear and, in the absence of legislative/ mandatory guidelines (Chafe *et al.*, 2008), it is suggested that they need the support of publicly approved guidance when making the toughest decisions (Norheim, 1999). Explicit rationing processes (i.e. ones which involve the public) can, according to Fleck (1994), help physicians to balance their competing demands as both patient advocates and gatekeepers of societal resources whilst maintaining their moral integrity; this is another motivation for public involvement.

If organisations are to seek public involvement then there is a suggestion within

the literature that they must find the right approach and ensure that they are able to incorporate public views effectively; if the involvement exercise is deemed to be unsuccessful by the public/ media/ politicians, then it could put an organisation's reputation at risk (Chafe *et al.*, 2008). Examples of unsuccessful or tokenistic involvement criticised in the wider priority setting literature include the UK governments attempts to elicit public views by handing out 12 million leaflets in GP surgeries and supermarkets then asking the public to return a postal slip or log on to a website to inform them of their top three health spending priorities- this approach was criticised because the results and outcomes were not publicised after the event and the influence that they had had on spending was not made clear (Anderson and Florin, 2000)

4.9 Proposition two: There is no 'one size fits all' Approach to Public Involvement in Priority Setting, but Poorly Implemented Public Engagement is Worse than None at All

4.9.1 Multitude of Approaches

As was suggested in Chapter Three, public involvement in priority setting and disinvestment decision making could raise citizens' expectations of what can be achieved, with failure to act on public advice potentially met with anger and cynicism (Meetoo, 2013). For Jacobson and Bowling (1995, p.874), the political restrictions placed on organisations and their difficulty in meeting public expectations actually mean that public involvement "potentially raises more problems than can be resolved." If organisations are to involve the public then it is suggested that they must have a clear motivation for doing so, and a clear approach

in mind; without these any attempt at public involvement is likely to be flawed and will not deliver the desired outcomes (Stewart, 2013). This implies that decision makers are faced with a dilemma as to how best to involve the public and the extent of influence that they should be afforded. In order to avoid flawed involvement they must make a careful decision over the method used to illicit public views.

The findings from this literature review, although inconclusive for disinvestment-specific decisions, reinforce those of Mitton et al.'s (2009) scoping review which investigated public involvement in priority setting. Mitton et al. (2009) found that there was no consistency in the approaches taken by decision makers to involving the public, and that a huge range of approaches spanning the length of Rowe and Frewer's (2005) Public Involvement Typology ('Communication' through to 'Participation') were in evidence. Whilst this lack of consistency could be viewed as a weakness in organisational priority setting processes, an alternative view put forwarded by Menon et al. (2007) is that each organisation is unique and that there cannot possibly be a 'one size fits all' approach to public involvement; it is therefore appropriate to analyse some of the approaches taken within the reviewed literature in more depth.

One of the conclusions from Mitton et al.'s (2009) review was that there was a general trend towards more deliberative methods for involving the public. This review can report similar findings, in relation to the wider priority setting literature, with public involvement efforts from the earlier part of the included

period i.e. 1990-2000 often revolving around large scale surveys or questionnaires completed by individuals and detailing the services that they, as an individual, valued most highly (Richardson et al., 1992; Bowling et al., 1993; Lees et al., 2002). Approaches then seem to advance to more collective, deliberative methods in later years (Goold et al., 2005; Danis et al., 2010; Williams et al., 2014).

4.9.2 <u>Non-Deliberative and Deliberative Involvement</u>

Discrete choice experiments (DCEs) can be used to elicit public values and to establish which health service attributes are most important to the community. DCEs ask participants to decide between pairs of services- the descriptions of these services have been written specifically to accentuate particular attributes (e.g. proximity to patient's home or service opening hours). None of the service options are 'perfect' and the pairs of services are rigged so that the participants are forced to make a decision based on the attributes that they value most- following a number of service prioritisations calculations can be carried out to establish which attributes outweighed others most often and were therefore considered to be most important.

In the case of Watson et al. (2011) participants were asked to decide between 64 pairs of services in order to establish which of 10 attributes of health they considered to be most important in prioritising future health spending in Dumfries and Galloway, Scotland. Green and Gerard (2009) also promote the use of DCEs, with their work focusing on the incorporation of public values into investment decisions made using Health Technology Assessment (HTA)- it is possible that

DCEs could be used in a similar way to meet the challenge posed by public involvement in HTA disinvestment too (Henshall et al., 2012). Further, more in depth analysis of the broader DCE literature, which was not identified in this review, was carried out by DeBekker-Grob et al. (2012) and they provide a more comprehensive introduction to the method.

One of the more prominent early examples of public involvement in rationing identified within the literature took place in Oregon, USA. The background to this prioritisation exercise i.e. the desire to increase eligibility for health services to all Oregonians who fell beneath the federal poverty line (Kitzhaber, 1993) was detailed in Chapter Two, but the specific efforts to incorporate the public voice were not mentioned.

The public were involved throughout the process of ranking the possible treatments and services. The methods used to gather public opinion were typical of the time, with a telephone survey used to rate different disability states (these ratings would then feed into economic analysis), a series of public meetings held to establish the value that citizens placed on nine broad service areas (e.g. "treatment for alcoholism or drug addiction") and a follow up series of public hearings allowing for 'special pleading' on behalf of particular services (Dixon and Welch, 1991). Oregon remains significant because it was amongst the first genuinely explicit health rationing programmes in the world; within the literature it was referenced regularly and used as a comparator for other priority setting processes (e.g. Redden, 1999).

Despite its significance, the methods used by Governor John Kitzhaber and his team in the Oregon experiment were soon superseded in the literature and, as noted by Mitton et al. (2009), a move towards more deliberative processes took place. As knowledge of deliberative approaches spread following the first UK based citizens jury (Lenaghan *et al.*, 1996), more and more innovative approaches to public involvement in priority setting became evident.

Amongst the examples uncovered during this review of the literature was Williams et al.'s (2014) combined '21st Century Town Hall Meeting' and 'World Café' approach which incorporated group discussion, interactive voting and dice games to demonstrate to the participants the potential effects of the prioritisation decisions that they were taking; in this instance they were asked to set general principles for spending at a Primary Care Trust level. Another similar approach was the 'Choosing Health Plans All Together' (CHAT) technique used by Goold et al. (2005) which asked public participants to allocate limited funds to different health services by inserting pegs into a wooden game board- each service required a different number of pegs and there were not enough pegs to deliver all of the services. Participants allocated their pegs firstly as an individual, then as a small group, then as a larger group and lastly as an individual again (the last allocation of pegs was taken as the participants' preferred prioritisation of services). In between each round, group discussion took place and adverse events/ health conditions were assigned randomly so as to demonstrate the effects of the decisions not to fund.

Both of the Williams et al. (2014) and Goold et al. (2005) examples use discussion, chance, deliberation and game play to make participants think their decisions through thoroughly and they were both shown to be successful in eliciting views, but they were time-consuming. Both approaches also relied on participants working together, compromising and seeking to find consensus which may not always be possible (Hofmann, 2013). In the case of Williams et al. (2014), despite the success of the approach, it was reported that, operationally, public opinion had little impact on the spending decisions of the PCT (Primary Care Trust)- it was not made clear the difference that Goold et al.'s (2005) findings made to actual spending decisions. Whilst these approaches may be suitable for specific decisions at a regional or national level, they may not be appropriate in all cases; within the wider priority setting literature, although not the disinvestment-specific literature, an alternative to these deliberative approaches cited on a number of occasions was the DCE.

4.9.3 Priority Setting Boards and 'Informing' as Involvement

Within the literature there is a common theme which suggests that, despite the public being the 'most important' stakeholder (Bruni *et al.*, 2008), their voice should be just one amongst many involved in the decision making process (e.g. Robinson et al., 2013). One way to incorporate public input alongside other stakeholders, suggested in the wider priority setting literature, is to form a priority setting board or committee which includes public representation (Ayres, 1996; Goold, 1996; Hofmann, 2013) alongside general and specialist clinical

representation, management representation, patient representation and a committee chair (Martin *et al.*, 2002a).

Priority setting boards are, however, criticised in the literature as 'mediating' institutions which interpret information (including public values) and make decisions on the basis of this interpretation (Tenbensel, 2002). Depending on the make-up of the board (and the strength of influence of the public representatives), the result may be that the final priority setting or disinvestment decision is not actually representative of public views. Despite this, there is little call in the literature for the public to be given final decision making responsibility- they are usually given information and asked to deliberate and make a recommendation (e.g. Goold et al., 2005; Watt et al., 2012) but they are rarely asked to make a decision which will definitely be acted upon. Indeed, in the literature it is unusual for the overall outcomes of public involvement in priority setting (i.e. the effect that involvement had directly on investment/ disinvestment decisions) to be reported. One exception to this rule is May (2008) who concludes his empirical investigation into community priorities in Barnet, London by publicising the fact that the PCT had acted upon the recommendations from his involvement exercise by increasing funding for hip operations, increasing GP access and reducing funding for 'low priority treatments' e.g. varicose veins- these were the top three priorities identified.

The notion of informing the public of decisions that have been taken, how they have been taken and what influence citizens have had is central to the publicity

condition of Daniels and Sabin's Accountability for Reasonableness (A4R) framework detailed in Chapter Three (1997; 2000; 2008). Friedman (2008) questions whether public involvement is sufficiently scrutinised under A4R and suggests that a fair and legitimate priority setting process should do more than simply publicise- the public should be involved throughout the process (depending on the type/ level of decision- see Proposition Three) in order to ensure that the 'relevance' criteria is also delivered sufficiently. One priority setting process that may struggle to meet Friedman's (2008) more stringent criteria is put forward by senior decision makers in Australia who suggest that the role of the public in setting priorities for high cost medications should be limited because of the highly technical nature of the decisions. They suggest that it would be sufficient for the public to simply be kept informed of the outcomes (Gallego et al., 2011); this not only demonstrates the need to consider the method and extent of involvement on the basis of the type of decision but also shows the subjective nature of questions around fairness and legitimacy of processes.

4.10 Proposition three: The Public Should be Involved in Disinvestment Decision Making Because they Want to be Involved.

4.10.1 Public Views on Involvement

Wiseman et al. (2003; 2005) conducted a survey of 373 members of the public and 43 health professionals (the professional backgrounds of these participants is not clear although the research setting suggests that they may be GPs) in Sydney, Australia. Both groups were asked whether they felt that public preferences should

be taken into account in decisions at different levels (health care programme level, medical procedure level and population group level) and which other groups could/ should be involved. Both the health professional group and the public group showed clear support for public involvement at all levels. Wiseman et al.'s findings are supported by research carried out using the same methodology in Greece by Theodorou et al. (2010). Support for their own involvement in priority setting decision making amongst purely public samples has also been shown by Dolan et al. (1999) and Litva et al. (2002) in their focus group based research in the UK; there is, however, little empirical evidence relating specifically to disinvestment decisions.

Despite this demonstration of public support for involvement in priority setting, earlier research by Bowling et al. (1996) found that a majority of the participants in their interview survey (56%) actually felt that such decisions should be taken by doctors at a local level, rather than citizens. The results from Bowling et al.'s (1996) study could have resulted from the fact that participants were only allowed to choose one stakeholder group (e.g. doctors, the public, politicians) to have the most important say in decision making- if participants felt that there was a role for multiple stakeholders then the methodology did not allow for this view to be expressed. Despite this, the call for doctors to take precedence in priority setting decision making was also supported by Lees et al. (2002), who surveyed large public and clinician samples in Scotland and Mossialos and King (1999) who report findings from a survey of 1000 households across six European countries-

both of these studies allowed for multiple choices to be made.

4.10.2 <u>Public Understanding of 'Priority Setting'</u>

It seems difficult to countenance the idea that the findings of both Wiseman et al. (2003; 2005) and Bowling et al. (1996) could genuinely reflect public opinion i.e. that the public want to be involved in priority setting decision-making but they also want these decisions to be taken by doctors. Whilst the two conclusions appear contradictory, however, it is possible that, in addition to the methodological considerations highlighted previously, one or other of their results was swayed by the participants' understanding of what 'priority setting' actually was. There could be a number of explanations for this.

First, this (lack of) understanding could have stemmed from the fact that Bowling et al. (1996) asked their participants, "If health services rationing is inevitable, who should have most say in setting priorities for health services?"- the use of the term 'rationing' brings to mind the effects that broader priority setting allocation decisions have on individual patients or patient groups (Klein, 2010). Wiseman et al. (2003; 2005) referred to setting priorities, but did not use the term 'rationing', thus potentially evoking a less cautionary reaction from participants and leading them to consider the priority setting process itself rather than the consequences of specific decisions.

Second, through their methodology, Wiseman et al. (2003; 2005) made it clear that different levels of priority setting existed and that it was possible for the public to

have more or less input at different levels; Bowling et al. (1996) did not give participants this option. Wiseman's research showed that, whilst the public wanted to be involved in decision making at all levels, this support, was slightly less (74%) at the medical procedure level than it was at the health program level (78%). Similarly, Litva et al. (2002) presented eight public focus groups (n of participants=57) with three priority setting scenarios (one each at the 'system', 'programme' and 'individual' level) and then asked the groups whether or not they felt that the public should be involved in each of the decisions. Whilst these levels of priority setting focused even further towards micro level decision making than Wiseman et al. (2003; 2005) the findings do show a consistent pattern. The focus groups showed strong support for public involvement in decision making at the 'system' and 'programme' levels but they were more reticent to be involved in decisions relating to individual patients- they suggested that their involvement in these decisions should be limited to setting values or criteria but they did not want to be involved in actual decision making. Gold (2005) also noted a similar reticence on the part of the public to ration at the individual patient level and Lomas (1997) referred to citizens as 'reluctant rationers' when faced with such tough decisions.

Bowling et al. (1996) asked participants to prioritise between 12 pairs of treatments/ services, before asking them which groups they felt should be involved in decision making. The decisions focussed on treatments for groups of patients but not on decisions between specific individuals. On a priority-setting continuum,

the decisions in Bowling's work would seem to fit somewhere between Wiseman et al.'s (2003; 2005) 'medical procedure' level and Litva et al.'s (2002) 'individual' level. When viewed like this it is possible to understand why the public may sometimes seem keen to be involved in priority setting and, at other times, seem happy to leave decisions to others. The key point is the kind of question which is being asked (or perceived to be being asked) - the closer to the micro end of the priority setting scale, the more reluctant to being involved the public appear to be.

Another issue of understanding which could potentially influence the public's willingness to be involved in priority setting is the extent of decision making responsibility that they perceive to be placed upon them. In both the Bowling et al. (1996) and Wiseman et al. (2003; 2005) studies, the public were asked to consider a range of groups that could/ should be involved in priority setting e.g. clinicians and politicians. The Litva et al. study (2002) simply asked participants to consider whether or not the public should be involved in each type of decision- depending on understanding and perception, participants may have thought that referred to the public having final decision making say, or to them taking the decision on their own, and this may have made them uncomfortable in taking individual level rationing decisions. In much of the literature uncovered in this review, the public are promoted as one stakeholder amongst many involved in priority setting decision making (e.g. Doyal, 1998; McKie *et al.*, 2008; Henshall *et al.*, 2012) and the findings from Wiseman et al. (2003; 2005) and Litva et al. (2002) would

suggest that this is where they feel most comfortable in participating.

4.10.3 Public Willingness to be Involved

Regardless of whether or not empirical research suggests that the public have a desire to be involved in priority setting decision making, there is an assertion within some of the literature that, when it comes to actually taking part, there is still a lack of interest amongst some groups in society. It is argued that many individuals have neither the time, skills nor inclination to participate in the political process at all and even the convenience of modern technology has done little to encourage significant swathes of the public to voice their opinions (Street *et al.*, 2011). Even elections, as the most basic and fundamental form of involvement, often fail to capture the public imagination (Leichter, 1992).

Rates of involvement and interest in health priority setting and rationing vary by organisation or approach and, according to Redden (1999) who conducted a theoretical comparison between rationing exercises in Canada and the US, may be affected by the health service funding model. Redden (1999) suggests that the Canadian public may feel less obligated to contribute to priority setting decision making because they have come to see universal health care as a basic right; the same may be true of disinvestment-specific decision making but the evidence base is not yet well enough developed to support this claim.

Regardless of whether or not organisations give the public the opportunity to take part in decision-making, the wider priority setting literature suggests that they may

lack the motivation to take it, or may simply not want to be involved (Richardson *et al.*, 1992; Bruni *et al.*, 2007). This lack of willingness to become involved was demonstrated inadvertently by Rosén (2006) who conducted research in Sweden into the effect that different forms of information had on the public's priorities for health care. Initially 2500 randomly selected participants were asked to complete a questionnaire on health priorities- this included a question on whether or not they felt that the public should have more input into priority setting. The questionnaire then asked all of the participants if they would be willing to take part in a further priority setting exercise- this would include receiving different forms of information (including face to face dialogue) and then completing the priority setting questionnaire again to assess if the information had affected their choices. Of those that returned the survey, 862 individuals felt that the public should have more involvement in priority setting, but only 200 of these individuals then put themselves forward to take part in the second priority setting exercise (and only 155 actually took part in the end). Whilst not being Rosén's (2006) main research interest (or finding), this quirk in his results demonstrates the duality of members of the public's views on their own involvement in priority setting well- they want there to be more public involvement but they are often not willing to take the time themselves to participate.

Low levels of public response could be due to a number of reasons but one of the explanations put forward in the literature is that the sheer number of health reforms and restructures over the years, and the range and variety of public involvement

events and consultations which have accompanied these, have left the public disillusioned (Edgar, 1998b) and feeling that they do not have an important role to play (Meetoo, 2013).

4.10.4 Public Propensity to Prioritise

Whilst some of the literature has shown that the public understand trade-offs and want to be involved in tough decisions around health care (Richardson *et al.*, 1992; Nelson, 1994) other papers suggest that they are incapable of prioritising; this is another potential explanation for the lack of public willingness to participate reported in the literature. The main purpose of Lees et al.'s (2002) survey work was to establish how the participants (a public sample and a clinician sample) would rank a selection of services and whether their rankings were in line with existing organisational protocols. In addition to the ranking, however, participants were also asked if they felt that NHS budgets should be restricted i.e. whether there should be a cap on what is spent on health. Forty five per cent of public respondents suggested that there should be no limit on NHS spending whereas only 12% of the clinicians answered no; the public overwhelmingly felt (80%) that additional NHS funding should come from the National Lottery whilst less than 5% supported reallocating other government budgets (housing, education or pensions) to support health. Similar results from research carried out in New Zealand suggested that, when given the option to avoid rationing or prioritising, the public look to shift resources from other budgets or departments before making tough choices (Campbell, 1995). These findings suggest that the public can find

difficulty in grasping the concept that resources are finite and/ or that they may refuse to accept that it is necessary. Both of these possibilities, if shown to be the case, would call into question the public's ability to effectively participate in disinvestment decision making.

Arvidsson et al. (2009) conducted similar research in Scandinavia, asking visitors to four health centres in Southern Sweden to complete a survey and indicate their level of agreement with seven statements relating to priority setting, in total over 2500 members of the public took part. Of the seven statements, three were of particular interest to this review, these were entitled the 'priority-oriented questions' and aimed to establish the extent to which the respondents understood the need to prioritise. The research concluded that the public were not 'priority oriented'; 94% fully or partially agreed that the health service should always provide the best care regardless of cost and 40% disagreed that the health care system could not afford to provide all possible services and that some must be excluded.

Lees et al.'s (2002) and Arvidsson et al.'s (2009) quantitative findings are supported by qualitative research by Bradley et al. (1999) who conducted 24 focus groups in the South West of England aiming to establish the level of public agreement/ disagreement with the priorities and targets laid out in the UK government's 'Health of the Nation' strategy. The paper essentially presents a wish-list of ideas and priorities that the public would like to see implemented in the NHS, without explaining where funding could come from, or what the

opportunity cost may be. This may be a criticism of the research, of the paper or of the public themselves (or possibly all three) but the lack of any sort of prioritisation/ disinvestment at all suggests that those people who took part were not 'priority oriented'.

The research by Campbell (1995), Bradley et al. (1999), Lees et al. (2002) and Arvidsson et al. (2009) throws doubt over the public's ability to comprehend and/ or willingness to accept the need to set priorities in health care, and suggests that they may lack the abilities needed to contribute effectively to decision making. Despite this, there is some support in the literature for the idea that failure to involve the public in decision making could constitute an organisation acting in a paternalistic way (Owen-Smith *et al.*, 2010). It is suggested that the public face tough spending choices in their everyday lives (Nelson, 1994) and, whether they know it or not, they are familiar with opportunity cost; this could be particularly important if they were to become involved in decisions relating specifically to disinvestment although evidence to support this assertion is lacking in the literature. Some have argued that if the nature of priority-setting decisions is presented and explained in the right way, then the public can prioritise rationally and without self-interest affecting their judgement (Wilmot *et al.*, 2004), and that they do have a desire to be involved at some level (Litva *et al.*, 2002; Wiseman *et al.*, 2003; Owen-Smith *et al.*, 2010; Theodorou *et al.*, 2010).

4.11 Proposition four: The Public have a Different View from Health Professionals and Decision Makers- they Should be Involved Because Otherwise their Views Would not be Adequately Represented

4.11.1 Differences of Opinion

A key argument in favour of public involvement in priority setting decision making is that the public and decision makers do not necessarily hold the same views. As such, it is suggested in the literature that the views of the public are not always adequately represented within decision making circles and that they cannot always rely upon decision makers to speak up for them (Edgar, 1998b). Bowling et al. (1993), for instance, carried out a survey which asked 454 members of the public from London, UK to prioritise 16 health services, this survey was then also completed by a group of over 300 clinicians including Hospital Consultants, General Practitioners and Public Health Consultants. The results showed that the public cohort gave mental health a much lower priority score than the professional cohort, whilst giving much higher priority to 'life saving treatments' than the clinicians. In this case the public could be seen to take the ethical standpoint known as the 'rule of rescue' whereby life would be preserved regardless of cost (Jonsen, 1986), the professionals seem to have taken a more utilitarian view based on the potential benefits of the treatment weighed against the financial cost. Bowling et al.'s (1993) findings relating to the ways that different groups prefer to distribute resources are mirrored by Lees et al. (2002) who carried out similar survey work with larger public and professional samples in Western Scotland, and Shickle (1997) who used a range of pre-existing data to draw conclusions on the

differences between public and professional preferences.

It is possible that the disparity in prioritisation choices shown in the research (Bowling *et al.*, 1993; Shickle, 1997; Lees *et al.*, 2002) resulted from a lack of knowledge/information on the part of the public, although closer inspection of the results from the professional survey in Bowling et al.'s (1993) work would dispute this; there were notable differences of opinion even within the professional group. It could be argued that these differences give weight to the arguments in favour of public involvement and give legitimacy to public views. It is also possible that the views of the different groups may converge in a disinvestment (rather than wider priority setting) decision making context but there is insufficient evidence within the literature to support this assertion.

One section of the 'European Value of a Quality Adjusted Life Year' Study by Donaldson et al. (2010a) used Q-Methodology to demonstrate shared points of view (factors) on health care priorities amongst a sample of the general public and a sample of decision makers across 10 European countries. This work showed that not all members of the public and decision makers disagree on priority setting, indeed two of the five factors identified for both the public and the decision makers were essentially the same- one promoting egalitarian allocation of resources and the other seeking to preserve life. The remaining three factors identified for both groups, however, showed some differences in opinion with, for instance, the 'Quality of life above all else' perspective amongst the public somewhat countered by the 'Fair innings and priority for younger patients' view

held amongst decision makers. In this case, decision makers sought to prioritise quality of life amongst younger patients, not necessarily across all patient groups. This work demonstrates the range of views held within both decision making and public samples well, showing that small scale involvement of decision makers and/or the public cannot ensure that all public views are necessarily represented.

Economic evaluation is a technical approach to priority setting that has been espoused in the literature as a means of overcoming some of the barriers relating to different subjective points of view and vested interests (see Chapter Two). It has been suggested that using QALY maximisation as a means of deciding which services to prioritise could, potentially, remove the need for direct public involvement in decision making if the public supported utilitarianism and the QALY maximisation principle. Unfortunately for advocates of economic evaluation, interview based research by Roberts et al. (1999) shows public opinion to be at odds with QALY maximisation and suggests that the public are more concerned with increasing quality of life in the short term than with extending poor quality life indefinitely. Similarly, Mason et al. (2011), who used Q-Methodology to identify shared public perspectives on the types of health gain that they value from interventions, found five distinct perspectives amongst a sample of 52 members of the public. The perspectives identified were, in some cases, in contradiction with each other, with one, for instance prioritising life-saving treatments for all and another prioritising life-saving treatments for children. In this research a range of views on QALY maximisation was evident within a purely

public sample; this adds further weight to the idea that experts, be they economists or clinicians, will always struggle to fully represent public views in decision making.

The results of Roberts et al.'s (1999) and Mason et al.'s (2011) research suggest that if economic evaluation is to be used to set priorities then there must be a means by which to incorporate a range of different public views. This sentiment is shared by a number of academics in the field who question whether purely technical means are sufficient to work through value judgements, and call for lay opinion to complement technical expertise in order to ensure the credibility of economic analysis (Tenbensel, 2002; Coulter, 2003; Mooney, 2005). This literature suggests that the only way to know what public views on priority setting are is to actually ask them in the same way that decision makers may seek technical advice from experts (Garland and Hasnain, 1990).

In practice, incorporating public values into economic evaluation may not be as straightforward as decision makers might hope; potential conflicts between decision makers and the public still exist. One example of this from the priority setting literature comes in balancing societal values against moral principles (Walker and Siegel, 2002). For instance, if societal value preferences valued life years under the age of 75 more highly than life years over the age of 75 then this may be viewed, from some perspectives, such as the 'rule of rescue' (Jonsen, 1986) as being ageist. Because, to some, this preference may not be considered to be morally acceptable there is an argument to say that it could and should be ruled

out of cost effectiveness analysis: but who would have the right to make that decision? The same could apply for a range of social value preferences; regardless of their moral or ethical acceptability, if these values reflect societal preferences then there are arguments to suggest that they should be incorporated. According to Walker and Siegel (2002) this dilemma has yet to be overcome and, as such, the only way around it is to remove social value preferences from cost effectiveness analysis all together.

4.11.2 <u>Explanations for the Differing Views</u>

A number of explanations as to why the views of the public may differ from those of 'decision makers' are evident in the literature. One of these explanations relates to cultural sensitivity and the fact that many different views and cultures exist within society that may not exist within decision making organisations- it is suggested in the literature that the only way to make decisions with this in mind is to involve the community (Wiseman *et al.*, 2003).

The public also offer life experience and they interact with public services and come up against barriers every day- parts of the literature suggest that they can bring common sense into decision making (Russell *et al.*, 2011) as well as offering innovative ideas and solutions (McIver, 1995; Bradley *et al.*, 1999; Wiseman *et al.*, 2003) and allowing for new options to be considered (McKie *et al.*, 2008). Involving the public in priority setting decision making may allow health organisations to garner new insights into the preferences of the public or the local health context (Mitton *et al.*, 2011) which could, for example, be used to target

interventions aimed at tackling health inequalities at a local level (Murphy, 2005).

Another reason why public views may differ from those of decision makers is that they view decision making from the perspective of current (or potential) service users- not as experts. It is argued in the literature that by involving the public decision makers can ensure that provision meets their requirements (Litva *et al.*, 2002) and that they are aware of what services are most valued by citizens and what the most pressing health needs of the local community are (Obermann and Tolley, 1997; Theodorou *et al.*, 2010). By focusing investment on what is valued by local communities, there is a suggestion in the literature that health organisations can target their service offerings in these areas and make efficiencies in the areas that are not so highly valued. In this way, it is argued that public involvement can help to ensure the responsiveness and value for money of the services provided (Rosén, 2006); it may also ensure that those services which least meet the needs of the community are disinvested in although the literature relating specifically to disinvestment decisions is in need of further development.

4.11.3 Decision Makers as 'Agents'

Despite the differing views held by the public and those with decision making responsibility, some of the literature suggests that there is an acceptance on the part of many citizens that agents are best placed to make priority setting decisions on their behalf. Coast (2001) used qualitative data derived from semi-structured interviews with 13 members of the public and 11 'agents' (health service managers and clinicians) in the UK, to build upon the theoretical construct of a principal-

agent relationship as a possible explanation for this. Coast extends the principal-agent relationship, whereby individuals cede responsibility for decision making to nominated agents, to incorporate decisions made on behalf of society by these agents- she refers to this as the 'citizen-agent' relationship. Coast (2001) suggests that citizens are often willing for agents, e.g. doctors or health service managers, to take priority setting decisions on their behalf (depending on the type/level of decision) because they offer knowledge and experience, because most citizens do not usually use the services themselves, and because the public are unwilling to deny care. For their part, the agents agreed that the public should employ them to take decisions on their behalf. This notion of professionals being better placed to make decisions and the view that they can be trusted to act on behalf of, and in the best interests of, the public could explain the survey findings detailed earlier (Bowling, 1996; Mossialos and King, 1999; Lees *et al.*, 2002).

A logical extension to Coast's (2001) Citizen-Agent theory is provided by Leichter (1992) who characterises those charged with making decisions as the 'elite' and puts forward a number of reasons why it is acceptable for them to take decisions on behalf of the public. Leichter (1992) suggests that the elite are better educated than the public and that, due to their positions within public service, are aware of, and demonstrate, community values, perhaps more so than the citizens themselves. This elite are potentially more capable of acting responsively and responsibly than the public they serve. Sabik and Lie (2008) would seem to support this notion- they found that successful priority setting could be carried out by experts, with

only a minimal level of public involvement, and cited examples (including the UK, New Zealand and Israel) where public acceptance of decisions had been high despite low levels of citizen involvement. The evidence-base is not yet well enough developed to support this assertion for disinvestment decision-making as well as priority setting.

Involving the public in decision making, it is suggested by some authors, could even cloud the judgements of the 'elite' and encourage them to avoid or shirk difficult decisions (Goold and Baum, 2008; Clark and Weale, 2012). By taking rationing decisions away from public view, it is suggested that health professionals can continue to fulfil their duty to set priorities whilst reducing the risk of personal distress caused by making tough decisions in public (Owen-Smith *et al.*, 2010).

Despite the enduring 'citizen-agent' relationship, recent decades have seen the public gain increased knowledge of their rights as consumers and, according to the literature, in some cases, they have lost faith in the legitimacy and superiority of health professionals to make priority setting decisions (Charles and DeMaio, 1993). Involving the public in priority setting decision making could, it is argued, help to restore this faith, as well as increasing public support for the organisation/ health service as a whole (Edgar, 1998a; Lenaghan, 1999; Meetoo, 2013); it may even result in the public taking more responsibility for their own health (Murphy, 2005).

4.11.4 <u>Influences over Public Views</u>

Whilst one of the main motivations for involving the public in decision making is their unique perspective, parts of the literature suggest that it is not always the case that they hold their own, independent view. Public opinions can be swayed by the media or the views of politicians; this may result in the public finding difficulty in seeing beyond emotive stories of individual patients and considering the needs of the wider community and what broader public values are (Richardson and Waddington, 1996; Mossialos and King, 1999). It is suggested that the influence of politics and the media may bias the public towards technology intensive or life-saving treatments (Mitton *et al.*, 2005) ahead of 'less fashionable' services such as Mental Health or Elderly Care. This potential bias could add weight to those arguments against public involvement in priority setting and disinvestment decision making.

From the literature uncovered during the review there is an argument to say that the differences between the views of the public and health professionals (Bowling *et al.*, 1993; Lees *et al.*, 2002) make it imperative to involve the public in priority setting decision making. If, however, the differences result from a public view influenced by the media or other influential figures such as politicians (Mitton *et al.*, 2005), rather than from citizens' own opinions and experiences, then they could just as easily be a reason not to involve the public. Similarly, where the public and professionals disagree legitimately, whose views take precedence? A process which attempts to appease all sides could be protracted (Bowling *et al.*,

1993) but one which involves the public and then sides with the experts could risk citizens losing faith in their ability to influence decisions and becoming disillusioned about future public involvement (Edgar, 1998a).

Another cautionary note from the literature on public involvement is that public opinions change frequently and their values can alter depending on the way a particular question is asked or worded (Doyal, 1995; Shickle, 1997; Ubel, 1999) or the perspective ('personal', 'social' or 'socially inclusive personal') from which they view a priority setting task (Dolan *et al.*, 2003). One explanation for this is provided by Lloyd (2003) who suggests that the public employ cognitive shortcuts, or heuristics, to simplify the prioritisation task that they have been faced with and, in so doing, bypass important information and rush to conclusions. Another explanation offered within the literature is that the public are fickle and their views could change on the basis of media coverage or on the views of a charismatic leader (Edgar, 1998b), rather than remaining constant throughout the decision making process. This difficulty in, first, measuring public views accurately and, second, keeping track of changing public views, calls into question the value of involving the public in decision making. If the outcomes of a priority setting process take months or years to implement then there is a suggestion in the literature that it can become an increasingly difficult task for decision makers to ensure that service changes continue to reflect public views at the time of implementation.

4.12 <u>Research Questions</u>

Returning to the research questions, the significant priority setting literature uncovered offers a number of insights which, in the absence of evidence relating to specifically to disinvestment, are helpful in beginning to formulate answers. The findings from this literature review can shed light on the issue of whether or not (and why) to involve the public in disinvestment decision making. They can also start to give some answers as to the extent to which the public should be involved and the types of decision that they should be involved in, but they offer little assistance as to the stage at which the public could or should become involved in decision making.

The literature identified in the review is broadly supportive of public involvement in priority setting decision making- empirical evidence shows that the public want to be involved and that they can offer a unique perspective. The review suggests that public involvement can help to bring communities together and develop an active citizenry which is willing and capable of sharing the burden of responsibility with decision makers.

Despite this support, however, sections of the reviewed literature raise questions about the public's ability to prioritise and suggest a potential lack of willingness to engage when actually faced with the opportunity to contribute. The question of whether or not to involve the public in disinvestment decision making is subjective, with the advantages and disadvantages highlighted by this review open

to interpretation by interested parties. For instance, some groups may consider the disparity between public and decision maker views over health priorities to be a key reason to involve the public, whereas others may view it as a reason not to. Further empirical inquiry taking this subjectivity into account is required in order to provide a more conclusive answer to the question; 'Should the public be involved in disinvestment decision making?' Why?'

In terms of the extent to which the public should be involved in disinvestment decision making, this literature review suggests that there is no 'one size fits all' answer to this question, although selection of the 'wrong' method may result in tokenistic involvement which is less effective than no involvement at all. The review suggests that the method used to involve the public, and therefore the extent of their involvement, should be determined by the nature of the disinvestment decision and the type of public feedback that decision makers require in order to proceed.

The literature review suggests that the public have limited appetite to be involved to the extent of actually taking final decisions, instead demonstrating support for public involvement as part of a shared decision making process amongst a number of stakeholders. The review also suggests a developing preference for the use of deliberative methods in practice which, even when the public are the only stakeholder involved in decision making, still push for shared responsibility and consensus seeking amongst groups of individual citizens. Where members of the public were asked for their views as individuals the literature highlighted

approaches such as large scale surveys and discrete choice experiments (DCEs) which seek to establish broad values which could then be incorporated into a wider decision making process- there was little call for individual citizens to have the final decision-making say.

Within the literature the question as to when to involve the public within the decision making process was not adequately addressed. It can be inferred from the methods used to illicit public views that there is support within the literature for early involvement i.e. through the collection of broad values using DCEs but this is not explicitly stated. Similarly, the lack of support in the literature for public involvement in the making of final decisions also implies that if the public are to be involved in decision making then it should be early in the process.

In relation to the types of decision that the public could/ should be involved in, there is some support in the literature for public involvement in macro and meso level decisions but less support for involvement in decisions at the individual patient level. Despite concerns about levels of knowledge and information, GPs and decision makers seem happier for the public to contribute to micro level decision making than the public themselves do- one possible explanation for this is that decision makers are seeking to share responsibility.

4.12.1 Gaps in the Literature and Implications for Study

Whilst contributing towards answers to the research questions, the literature review has also highlighted significant knowledge gaps. First, the research

questions relate specifically to disinvestment- barely any disinvestment-specific literature was uncovered in the review and answers to the research questions came from the existing priority setting and rationing literatures. Whilst there are clear similarities between priority setting and disinvestment, the latter is worthy of research in its own right (see Chapter Two) and the lack of empirical work focused purely on disinvestment is a significant gap.

Second, the literature fails to adequately address the question of the stage at which the public should become involved in decision making. Third, the empirical research into public involvement in priority setting focuses on the views of the public themselves (e.g. Gallego *et al.*, 2007), senior level decision makers (e.g. Obermann and Tolley, 1997) and GPs (e.g. Ayres, 1996)- one significant group whose views were rarely represented were health professionals (aside from GPs). Where their views were sought it was in relation to the involvement of patients in the explicit rationing of services that they, themselves, could benefit from (Owen-Smith *et al.*, 2010) or, similarly, in relation to the role of health professionals as agents (Coast, 2001). These front-line staff and middle managers have day to day contact with the public and know their capabilities, thoughts and opinions, they also have to live and work with disinvestment decisions and have knowledge of the impact of decisions and how they are taken. Failure to incorporate the views of this broad group in previous empirical research is a significant gap in the literature.

The findings from this literature review and the gaps in the literature identified demonstrate the need for further empirical inquiry in order to provide answers to

the research questions. The failure of the existing literature to gauge the views of health professionals suggests that these would be an ideal group to include as research participants. The range of views around the question of whether to involve the public, and why, suggest the need for a research strategy which can take subjectivity into account and can quantify the different views held. The research strategy should also aim to establish why these views are held and what their impact on disinvestment decision making practice is, as well as considering the impact that past public involvement and disinvestment experience has had on the participants.

4.13 <u>Summary</u>

This literature review has used a series of propositions to map out existing theoretical and empirical knowledge relating to public involvement in priority setting. The review has begun to answer the research questions, but has also highlighted significant gaps in the literature which must be filled through empirical inquiry in order to provide a more comprehensive picture.

An interpretivist mixed methods approach to research is proposed, using Q-Methodology to measure subjectivity and in-depth qualitative inquiry to gain a thorough understanding of the constructed meanings and views that health professionals ascribe to public involvement in disinvestment decision making. The methodology and methods used in this research are detailed in the chapters that follow.

Chapter 5- Methodology, Research Design and Sampling

5.1 Introduction

The previous chapter outlined the existing literature on public involvement in disinvestment decision making and identified significant knowledge gaps. The focus of the thesis will now shift to the methodological assumptions that were made and the research design that was employed in answering the research questions and filling these gaps. This chapter first highlights the empirical evidence needed to bridge the knowledge gaps and then introduces the constructionist/ interpretive research paradigm and the mixed methods approach used to collect the requisite empirical data. The applicability of constructionist/interpretive assumptions to the research questions is explored in depth as well as the implications of these assumptions for the data collection phase.

5.2 Re-Visiting the Research Questions

Without clear and well-formulated research questions the resulting study is bound to be of poor quality (Bryman, 2008). In light of this, and the fact that the research design and methodology should follow from the questions, the research questions will remain a focus for the chapter.

- "Should the public be involved in disinvestment decision making? Why?"

- "To what extent should the public be involved?"

- "At what stage should they become involved?"

- "What types of decision should the public be involved in?"

Chapter four provided an in-depth review of current literature and used a series of four propositions to demonstrate the ways in which these questions had been approached by a wide range of authors. Existing empirical and theoretical work was presented to show the range of views that have been taken on public involvement in priority setting and rationing, and the canon of knowledge that already exists.

Despite the depth and breadth of existing literature, and the answers to the research questions it provided, the review also served to highlight important gaps in knowledge relating to the research questions and these will be used to shape the research design and methodology. The gaps in the research detailed in full in Chapter Four include: a lack of disinvestment-specific research, a lack of evidence around the stage in decision-making at which the public should become involved and a lack of engagement with the views of health professionals

The lack of investigation of the views of health professionals (i.e. a broader group than just physicians and/ or senior managers) was a gap in the literature which required particular attention. This group have a unique position from which to offer insight into the questions of whether, when and how, the public should be involved in disinvestment decision making.

Nurses, physicians and allied health professionals meet and treat the public on a daily basis and can offer insight into the desires and capabilities of citizens, they

also have first-hand knowledge and experience of disinvestment decision making and the effects of these decisions. Similarly, middle managers (i.e. below board level) in hospital and commissioning organisations meet the public regularly either through informal feedback, engagement events or complaints management, and have a similar opportunity to clinicians to gauge public mood, capability and desire to be involved in disinvestment decision making. Middle level managers also have a unique position as makers and implementers of disinvestment decisions.

Following the literature review and consideration of the different roles within the decision making process, it was decided that a broad sample of health professionals including physicians, nurses, allied health professionals and mid-level managers could provide the most rounded, unique and interesting view on the research questions, and that their involvement should be sought for the research.

5.3 <u>Involving the Public in Research</u>

At this stage it should be noted that, in the initial research design, the researcher had also intended to seek the views of the public alongside those of health professionals but that this arm of the research was discontinued after four months of unsuccessful recruitment attempts.

The researcher initially contacted 200 potential participants by post to ask them to take part in the Q-Methodology study, giving them the opportunity to either participate online or face to face. These individuals were purposively sampled on

the basis of the electoral ward in which they lived. The sampling process took account of the average income of the ward and the proportion of black and ethnic minority inhabitants. In total eight wards across the city of Birmingham were selected, two each in the top and bottom quartiles for income, and two each in the top and bottom quartiles in terms of the numbers of BME residents. 25 letters were sent to randomly selected names taken from the electoral register in each ward. The purpose of the sampling approach was to deliver a public sample which aligned closely with the ethnic and social make up of Birmingham.

After a slow initial response, reminder letters were posted, followed by invitations to a further 200 purposively sampled individuals. In total this approach yielded just six participants so the researcher placed an advert in a local free newspaper distributed to over 10,000 homes- this approach yielded a further two participants. The eight participants that did come forward were disproportionately drawn from the more affluent wards that had been targeted by the postal recruitment, and the group was predominantly white, middle-aged males. After several months attempting to recruit public participants for the study, the researcher opted to re-design the empirical research focussing solely on the health professional arm of the study, and increasing respondent numbers from this group as the next best way to answer the research questions. The approach taken to the research is detailed in the next two chapters. The implications of the failed attempt to recruit the public for the study are returned to in the Discussion chapter.

5.4 <u>Data Requirements and Research Paradigm</u>

The research questions sought to establish not only the opinions of the participants on whether the public should be involved in disinvestment decision making, but also why and how they could be involved. They aimed to investigate whether disinvestment was different from priority setting and whether public involvement was more important in some decisions that others. Providing answers to these research questions required data which would not only explain what the participants thought but also explain why they held these opinions and how their previous experiences had affected their views. Whilst numerical survey data has been used in the past to answer questions regarding the role of the public in health priority setting (e.g. Mossialos and King, 1999; Wiseman, 2005), these more in-depth research questions required richer data in order to be answered fully.

Paradigms are the "models or frameworks for observation and understanding which shape both what we see and how we understand it" (Babbie, 2007, p.32); the first step in defining the research paradigm was to consider the ontological assumptions of the research as to the nature of existence and reality (Hesse-Biber, 2010). The ontological spectrum runs from objectivism, which suggests that there is an objective 'real' world which exists externally to humans and is made up of rigid structures which can be modelled and within which humans fit (Jonassen, 1991), through to subjectivism which suggests that reality is imposed by humans (Crotty, 1998).

Constructionism (or constructivism) falls between objectivism and subjectivism in the ontological spectrum. It suggests that a 'real' world exists but that individuals construct their own meanings, understandings and structures based on their interactions within the world (Crotty, 1998). Bryman (2008) suggests that these structures are formed as a result of experiences or social interactions and that they can change regularly as agreements between individuals are reviewed or withdrawn (Bryman, 2008). This ontological assumption that the world is viewed differently by different individuals and that it is constantly changing as their views, experiences and interactions evolve underpinned the research philosophy for this project. The view that the world, and processes and structures within it, are socially constructed drove the methodological choices made in answering the research questions; the following paragraph demonstrates how constructionist assumptions were applied to the research questions in this study.

In giving their opinions on public involvement in disinvestment decision making, the participants would be asked to call upon their personal experiences of the public, and their opinions and capabilities, as well as their experiences of disinvestment. These views would have been formed through interactions with colleagues, through perceptions at the time of disinvestment, through the professional roles and lenses of participants, and through reflection following disinvestment or interaction with the public. The experiences and views of individual participants would also be different, and these views would change over time (Bryman, 2008). Indeed, even if each participant had the same experiences,

their views may still be different; this is due to the different ways that individuals actively interpret and construct knowledge (Jonassen, 1991); this idea that different individuals interpret phenomena in different ways depending on their specific view is known as hermeneutics (Mertens, 2010) and is fundamental to the design of this research.

The approach taken to building and understanding knowledge is driven by the ontological assumptions; this is known as epistemology (Hesse-Biber, 2010). The epistemological spectrum runs parallel to the ontological spectrum, with ontological issues often emerging alongside epistemological issues, and the two combining to inform the overall theoretical perspective of the research (Crotty, 1998). Positivist views of knowledge mirror an objectivist view of reality, with positivism essentially promoting a more scientific approach to research, seeking generalizable results, testing hypotheses and linking outcomes with causes (Johnson and Onwuegbuzie, 2004): there is an objective reality and it can be tested. Positivism is usually linked with quantitative research methodologies which either prove that a phenomena exists or prove that it does not; it aims to be free of both context and time (Nagel, 1986).

Towards the other end of the epistemological scale is interpretivism which recognises the role of the researcher, and the social world, and the impact that the two can have on each other. In positivist research the researcher strives to maintain objectivity (Hammersley, 2000), although this is difficult, if not impossible, because they must make choices relating to the instruments and tests to use, the

topic of the study and the elements of the data to emphasise when writing studies up for publication (Johnson and Onwuegbuzie, 2004); these choices are bound to result in the researcher having some influence on the findings. In interpretive research, the inevitability of researcher influence is accepted, as long as there is transparency and reflection regarding researcher values and assumptions (Ritchie and Lewis, 2003). Interpretivism aims to "make sense of, or interpret, phenomena in terms of the meanings that people bring to them" (Denzin and Lincoln, 2008, p.4). Key to the success of interpretivist research strategies is identifying issues from research participants' perspectives and understanding the meanings, interpretations and significance that they ascribe to phenomena (e.g. behaviour, events or objects) by calling upon their own experiences (Hennink *et al.*, 2011). Because of this focus on meanings and the interpretation of the views and personal experiences of participants, interpretivism is usually associated with qualitative research methods. Examples of research conducted within the constructivist/ interpretivist paradigm uncovered during the literature review include Coast (2001), Mitton et al. (2005), and Robinson et al. (2013).

5.5 <u>Research Design</u>

The lack of existing empirical research into public involvement in disinvestment decision making, highlighted by the in-depth literature review, suggested that exploratory research would be most appropriate (Babbie, 2007). In addition to the emerging nature of the research field, the research can also be considered to be exploratory because of its scale- whatever the findings from the research, there

would still be more knowledge to uncover in future studies. This study was the first of its kind and will be built upon in the future.

In terms of temporal design, this study is cross-sectional, with the views and experiences of participants having been sought at one specific period in time (Bryman, 2008). This decision was taken because it enabled the data captured to present a snap-shot of health professionals' views at a time when the English NHS was facing one of its most bleak financial outlooks ever (Appleby *et al.*, 2009). With no concrete knowledge of how public funding for health will change in the future there was little reason to consider incorporating any longitudinal element into the study- if funding prospects improve considerably in the future then the need for disinvestment decision making, and approaches to it, may change significantly.

When considering the most appropriate research design and methods to answer the research questions, significant consideration was given to Lincoln and Guba's (1985) measures of trustworthiness (credibility, transferability, dependability and confirmability). As more traditional measures of research quality i.e. validity, reliability and replicability are more readily applicable to quantitative methods (Bryman, 2008) it was felt that the trustworthiness criteria offered a more appropriate assessment tool.

Credibility is considered to be confidence in the truth of the findings that are being reported; transferability is the extent to which it can be shown that findings are

applicable in other contexts and the ease with which readers can use the description and information provided to extrapolate findings to other settings (Polit and Beck, 2010); dependability is the extent to which findings are considered to be consistent and repeatable, and confirmability is a measure of the extent to which the findings have been shaped by the participants in the research (Lincoln and Guba, 1985). The approach taken to the research design and sampling was driven by a desire to maximise trustworthiness as defined by these criteria. Performance against Lincoln and Guba's criteria (1985) will be analysed in the Discussion chapter.

5.6 Mixed or Multiple Methods?

In addition to the exploratory nature of the subject matter being investigated, this research also broke new ground in the 'fixed' mixed-methods approach taken (Babbie, 2007). Q-Methodology (which has only rarely been applied to health priority setting research (Donaldson *et al.*, 2010a; Baker *et al.*, 2014)) and in-depth interviews were used in an explanatory sequential design (Creswell, 2003, 2014; Fetters *et al.*, 2013) where the interviews were used to further explore the views of a purposive sample (see Sampling Strategy in Section 5.7) of the cases within the original Q-Methodology study. These interviews began two weeks after collection of the Q-Methodology data had ceased, and the questions asked (e.g. 'Who is responsible for involving the public in disinvestment decision making?') were directly influenced by the initial findings from the Q-study. The design was considered to be fixed rather than emergent because the methods to be used in both

stages had been decided upon before any data had been collected or any theory/findings had begun to emerge (Creswell, 2014).

At this stage it is important to recognise that the term 'mixed-methods' is somewhat contested in the literature, and there may be an argument to suggests that the research described in this thesis is 'multiple method' rather mixed method. Morse and Cheek (2014, p.3) define multiple method research as "two or more complete projects attached to one overall inductive aim", with these projects answering slightly different research questions and able to stand alone and produce findings individually. Mixed method research is considered by Morse and Cheek to be one complete research project which is supplemented by findings gathered using different analytical techniques. In this instance the complete research project would be able to stand alone, although it may lack depth of insight and richness, but the findings from the supplementary techniques would not stand alone.

This project could conceivably fall into either of Morse and Cheek's (2014) categories but, whilst it is true that the Q Methodology study and the in-depth interviews answered slightly different research questions, and the findings are reported separately before being brought together in the Discussion chapter, the researcher feels that mixed method is a fairer and more accurate description of the approach taken. First the Discussion chapter synthesises the findings from the two parts of the study, comparing and contrasting them, and drawing conclusions, rather than simply accumulating findings as one would expect in a multiple methods study (Morse and Cheek, 2014). Second, the researcher feels that the Q

Methodology study represents a complete project and that the interviews supplement the findings from the Q study. In this study the interviews were reliant upon the Q study for their sample and the sample was shaped by the views that participants expressed in the Q study and by their occupational backgrounds and experience. This data was used to purposively sample participants, ensuring that each staff group and each factor was represented (for further details see section 5.7); this data was not available to the researcher prior to the Q study. According to Feters et al (2013, p.2139) the sampling link between the two stages of the project, constituting "integration through connecting" at the methods level, would be enough to define the approach taken as mixed methods research in itself.

The interview schedule was also influenced by the findings from the Q Methodology study and the qualitative data collected and, as suggested earlier, a number of questions were asked specifically to add depth to the theory developed through initial analysis of the Q-Methodology data. The influence that the Q Methodology findings had over the interview sample and interviews, and the fact that the researcher left two weeks in between the first phase of the study ending and the supplementary phase beginning also help to demonstrate that the study was genuinely sequential (Creswell, 2003, 2014; Fetters *et al.*, 2013).

Lastly, in terms of the multiple/ mixed methods discussion, given the identified lack of disinvestment-specific research, the interviews, as they were conducted, were dependent for their meaning and integrity on the prior Q study. Without the preceding study, the interviews would jump to questions about the process for

involving the public in disinvestment decision making without first considering whether or not the public should be involved at all. This assumption would leave a significant knowledge gap around public involvement in disinvestment decision making and would severely diminish the value of the findings reported from the interviews. Indeed, had the initial findings from the Q Methodology study suggested that there was no role for the public in disinvestment decision making then the researcher would have re-visited the research questions ahead of the interview stage of the research.

The two stages of the research were sequenced so as to complement each other; one of the main purposes of following the Q-methodology study with semi-structured interviews was to further the insights generated by the Q-study. This complementarity is considered to be a fundamental aim of mixed methods research (Morgan, 1998). In this case, the interviews were able to give greater depth and explain why participants held their particular views and how they manifested themselves in public involvement practice, whilst the Q-Methodology study enabled subjectivity around public involvement in disinvestment decision making to be analysed in a systematic way. In addition to this, the interviews allowed for the theory developed through analysis of the Q-Methodology data to be further explored; this approach to mixed methods research incorporating Q-Methodology has previously been applied elsewhere (Glasby *et al.*, 2013).

Despite the advantages offered by mixed methods research, the literature is clear that there are also some limitations, and the researcher was cognisant of these

whilst designing and carrying out the data collection. In particular, mixed methods research is accused of taking significantly more time, resources and researcher effort than single method approaches (Curry *et al.*, 2009; Povee and Roberts, 2015). In this case, the effect of this criticism was reduced by the sampling approach; by inviting participants in the first part of the study to take part in the second the researcher was able to reduce time spent identifying participants, collecting demographic details and explaining the background and purpose of the data collection.

Another criticism of mixed methods research evident in the literature is the incompatibility of findings from different sections of the study and the potential for ontological and epistemological conflict (Roberts and Povee, 2014). Much of the literature citing this criticism, however, refers to mixed quantitative and qualitative studies, not to studies which employ Q-Methodology alongside qualitative data collection. As the Q-Methodology study described in this thesis was inductive in nature, it was compatible with the interviews which followed, and, whilst this criticism may be justified for some mixed methods studies, the researcher feels that it was not applicable in this case.

Having taken the potential limitations of mixed methods research into account, the researcher felt that the advantages of using Q-Methodology and in-depth interviews in a sequential procedures approach outweighed the disadvantages. As suggested earlier, the two stages of the research primarily aimed to answer different research questions. The Q-Methodology study aimed to establish whether

participants felt that the public should be involved in disinvestment decision making and why, and the interviews aimed to establish the extent to which the public should become involved, the stage they should become involved and in which types of decision.

Q-Methodology allowed for the range of subjective perspectives held amongst the participants to be identified and elaborated on, and for the areas of agreement and disagreement between participants to be explored fully (Sullivan *et al.*, 2012). The in-depth interviews which followed the Q-study allowed for participants to further elaborate their views on why the public should be involved in decision making (after the Q-study had identified support for involvement) and to consider what this involvement should look like. Using interviews allowed for participants to not only give their views but also to recount their experiences of disinvestment, and for the researcher to explore why they held their views and how they had been formed and constructed. This allowed the Q-Methodology findings to be assessed against practical experience and enabled the researcher to ensure that the outcomes of the thesis were more applicable to decision making in practice; this is a key feature of mixed methods research and is another of its main advantages (Morgan, 1998). Figure 5.1 gives a full diagrammatic representation of the mixed methods design and sampling strategy.

5.7 <u>Sampling Strategy</u>

The population for this study was health professionals in front line clinical and/or middle management roles in health provider or commissioning organisations. A

range of methods was used to achieve a large sample which was considered by the researcher to have a wide enough range of experiences, including drawing upon the alumni networks of the University of Birmingham and other UK institutions.

The majority of participants in the study were drawn from one of two academic programmes, one was a health care management course for practicing clinicians and the other a commissioning skills course. All participants in both programmes were aspiring to gain new skills but their levels of experience and roles varied widely, with attendee backgrounds ranging from senior Consultant Physicians through to relatively junior commissioners.

Potential participants were first approached by e-mail to take part in the Q-Methodology study. The initial e-mail introduced disinvestment as a topic and explained the stages and purpose of the study. A participant information sheet was attached to the e-mail to provide answers to frequently asked questions (see Appendix two) and to provide contact details if any potential participant had any questions or if they decided to take part in the research but then opted to have their data removed at a later date.

The Q-Methodology study took place online and a link to the study was included in the invitation e-mail. The whole population was e-mailed once to invite them to take part in the research. Those who had not taken part in the research after two weeks were then e-mailed again as a reminder.

Following completion of the Q-study participants were asked to provide contact

details if they would be interested in/ willing to take part in further research. Those who did provide details were invited to propose colleagues who may have interesting or different experiences/views of disinvestment and/or public involvement that they would be willing to share. These individuals were contacted by e-mail in a 'snowballing' approach. Snowball sampling is commonly used in Q-Methodology research (Steelman and Maguire, 1999) to augment the initial sample with a wider range of views and perspectives. All participants who left their details (including the snowball sample) were then invited to participate in an in-depth interview.

In total, 55 participants took part in the first stage of the research (Q-Methodology) - further information relating to their backgrounds and experience is included in the results chapter. Of these participants, 39 said that they would be willing to take part in further research. After one e-mail to each of these interested participants inviting them to participate in an in-depth interview, 16 participants responded and interviews with these individuals were arranged and carried out accordingly.

| Initial Population (n=219) | Study Phase One (n=55) | Study Phase Two (n=20) |

Programme A (n=127)

Snowball Sample (n=5)

Q-Methodology Study

In-depth Interview (n=20)

Programme B (n=92)

| Participants approached by e-mail to take part | Q-Study Participants invited to take part in further research and to recommend colleagues to take part | Those interested in taking part in further research invited to take part in in-depth interview |

Figure 5.1 : Mixed Methods Design and Sampling

After completion of these interviews the sample and initial findings were assessed by the researcher to ensure that they were satisfied that a broad a range of experiences, organisation types, perspectives (as identified in the Q study) and professional backgrounds was represented. A number of gaps in the sample were identified, as well as some findings which were felt to be worthy of further exploration and clarification. Following this appraisal, the characteristics of the remaining 23 participants who had shown an interest in the further research were assessed, and a process of purposive sampling identified nine that could potentially add significantly to the research findings and the broadness of the overall sample. After another follow-up e-mail invitation, a further four participants agreed to take part in an in-depth interview. Further information relating to the backgrounds and experience of the 20 interview participants is included in the results chapter.

5.8 <u>Summary</u>

Having detailed the nature of the evidence required to fill the gaps identified in the literature review and provide comprehensive answers to the research questions, this chapter then introduced the constructionist/ interpretative research paradigm which would guide the approach to empirical data collection. The mixed-methods research design and sampling approach used to collect the necessary data were then detailed. The next chapter will give an in-depth account of the steps taken within the research and a full analysis of both the Q-Methodology and in-depth interview phases of the study.

Chapter 6- Research Methods

6.1 Introduction

Having introduced the methodological underpinnings of the research in the previous chapter, this chapter will give a detailed account of the steps taken within the research itself. The chapter begins by introducing Q-Methodology as an approach to research before giving an in-depth description of the way that it was applied as the first stage of this mixed-methods project. The chapter then gives a comprehensive account of the semi-structured interviews that were carried out following the Q-Methodology study as the second stage of the mixed-methods design.

Within the two stages of the mixed-methods research approach, the Q-Methodology study was aimed primarily at answering the first research question;

- Should the public be involved in disinvestment decision making? Why?

The primary aim of the semi-structured interviews was to provide answers to the remaining questions;

- To what extent should the public be involved?

- At what stage should they become involved?

- What types of decision should the public be involved in?

Within the findings from both stages, however, there is some convergence between

the individual research questions.

6.2 <u>Studying Subjective Views on Public Involvement</u>

Discussion around health disinvestment and priority setting is emotive and value-laden (Menon *et al.*, 2007), and it attracts significant publicity. Given this, the varying degrees of exposure that health care professionals have had to disinvestment, their diverse experiences of patient and public involvement and differing views on who or what the public is (Barnes *et al.*, 2003), there are liable to be a myriad of different views regarding public involvement in disinvestment decision making. The range of views held amongst decision makers, academics, GPs and members of the public themselves was evidenced in the earlier literature review (see Chapter Four).

In order to establish the extent to which health professionals felt that the public should be involved in disinvestment decision making and the types of decision that they should be involved in, it was first important to measure this subjectivity around public involvement in disinvestment decision making and to broadly establish what the different perspectives were. Standard quantitative or qualitative methods would have been able to capture some of the views on public involvement in disinvestment decision making, but in order to systematically analyse the subjectivity of the participants, in relation to their attitudes, perceptions and values, the most effective approach to take was Q-Methodology (Dennis, 1986). Q-Methodology has been applied to a number of fields (see below) but is particularly well suited to capturing debates around policy issues or initiatives (Dickinson *et*

al., 2013) and topics where subjectivity may be more tacit than explicit (Sullivan *et al.*, 2012).

There is a suggestion in the literature that previous experience affects the way that health services researchers, including health professionals, view public involvement and gives them pre-conceived ideas about what approaches deliver the desired outcomes and when the public should be involved (Oliver *et al.*, 2008). Because of this the researcher reasoned that the views of the participants in the study would have been similarly shaped and constructed, unconsciously, by their past experiences. This made Q-Methodology a particularly apt approach for tackling the questions of whether or not the public should be involved in disinvestment decision making and why.

6.2.1 Q-Methodology

Q-Methodology was first introduced by William Stephenson in a letter to the journal Nature in 1935 (Brown, 1996). Stephenson, who had worked in a number of different fields including Physics and Psychology, sought to find a way to systematically and scientifically evaluate subjectivity amongst and between individuals and make it operant (Ramlo and Newman, 2011). His Q-Methodology built upon existing quantitative techniques (which he termed 'R-methodology'), evolving from Spearman's Factor Analytic Theory (Brown, 1997), to allow for the measurement and analysis of different types of people and their points of views and moods towards particular subjects and topics (Watts and Stenner, 2012).

Stephenson was working in the field of Psychology when he first applied Q-Methodology and, as such, many of the early applications of the tool were also in Psychology (Addams and Proops, 2001). In recent years, however, Q-Methodology has begun to be applied in a wide range of different fields and, despite its US origins (Barry and Proops, 1999), it has also now been used internationally. Examples of diverse applications of Q-Methodology include; policy analysis (Durning and Osuna, 1994), education (Anderson *et al.*, 1997), health and lifestyle choices in diabetes (Baker, 2006) and rural research (Previte *et al.*, 2007).

Q-Methodology is applicable across a broad spectrum of ontological and epistemological positions- the way in which it is defined is shaped by the position taken by the researcher (Previte *et al.*, 2007). Perhaps unsurprisingly, given the origins of Q-Methodology in Psychology, its scientific merits are strongly promoted by a number of exponents (McKeown and Thomas, 1988) but with applications in more diverse fields, however, Q is now coming to be seen as a more 'discursive and critical approach' (Billard, 1999, p.357). This juxtaposition between more scientific, positivist traditions of research and more analytical, inductive approaches has led Stenner and Stainton Rogers (2004) to label the method as 'qualiquantological'.

Although building upon long standing quantitative traditions, Q-Methodology differs from R- Methodology in that the human participants in Q-Methodology are essentially the experimental condition (Kitzinger, 1987), rather than being the

subject of interest. Where R-Methodology is concerned with links between objective variables, Q-Methodology looks for "patterns of subjective perspectives across individuals" (Steelman and Maguire, 1999, p.363). Q-Methodology uses a standard set of stimuli to assess the views of participants, and, by focussing on the ways that the participants prioritise these stimuli, it can isolate the different subjective views amongst the participants. The stimuli used in Q-Methodology are usually statements about a subject, although the stimuli have ranged from photographs and works of art through to pieces of music (Akhtar-Danesh *et al.*, 2008). Essentially Q-Methodology is focussed upon the different constructions which the participants create rather than on the participants (or constructors) themselves (Stainton Rogers, 1995).

Implementations of Q-Methodology can differ in the exact steps taken (Dziopa and Ahern, 2011) but there are essentially two main components which make up a Q-study; these are the 'Q-sort' and the correlation and factor analysis (Stenner *et al.*, 2003). The ways in which these two steps were tackled in this research are presented in the following section.

6.2.2 Identification of the Concourse

The first stage in the Q-Methodology process was to identify the 'concourse' or "the flow of communicability surrounding" the topic (Brown, 1993, p.94). The bounds of the concourse are defined by the researcher but it aims to represent as wide a spectrum of opinions and views on a particular topic as possible and is used to produce the stimuli to be sorted by the participants. In this case the stimuli

produced were in the form of short, written statements. The statements related to, and provided possible answers to, the following research questions;

- Should the public be involved in health care disinvestment decision making?

-If yes, why? If not, why not?

In order to establish the concourse around whether or not the public should be involved in disinvestment decision making three key resources were employed; a focus group of fellow University of Birmingham Social Policy PhD Students (n=20), popular and academic literature.

The focus group were presented with three hypothetical disinvestment decisions (one each at the micro, macro and meso level) and were asked to consider whether they felt that the public should be involved in each of the decisions and why. Detailed notes were taken of the discussion and these were thematically analysed to highlight the range of different views expressed. These themes were then condensed into brief statements.

Whilst it is recognised that the focus group was not representative of wider society, the individuals within the group did have significant experience of public engagement methods from a range of fields and, from their own experience and research, they were able to identify a large proportion of the different opinions, even if they didn't happen to agree with them themselves. Using the focus group ensured that the production of the Q sample was not solely reliant on the

judgement of the research team[3] and ensured that the widest possible range of views were represented (Cross, 2004).

The popular literature used to develop the concourse was a selection of right and left leaning UK newspapers with a broad target readership. The online archives of 'The Sun', 'The Daily Mirror', 'The Guardian' and 'The Telegraph' were searched for news articles relating to public involvement in health care spending decision making, including decisions where services had been withdrawn or downgraded. In addition to using the articles themselves to inform the concourse, the comments sections at the end of the articles were also interrogated to establish public response to what was written. In the absence of focus groups involving the wider public, it was hoped that interrogating the comments sections would bring to light the extremes of opinion which may not surface elsewhere in the development of the concourse; this approach has also been successfully taken in the past by Street et al. (2011) when researching public opinions on disinvestment.

The academic literature used to develop the concourse came from published journal articles and reports uncovered during the comprehensive literature review detailed in Chapter Four. The search strategy and inclusion criteria were as detailed in the earlier chapter and the tables produced to summarise the literature were used to aid the extraction of the different perspectives. Data collection was focused around the central question- should the public be involved in

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[3] Throughout this thesis, the term 'research team' refers to the researcher and their four supervisors. As is common within PhD level research, the researcher led the research project with guidance from supervisors.

disinvestment decision making and why? Each piece of academic and popular literature was analysed to uncover the arguments held within it that related to this central question. Notes were taken and these were thematically analysed, with the key themes and arguments condensed into short statements. In total the focus group, popular and academic literature reviews yielded a concourse of 153 statements.

6.2.3 Production of the Q Sample

The second stage of the Q-Methodology process was to refine the concourse into a manageable subset of statements which, in the researcher's judgement, based on their knowledge of the wider literature, fairly represented the breadth of views in evidence within the concourse (Webler *et al.*, 2001); this subset is known as the Q sample. In order to ensure that, as far as possible, all of the perspectives were fairly represented and that there was no duplication (Cross-Sudworth *et al.*, 2011), a matrix representing all of the key themes of the concourse was created, and, after deletion of any which did not directly address the research questions, and removal/ combining of duplicate or highly congruous statements (Baker, 2006), the remaining stimuli were assigned to the sectors that they fitted most appropriately. The matrix was produced through analysis of the key themes of the statements by the researcher and, similarly to other Q studies, it was predominantly inductive in nature whilst being influenced by existing frameworks (Sullivan *et al.*, 2012). By ensuring that the widest possible range of answers to the research questions was represented, the matrix used (see Table 6.1) ensured a more structured Q sample

(Brown, 1993) which, from the researcher's perspective, fairly represented the whole concourse.

		Support for Public Involvement?		
		Yes	No	Total
Rationale/ Reason	Motivation/ Perspective	8	7	15
	Outcomes	6	7	13
	Process	7	7	14
	Total	21	21	42

Table 6.1: Q sample Matrix

The statements were first divided into two groups- those which broadly agreed with the idea that the public should be involved in disinvestment, and those that did not. These two groups were then further divided into three sub-groups on the basis of why they demonstrated the perspective that they did. The three sub-groups emerged from thematic analysis and further examination of the concourse by the researcher (VanExel and DeGraaf, 2005).

The researcher recognises that it is more usual within Q Methodology studies to map statements against existing pre-defined theoretical frameworks than to construct new frameworks and sub-groups (Akhtar-Danesh *et al.*, 2008), but in this case they felt that the concourse was not sufficiently described by any single existing framework. First the concourse covers all views on public involvement, from strong support to strong opposition and, to the researcher's knowledge, there is no existing framework which categorises both the advantages and disadvantages of involvement. The frameworks which do exist, such as Litva et al. (2002) and Williams et al. (2012), focus solely on the benefits of involvement. In order to

fairly represent the whole concourse the researcher felt it necessary to build on these frameworks. In addition to this, thematic analysis of the statements suggested that neither of these frameworks adequately covered the concourse on their own, Litva et al. (2002), for instance did not cover all of the benefits relating to accountability and democratic processes that were identified in the construction of the concourse. It was also felt that the Williams et al. (2012) framework did not completely cover the personal benefits (e.g. personal fulfilment) that participants could gain from involvement. In order to demonstrate the linkages between the emergent categories and the existing literature Table 6.2 gives a read-across from the emergent categories to the Williams et al. (2012) and Litva et al. (2002) frameworks as well as the literature review propositions from Chapter Four.

The three emergent sub-groups were 'motivation/ perspective'- the public can (or cannot) offer a different perspective to the decision making process and they have (or have not) got the motivation to do so, 'outcomes'- public involvement in the decision making process would either yield positive or negative outcomes and 'process'- public involvement would either improve or detract from the decision making process.

New Categorisation	Litva et al. (2002)	Williams et al. (2012)	Propositions from literature Review
Outcomes	Instrumental/ Educative	Instrumental/ Educative	Proposition Four/ Proposition One
Motivation/ Perspective	Expressive		Proposition Four
Process	Communitarian	Democratic	Proposition Two/ Proposition Three

Table 6.2: Matrix Showing Linkages with Existing theory

In order to ensure that the Q sample represented the whole concourse evenly and contained "the comprehensiveness of the process being modelled" (Brown, 1993, p.99), an even number of statements was taken from each of the cells in the matrix as far as possible. In this case, numbers of statements were reduced through combining or deleting highly similar statements (as detailed earlier) rather than deleting statements at random from each cell of the matrix, as has been suggested elsewhere (Dryzek and Berejikian, 1993). Through taking this approach, a Q sample which covered "all the ground smoothly and effectively without overlap, unnecessary repetition or redundancy" (Watts and Stenner, 2012, p.59) was delivered.

In Q-Methodology the size of the Q-set depends on the nature of the research question and the resulting concourse- the wider the topic, the bigger the Q-set. Published studies have reported successful applications of Q Methodology with a wide range of Q-sample sizes. In their systematic review of Q studies reported in 2008, Dziopa and Ahern (2011) found that the Q samples used ranged from 27 items up to 82. In other literature it has been reported that reliable findings can be

delivered by Q samples ranging from 10 items (Stainton Rogers, 1995) to 140

items (Kerlinger, 1973), although studies often contain 40-50 statements (VanExel

and DeGraaf, 2005). One study which complies with VanExel and DeGraaf's rule

is Baker's (2006) investigation into the health and lifestyle choices of people with

diabetes (46 statements), another is Brewer et al.'s (2000) investigation into public

service motivations (40 statements).

In deciding upon the number of statements to include in the Q sample there were

two key concerns; first to ensure that the Q sample represented the whole of the

concourse and second to ensure that the number of statements was not so big as to

make it hard for participants to complete and "very unwieldy to deliver" (Dziopa

and Ahern, 2009, p.16). Pollitt and Hungler (1997) suggest that larger Q samples

are likely to deliver a more stable research instrument but this argument is

tempered by Dziopa and Ahern (2009) who reported that a Q sample of 140

statements took participants more than two hours to complete and risked

participants rushing to finish, or not finishing the sort at all. In light of these

arguments a decision was taken by the researcher to aim to represent the whole

concourse in a manageable number of statements- an assessment of manageability

was made based on the feedback from the pilot study participants (see below). This

decision reflected the fact that the participants were busy professionals and were

taking part without financial reward. In order to ensure that the Q sample was

manageable it was necessary to return to the statements and look again at the

perspectives which were represented in the concourse, continually altering the

statements which were included in the final Q sample.

After refinement and removal of duplicates the Q sample produced contained 50 statements (seven, eight or nine from each cell in the matrix) which, in the opinion of the researcher, fairly represented the whole concourse of views on whether or not the public should be involved in disinvestment decision making and why.

After production of the Q sample, several pilot Q-sorts (n= 10) were completed by a convenience sample of friends, family and colleagues. The purpose of this pilot testing was to ensure that the instructions for completing the Q sort were clear, that the statements were unambiguous, that no ground had been missed within the concourse and that the Q sort could be completed in a manageable amount of time. Participants were asked if they felt that process was too long and were asked if they rushed to get finished or if they felt as though they could have given up before completing; the assessment of manageability was based solely on these views. Most of the pilot sample felt that the length of time was about right, but several commented that if they had been busy professionals then they may have been inclined to rush through the process or to give up.

In light of the pilot study feedback the researcher sought to reduce the size of the sample further by merging eight pairs of statements that they considered to be similar. They also altered a number of the statements to ensure that the language that they were written in was as natural as possible (Dickinson *et al.*, 2013) and the instructions were extended to give participants a better insight into the importance

of each of the Q study stages. The final Q sample is shown in Table 6.3.

Some participants in the study itself reported finding a small number of the statements to contain more than one sentiment and therefore being more difficult to rank; particular problems were reported with statements 9, 14, 24, 29, 32 and 34. This combining of sentiments came as a result of the data reduction process aimed at reflecting the concourse in a manageable number of statements. The statements which could potentially have caused conflict for participants were not initially deemed to be confusing by the researcher. On reflection, however, some of the statements could be conceived as expressing more than one sentiment, and this is recognised as a limitation. Had the research been carried out face to face it would have been possible for the researcher to give some explanation to participants as to what the statements meant and to reduce confusion. The researcher's presence may also have encouraged participants to take more time over sorting the statements, ensuring that they finished the sort and allowing for a larger Q-set to have been used in the first place. These are recognised by the researcher as key limitations of using the online Q-sorting technology.

	Statements
1	Some groups of people are hard to reach and may never get involved in decision making, so public involvement can't be representative.
2	By participating in the process, the public are agreeing that there needs to be cuts which isn't true.
3	The public's views should be represented by elected officials e.g. MPs.
4	The public pay for the NHS and they are better placed than doctors or managers to decide how to spend their money.
5	The public should be involved in decisions on health care disinvestment because they know the needs of the local community.
6	Individuals have more pressing personal concerns than decisions on health care disinvestment.
7	The public don't trust public institutions and feel that they need to be involved in decision making to look after their interests.
8	The public are put off becoming involved by the complex, technical nature of health care funding and the lack of information.
9	The public are capable of over-looking their own self interest for the good of the community. Being involved can help build the community.
10	Health professionals don't consider the impact on individuals when making decisions; public involvement allows individuals to express themselves.
11	The public must be involved as decision makers will take instructions from government, who don't represent the interests of the public.
12	The public have different priorities to those people who run the health service. The public don't trust decision makers to represent their interests
13	Decision makers represent the best interests of the public so there is no need for public involvement.
14	The public are too subjective to be involved. The public want everything and their views will change depending on their personal circumstances.
15	The public should be involved in decision making because health care is a vital public service and they have a democratic right to be. Health care staff and decision makers are not elected.
16	Whether the public are involved or not, decisions will always depend on what politicians want, so there is no point involving the public.
17	Public participation can make decision makers less remote and can help the public understand the decision making process.
18	Public involvement can make difficult decisions easier to accept and it can give the process credibility.
19	Public involvement gives citizens a sense of belonging and responsibility and can help to improve society.
20	The public are too aware of existing perspectives and beliefs to give a fair view, and the media can bias their opinions.

21	Involving the public in decision making can lead to more cost effective health care and they could suggest alternative ways to make savings.
22	It is hard to show that involving the public is effective and influences the decisions that are made.
23	Involving the public will ensure that that resources are distributed fairly and 'unfashionable' services e.g. Mental health are not forgotten.
24	Involving the public in decision making allows individuals to take more responsibility for their own health. They have a responsibility to contribute to decision making.
25	Public involvement is pointless as it only achieves anything if the decision makers agree with what the public think.
26	Involving a wide range of people (including the public) ensures that a range of knowledge and experience is taken into account when making decisions.
27	The public are sensible enough, and now have enough knowledge of health services to be able to contribute to rational decisions on disinvestment.
28	The public need to be aware of the consequences of the decisions they are making.
29	Doctors know best, they know what different groups want, so they should decide for themselves how the budget is spent.
30	Decision makers are self- interested and don't know what the priorities for public health care spending should be.
31	The public don't know enough about health disinvestment to make decisions.
32	Health service managers can't be trusted to make the right decisions. Public involvement is needed to understand and uphold the public's values.
33	Members of the community should have a choice whether they are involved in decisions or not.
34	Decisions should be made on value for money, not public opinion. Involving the public makes the process more cumbersome.
35	The public can't trust the information that is provided because statistics can be manipulated, so there is no point in getting involved.
36	Public participation gives a more transparent process which delivers fairer results and ensures that the consequences of decisions are thought through.
37	The media and interest groups represent the views of the public, and decision makers listen to these groups, so there is no need for public involvement.
38	Decision makers are shirking their responsibility to take difficult decisions if they involve the public.
39	Efforts to involve the public are tokenistic. Public involvement won't change anything.
40	The debate on disinvestment has to be made public otherwise it will be dominated by self-interested parties.
41	The public don't understand the need to prioritise and make health disinvestment decisions
42	Involving the public in decision making will bias decisions towards 'fashionable' services (e.g. away from mental health).

Table 6.3: Final Q Sample

6.2.4 <u>Identification of the P Sample and Q-Sorting</u>

Watts and Stenner (2012) point out that, as the participants are considered to be the variables in Q studies, it is not necessary to have a large P sample in order to gain reliable results; the statistical power of Q-Methodology comes from the Q sample and not the P sample (Militello and Benham, 2010). Q-Methodology aims to show that particular viewpoints exist within a population, not to draw generalizable conclusions about the proportions of individuals who might hold that viewpoint (Brown, 1980). As such it is possible to gather workable results with a much smaller sample than would normally be required for quantitative studies.

In UK studies, a P Sample of 40-60 participants has traditionally been considered to be adequate (Stainton Rogers, 1995), however studies have delivered reliable results with far fewer Q sorts (Watts and Stenner, 2012). In the literature review carried out by Dziopa and Ahern (2011) the P samples ranged in size from 26-103, and Barry and Proops (1999) carried out a successful study into environmental issues and sustainability using just 25 participants. At the opposite end of the spectrum, Ahmed et al. (2012) required 98 participants to deliver a reliable factor solution in their study into informed choice in antenatal screening. In the study reported in this thesis, a total of 55 health professionals took part in the Q-Methodology stage.

As has been shown by the wide range of P samples used in existing studies, it is difficult to decide at the outset exactly how many participants should be involved

in the study. In line with the interpretive methodological underpinnings of this study, additional participants ceased to be sought when data saturation had been reached and repeated analysis of the data was no longer yielding additional factors (Saumure and Given, 2008). In this case factor analysis was run after 45 participants had taken part and then re-run after 55; the additional 10 participants did not enable any additional factors to be unearthed thus demonstrating that data saturation had been reached. This methodological decision demonstrates the influence that the researcher had over the data collection process but is reinforced by Brown (1980, p.192) who suggests that, in Q-Methodology, it is only necessary to involve "...enough subjects to establish the existence of a factor for purposes of comparing one factor with another."

6.2.5 Completing the Q-Sort

Participants were invited to take part in the study via e-mail and were asked to complete the Q-sort (the ranking of the statements) online, using 'PoetQ' software (Jeffares *et al.*, 2012). Having consented to take part in the study and read an introductory welcome page, occupational data was collected from all participants. This consisted of participants' role (i.e. their current job title), occupational background (whether they were a doctor, nurse, manager or AHP), experience of disinvestment (whether they had any experience of the removal of funding from services, treatments and technologies, affecting their accessibility to patients, and what that experience was) and the type of organisation by whom they were employed. The purpose of collecting this information was to help to inform the

factor analysis and to enable conclusions to be drawn as to why some of the identified perspectives may have been held. In addition to this, the collection of participant information would also have enabled further targeted, purposive sampling to take place if any groups within the study were felt to be underrepresented.

Having provided the occupational information, the participants were then asked to complete a Q-sort. The process of Q-sorting is defined by Brown (1980, p.195) as "a modified rank ordering procedure in which stimuli are placed in an order that is significant from the standpoint of a person operating under specified conditions." In this case the stimuli which the participants were asked to rank in order were the Q sample statements; they ranked these in order of their level of agreement (the specified condition) and then, based on these rankings, PoetQ placed them into a pre-defined sorting grid (Stenner *et al.*, 2000).

In this study there were 42 stimuli and, as has become the norm in Q-Methodology (Eden *et al.*, 2005), the Q-sorting grid was shaped in a symmetrical, quasi-normal way (see figure 6.1). The grid ranges from 'strongly disagree', which is given a value of (-4) at its left extreme through to 'strongly agree' (+4) at its right extreme. Using this sorting grid delivered what Woods (2011) refers to as a forced sort whereby participants were forced to assign equivalent and comparable levels of agreement and disagreement with and between pairs of statements. Using the grid shown in figure 6.1 allowed participants to give equal ranking to more than one statement, thus avoiding some ranking dilemmas, and forcing participants to not

only consider whether or not they agreed with the statements, but also how much they agreed with them compared to the rest of the Q sample. This helped to show their strength of feeling towards particular aspects of the broader topic (Woods, 2011), ensured that participants considered the options more carefully (Prasad, 2001) and limited the number of uncertain responses (Cross, 2004). The particular sorting grid developed for this study ensured that participants were forced to be clear about the statements that they strongly agreed/ disagreed with but it also gave them the freedom to not have to express an opinion on the statements about which they were ambivalent.

Strongly Disagree								Strongly Agree
-4	-3	-2	-1	0	1	2	3	4

Figure 6.1: Example Q-Sorting grid

In the first stage of the Q-sorting process participants divided the Q sample into three groups- statements that they agreed with, statements that they disagreed with and statements that they were unsure about (McParland *et al.*, 2011). They were then shown the statements that they agreed with and were asked to pick the two that they agreed with the most, before selecting the two statements that they disagreed with most from those that they had earlier placed in the disagree group.

The participants then returned to the agree group and selected the four statements that they agreed with the most, before then repeating this for the disagree pile. PoetQ continued to move from one group to the other asking participants to complete the sorting grid working from the outer extremes inwards until the statements in either the agree or disagree group had been exhausted; at this point the statements from the unsure group were added and participants were asked to select which of these they agreed/ disagreed with the most until the whole of the grid was filled.

After sorting all of the statements the participants were shown their final sorting grid and were asked to check that they were happy with the placing of each of the cards before being given the opportunity to switch any that they felt were misplaced (Baker, 2006).

In order to aid interpretation following factor analysis (Bryant *et al.*, 2006) participants were asked why they decided to place the statements in the order in which they did, with questions particularly focussing on the extremes of the participants' Q-sorts. The statements with which the participants most agreed or disagreed were likely to be what distinguished their Q-sorts from others (Brown, 1993) and this is why the extremes were of particular interest. During this data collection participants were given a free text box in which to type their answers as to why they most agreed and disagreed with the statements at either end of their Q-sort. This approach delivered a qualitative dataset which was of great assistance in interpreting the factors.

In answering the questions about the extremes of their Q-sorts it was hoped that the participants would reveal the rationale behind their choices and the values and beliefs which influenced their decision making, thus allowing new theory to be constructed when considered in conjunction with the previously collected occupational data (Gallagher and Porock, 2010; Woods, 2011). During factor interpretation, the qualitative data collected from the exemplars of each of the factors is of the most interest as these Q-sorts most closely resemble the viewpoints displayed by the factors. Following factor analysis the qualitative data provided by these exemplars was extracted from the wider dataset and was thematically analysed. Data from this analysis, including direct quotations, is incorporated into the Q-Methodology findings detailed in Chapter Seven.

6.2.6 Bi-Variate Analysis and Factor Analysis

After the completion of the sorting process and collection of qualitative data about respondents' rationales for their Q sorts, the final stage in Q-Methodology is the statistical analysis and interpretation of factors. In this study "PQ Method" software was employed to aid analysis. Whilst the advent of technologies such as PQ Method has made it less important for researchers to have a detailed knowledge of the complex statistical processes used in Q-Methodology (Brown, 1993), it is still good practice to have an understanding of the steps in the statistical process. In light of this, detail of the basic statistical steps taken in the analysis process will be given. Please also note that a technical appendix giving further detail of the terminology and statistical process is included as Appendix five.

For clarification, in line with much contemporary Q-Methodology practice (Brown and Good, 2010), the researcher opted to employ the 'Centroid' method of analysis, rather than the alternative 'Principal Components' factor analysis. The reasons for this methodological choice were, firstly, that centroid analysis seeks to find commonality between the Q-sorts rather than drawing on the specificity of particular individuals (Webler *et al.*, 2009). With the exploratory nature of the research and the lack of a testable hypothesis the researcher felt that centroid analysis would give a factor solution which most fairly and equally represented the views of all participants, giving scope for further investigation and highlighting areas of strong agreement as well as disagreement. Secondly, the centroid approach to analysis was also preferred because of its indeterminacy (Goldman, 1999) and the fact that it left infinite factor solutions open to investigation (Watts and Stenner, 2005). This indeterminacy left open the possibility of hand rotation of factors later in the analysis.

The process began with a bi-variate analysis whereby the correlation between each of the Q-sorts was calculated to establish where there were areas of strong agreement and disagreement between pairs of Q-sorts. The level at which bi-variate correlation was considered to be substantial was calculated using a standard error calculation based on the size of the Q sample (Brown, 1993). The calculation was as follows (N= size of Q sample):

Substantial/significant correlation= 2.58 x (1/√ N) = 2.58 x (1/√42) = 0.398

Following the bi-variate analysis a factor analysis was carried out. The purpose of

this factor analysis was to establish whether there were clear groups or families of

Q-sorts and how many basically similar (or different) Q-sorts were evident

(Brown, 1993). Factors (or families) are groups of Q-sorts which are correlated

and resemble each other; they represent shared points of view (McKeown and

Thomas, 1988). Factor analysis revealed how many different shared points of

views there were and how strongly each participant (via their Q-sort) correlated

with, or 'loaded' on to, each. The factors were essentially the mid-point of the

clusters of different Q-sorts which bore a family resemblance and, as such, it was

very unlikely that any individual participant would show a perfect correlation

(+1.00) with any factor. Despite this, this approach did ensure that the factors

represented the shared views of several individuals with similar perspectives

(Barry and Proops, 1999).

6.2.7 <u>How Many Factors?</u>

The PQ Method software is able to extract and further analyse up to seven

different factors from one data set. In this research the decision on when to stop

extracting factors from the data, and how many factors to extract, was taken on the

basis of three well established statistical traditions within factor analysis; the

Kaiser-Guttmann criterion (Kaiser, 1960; Guttman, 1954), the Total Variance

Criterion (Kline, 1994) and the Two Exemplar criterion (Brown, 1980). By

following these rules, the researcher aimed to ensure consistency and to ensure

acceptability of the findings amongst the factor analytic community (Watts and

Stenner, 2012).

The first of tradition followed was the Kaiser-Guttmann criterion (Kaiser, 1960; Guttman, 1954) using eigenvalues. Eigenvalues are the sum of the squares of the factor loadings for each factor. The Kaiser-Guttmann rule states that factors with an eigenvalue greater than 1 should be retained (Kline, 1994). If the sum of the eigenvalues is less than 1 then that factor would be considered to account for less variance than any single Q-sort within the dataset.

The researcher also established whether as many significant factors as possible had been extracted by calculating the total variance that was accounted for by the entire factor solution. This was done using the following calculations:

Variance for factor N (%) = 100 x (Eigenvalue of factor N / No. of Q-sorts in study)

Total Variance = Variance for factor A + Variance for factor B…+ Variance for factor N

If the total variance accounted for by the factors was more than 35% of the variance for the whole study then, according to Kline (1994), enough factors would have been extracted to adequately describe the range of subjective viewpoints within the sample.

The third way that the researcher established that the number of factors extracted was appropriate was to follow Brown's (1980) advice and to only accept factors

which had two or more Q-sorts loading strongly on to them. In order to establish the level at which a factor loading became significant (at the 0.01 level) the following calculation was used (N= size of Q sample):

Level of significance= 2.58 x (1/$\sqrt{N}$) = 2.58 x (1/$\sqrt{42}$) = 0.398

In this study, as the researcher was following an inductive research tradition and was not seeking to test any existing theory, it was decided to extract as many statistically significant factors which were sufficiently different from one another (i.e. the level of correlation between factor scores was <0.4) as possible. Having experimented with different factor solutions, starting with a seven factor solution and working downwards, as recommended by Watts and Stenner (2012), the researcher established that a three factor solution would give the largest number of unique, significant factors. As discussed previously, the researcher considered data saturation to be reached when the addition of extra participants into the study did not alter the number of significant factors that could be extracted.

The researcher recognises that following these statistical rules to the letter may have resulted in an overly large number of factors being extracted, and that this may have made the factor solution unmanageable (Cattell, 1978; Kline, 1994; Watts and Stenner, 2012). Following the rules may also have resulted in factors which made no sense to the researcher, or were meaningless, being included simply because they met the criteria (Brown, 1980). Likewise, it is possible that some data which may have been interesting or helpful in describing the full range

of subjective views within the population could have been overlooked due to these rules. In particular, it is possible that the qualitative information provided by confounded participants, or those that loaded on to a factor which did not meet the criteria, may have been ignored.

The researcher was wary of these potential limitations to following strict inclusion rules prior to beginning the factor extraction. Had the analysis revealed an unmanageable number of factors, or revealed any factors which were considered to be spurious, then the researcher would have considered strengthening the inclusion criteria and using their own judgement to ensure that the final factor solution gave an accurate reflection of the views of participants.

In this case the researcher did not feel it necessary to strengthen the inclusion criteria, and the initial factor solution produced three operant and meaningful factors. Analysis of the qualitative data provided by the confounded participants did not produce any insights that the researcher considered to be revealing, or that were not adequately reflected in the factor solution. Despite the potential limitations of following strict inclusion criteria, the researcher feels that, in this study, the advantages, in terms of consistency and acceptability of approach, outweighed the disadvantages.

6.2.8 Factor Rotation

In order to reduce the number of confounded participants i.e. those who load similarly on to one or more of the factors, and increase the loading of the

participants on to one factor or another, the factors were rotated. As the study was inductive in nature, and was not working to test a particular theory, the researcher opted to employ a 'varimax' rotation. This technique allowed the data to speak for itself (VanExel and DeGraaf, 2005), thus maintaining the integrity of the inductive approach to research as well as ensuring that the mathematical variance of the factors, or orthogonality (i.e. the differences between the factors and the similarities within each perspective), was maximised (Watts and Stenner, 2005; Baker *et al.*, 2006). Varimax rotation, was also preferred by the researcher because it ensured that as many participants as possible loaded on to a single factor (Webler *et al.*, 2009).

One of the criticisms of varimax rotation is that, whilst it may maximise statistical variance, it can lead to a factor solution which is not operant i.e. genuinely functional (Brown and Good, 2010). An alternative approach to rotation is judgemental or hand rotation where the researcher uses existing theory, hypothesis and emerging ideas to guide rotation. In practice this could, for instance, entail using one participant as a reference variate (Baker *et al.*, 2006) i.e. setting one particular Q-sort as a factor and then establishing how many of the other Q-sorts load on to the factor, how strongly they load and what other different perspectives exist amongst the other participants.

In this study, in order to ensure that the factor solution was operant, a quick interpretation of the factors was completed directly after the varimax rotation using some of the crib sheet questions (as detailed below). This brief, face-value,

interpretation showed that the three rotated factors produced were operant, they made sense to the researcher, were coherent and did not contradict themselves, and were sufficiently distinct to provide insightful answers to the research questions. Had the initial interpretation raised questions about the functionality of the factor solution, or produced any factors which the researcher did not considered to be sufficiently qualitatively distinctive or rich, then the researcher would have acted to design and carry out a judgemental rotation to complement the computer-based varimax work. The absence of hand rotation in the analysis of this Q-Study data is not, however, viewed as a weakness by the researcher, as the literature suggests that varimax rotation is usually sufficient to give less experienced Q-methodologists rigorous results (Webler *et al.*, 2009), and previous research has shown minimal differences between the factor solutions produced by theoretical and varimax rotations (Brown, 1991; Baker, 2006). Further details about the approach taken to rotation are included in the technical appendix (Appendix five).

6.2.9 Factor Interpretation

After using the PQ method software to identify and rotate factors, these rotated factors were then interpreted by the researcher. Factor interpretation is a means of making sense of the factors that the analysis produces and it enables comparison of the similarities and differences between the shared perspectives that have been identified (Valenta and Wigger, 1997). The aim of factor interpretation was to appreciate each identified viewpoint in its entirety and to enable the research question to be viewed from each of the different perspectives (Watts and Stenner,

2012).

The task of interpretation can be approached in many different ways, depending on what is hoped to be accomplished from the research (Brown, 1980). According to Watts and Stenner (2012), most approaches to interpretation can be justified as long as there is a discernible strategy. Despite this freedom, or perhaps because of it, few published Q studies go into great detail about their interpretation strategy but, according to the methods literature, the majority of interpretation is based on the factor arrays produced during the analysis phase (Stenner *et al.*, 2003). Factor arrays or 'ideal Q-sorts' are a representation of how the statements would have been sorted under each factor and they are particularly important in assessing how each factor would view the topic in question and what the significant differences between the factors are.

In order to ensure that the ideal Q-sort for each factor fairly represents the views of each individual who identifies with that factor, the Q-sorts of all of those participants who load strongly onto each factor are taken into account by PQ Method. Depending on how strongly they load, the positions in which each individual placed the statements are weighted so that those that load most strongly have the biggest influence over the ideal Q-sort for that factor (Brown, 1993). The weightings assigned to each factor are known as z-scores (or factor scores) and they determine how each statement would be ranked under each factor (VanExel and DeGraaf, 2005) and the position that each statement would be placed in within the Q-Sorting Grid. The factor array produced in this study is shown in table 7.2 in

the first results chapter.

In this study, factor interpretation was based on the crib sheet system suggested by Watts and Stenner (2012); the researcher followed this approach in order to ensure that each factor was subjected to the same level of analysis and interpretation, and that important and relevant observations were not overlooked. Each of the factors was interrogated in turn by the researcher and a series of questions was asked to highlight where the different factors were in agreement and disagreement with each other, and which statements distinguished each of the viewpoints (Valenta and Wigger, 1997).

First, the researcher took the array for each factor and compared the placement of those statements placed at either extreme (+4/-4 strongly agree/ strongly disagree) with their placement under the other factors- was there any agreement between factors? Was there any significant disagreement? Did any of the statements distinguish this factor from the others? The researcher then repeated the process for those statements placed at +3/-3 and went on to work through the whole array.

The characteristics of exemplar participants, i.e. those that loaded strongly on to one or other of the factors, were then investigated as well as the qualitative feedback that they provided; was there any pattern or connection between exemplar professions or occupational backgrounds? Did exemplar qualitative feedback give any explanation as to why they held the views that they did?

A factor description was then produced for each of the factors. The description and

analysis, presented in the first results chapter, constitutes the empirical findings from the Q-Methodology study and seeks to use the answers to the crib sheet questions to synthesise the findings from the study and describe each of the factors and the way that they may view the research questions. Descriptive labels were devised by the researcher and attached to each of the factors in order to aid comprehension and to help to distinguish between them (Lee, 2000). The qualitative and background data provided by the exemplars was also drawn upon to aid the researcher's description. By focusing on the exemplars the analysis aims to add some explanation as to why certain perspectives were demonstrated and why there may have been differences in opinion between the participants as to whether or not the public should be involved in disinvestment decision making and why.

In this study, factor analysis uncovered three unique and distinct factors from the Q-Methodology data- these are presented in full in the 'results' chapters. Whilst Q-Methodology was able to explore some of the subjectivity around *what* health professionals views of public involvement in disinvestment decision making are and *why* some of these views may be held, it was clear from the outset that it would not be able to offer answers to the research questions on the extent to which the public should be involved, when and in what types of decisions. The researcher therefore took the decision to incorporate Q- Methodology into a mixed-methods research strategy alongside a series of semi-structured interviews carried out with key informants. These interviews aimed to delve deeper into the thoughts,

experiences and motivations of the participants and to help to triangulate the Q-Methodology findings (Lorenzoni *et al.*, 2007). The approach taken to the second phase of the research is detailed below.

6.3 <u>In-Depth Semi-Structured Interviews</u>

6.3.1 <u>Data Collection</u>

As was detailed in the previous chapter, the sample for the interviews was a subset of the initial Q-Methodology sample of health professionals based across England; the nationwide nature of the interviewee sample was both a blessing and a curse. Whilst ensuring that a wide range of disinvestment and public involvement experiences were incorporated into the study, it meant that face to face interviewing was impractical much of the time. In light of this a decision was taken to carry out interviews by phone unless the participant specifically requested a face to face interview. In total only two face to face interviews were requested and these requests were both accommodated by the researcher; the remaining 18 interviews took place over the phone.

The reasons for interviewing participants that had already taken part in the Q-Methodology study (and no new/ additional participants) were as follows. First, because of their earlier participation, this group were clear what was meant by the term disinvestment and they had been given the opportunity ahead of the interviews to reflect on their own thoughts and experiences, and were in a position to give fuller, more considered answers to the questions. Second, this group were known to the researcher and a rapport had begun to be built before the interviews

took place. The researcher contacted Q-Methodology participants after they had completed the first section of the research to thank them for their time and to explain why they felt that this area of research was particularly important. In explaining, they revealed that they had previously worked as a health services manager and that they understood the challenges posed by public involvement and disinvestment decision making- in a number of cases this resulted in long e-mail conversations ahead of the interviews. The researcher hoped that this contact, and the knowledge that they had previously worked in the health service, would make the participants more at ease and would make them more likely to reveal any privately held, genuine opinions (Duncombe and Jessop, 2002). Third, the data collected during the Q-Methodology study, and the findings of the study itself, enabled the researcher to purposively sample the interviewees more easily (Ritchie *et al.*, 2014). Knowledge of the interviewees' professional backgrounds, roles and experiences of disinvestment allowed for a broad range of views to be represented within the interview sample and allowed for each of the perspectives uncovered during the Q-Methodology study to be investigated in more depth.

The interviews were semi-structured in nature, with the structure following that proposed by Hennink et al. (2011)- introduction, opening questions, key questions and closing questions. An interview guide was followed (see Appendix three) to ensure that key topics/ themes were covered in the questioning and to act as an aide-mémoire, but the exact order of the questions and the wording was flexible depending on the progress of the interview. The interview schedules were

produced after initial analysis of the Q Methodology data had taken place- this allowed for the factors that were identified to be explored in more depth. One example of this was question nine which asked 'Are there any disadvantages to involving the public?'- This question was designed specifically to test and challenge the emerging 'Advocates of Involvement' factor (see Chapter Seven). Another example was question 12 which asked 'whose responsibility is public involvement?'- This sought to explore further the perspective demonstrated by the Freedom of Choice Group in the Q-study. During the interviews the main topics explored included: 'experience of disinvestment', 'opinions/ experiences of public involvement' and 'public involvement in different types of decisions'.

In order to explore the last of these topics, three scenarios were devised by the researcher, and participants were asked what they felt the role of the public should be in these decisions. Each of the scenarios (downgrading of an A&E department, withdrawal of a hospital based Dermatology service and a decision to withhold IVF treatment from those patients who had already had two unsuccessful cycles) represented a specific set of challenges for decision makers and involved a different set of actors. The three disinvestment scenarios were based on real-life examples that the researcher had uncovered during the review of popular literature carried out during the production of the Q sample. The three scenarios were selected because they varied according to dimensions identified as important in the empirical literature review e.g. scale and level of decision making. Using these scenarios helped to ensure that all interviewees had a similar understanding of

disinvestment decision making, even if they had no direct experience of it themselves.

If participants skipped ahead in their answers on to subjects scheduled for later in the interview then they were allowed to continue; questions were not repeated, this helped to avoid interviewee frustration (Adams and Cox, 2008). This flexibility allowed interesting themes and experiences to be probed more deeply and allowed questioning to develop depending on emerging findings as more and more interviews were conducted (Hennink et al., 2011).

In order to ensure that the interview questions were understood by participants, that the style enabled them to share information freely and comfortably, and that there had been no noticeable oversights, feedback was requested from each of the first six interviewees. Alterations and improvements were made based on the suggestions made by these participants and, in lieu of a pilot study, the researcher considered it to be an effective way to ensure that the interviews delivered as much interesting and useful data as possible.

All interviews were recorded and transcribed, with consent to record and use the data given verbally by the participants at the start of the interview. Transcription was completed in full by the researcher, this ensured familiarity with the emerging themes as the interviews progressed and ensured closeness to the data (Halcomb and Davidson, 2006). Field notes were also taken at the time of the interviews; both these and the transcriptions were incorporated into the analysis and

triangulation processes.

6.3.2 <u>Qualitative Analysis</u>

The first stage in the analysis of the interview data was the transcription of the interview recordings; as the researcher listened back to the interviews, transcribed them and listened/ read back through to ensure accuracy, early themes began to emerge (Wellard and McKenna, 2001). These themes were then built upon iteratively following the remaining four phases of Robson's (2011) 'Thematic Coding Analysis' process.

Following transcription of the interviews and uploading on to Nvivo 10 software, an initial set of codes was generated. This coding process took place inductively, with descriptive codes being identified on reading the data and assigned to individual words, lines or chunks of text throughout the transcription. Codes were assigned to all of the data across all of the transcripts, with all similarly themed data being attached to the same code; this allowed for all parts of the data to be systematically compared with each other (Gale *et al.*, 2013). As the researcher went through the transcripts, and data which did not fit into the emerging coding structure came to light, new codes and sub-codes were created as necessary. Data which appeared completely irrelevant to the research questions or the emerging coding structure was incorporated into a miscellaneous code.

Next a list of the codes produced (except the miscellaneous code) was exported into a Microsoft Excel spreadsheet and the researcher began looking for linkages

and similarities. Where codes appeared to be very similar they were merged to form categories or one code was moved to become a sub-code of the other. The final list of codes/ categories was then thematically analysed and those that were similar were placed together under overarching theme headings. The spreadsheet represented an analytical framework (Gale *et al.*, 2013), demonstrating a clear link between the original codes derived straight from the individual interviews and the more general overarching themes and categories devised to give a reflection of the dataset more broadly.

A report was then run from Nvivo which grouped quotations from all of the different participants under the different codes and theme headings. This report was used to ensure that the themes were coherent and that the words of the participants themselves were still reflected in the theme headings. Using this report in conjunction with other reports which showed the different themes and codes assigned to the responses of each individual allowed the researcher to not only view the themes in the context of the dataset as a whole but also in the context of each individual interview (Gale *et al.*, 2013).

The next stage was to construct a thematic network (again using tables in MS Excel) which grouped the themes in relation to the research questions (Attride-Stirling, 2001). This network was then used in the final stage of Robson's (2011) process to show links between the different themes and where the congruities and differences lay. Constructing this network aided the process of interpretation because it helped to show where possible contradictions in the data lay, making the

researcher question these and consider why they may have been apparent. This final stage, known as integration and interpretation delivered the findings of the thematic analysis; these are presented alongside descriptions, summaries and details of linkages between the themes in the results chapters.

6.4 Triangulation, Testing and Verification

One of the more common criticisms levelled at qualitative research is that it lacks scientific rigour (Mays and Pope, 1995) and that findings are sometimes difficult to verify. One way to maximise rigour is to put in place a clear and well described process for analysis (Robson, 2011) and another is to triangulate and verify results using different sources (Miles and Huberman, 1994). As has already been stated, one of the purposes of the interview phase was to further explore the theory emerging from the Q-Methodology study (findings from both studies will be compared and contrasted in the Discussion chapter), but first the qualitative findings themselves had to be triangulated.

Throughout each of the interviews field notes were taken. The purpose of these notes was to record initial thoughts as to the key points that the participant was trying to get across- what did they feel most passionate about? What had influenced their feelings? What were the interviewer's feelings/ reactions to what the participant was saying? What was the underlying/ key theme/message of their argument? Following transcription of each interview the researcher returned to the field notes to compare the early emerging themes with thoughts captured at the time of the interview. The researcher questioned whether the early emerging

themes were in general agreement with initial thoughts and, if they were not, questioned whether attitudes had changed during the research period or whether the transcription did not fully do justice to the thoughts of the participants e.g. because pauses, intonation and emphasis had not been fully recorded.

As the steps in Robson's (2011) Thematic Coding Analysis process were worked through the field notes were continually referred back to, knowing that they were written when the interviews were fresh in the researcher's mind and before other thoughts on themes had begun to emerge. The researcher sought to use the field notes, along with the thematic reports produced by Nvivo, to ensure that the themes that were identified reflected what the participants genuinely felt and thought. By constantly referring back to direct quotations and to earlier impressions and thoughts at the time of carrying out the research it was possible to triangulate findings and to add further rigour to the qualitative analysis.

6.5 <u>Ethical Approval</u>

Ethical approval for this research was granted by the University of Birmingham Humanities and Social Sciences Ethical Review Committee on 15th October 2012. As the planned research did not involve NHS patients it was deemed by the NHS National Research Ethics Service (NRES) not to require ethical approval from them. As the participants in the study were contacted in their capacity as health professionals, not as employees of any particular NHS (or other) organisation, ethical approval was not sought from any individual NHS R&D Committee. This decision is reinforced by the fact that participants were asked for their own views,

not those of their organisation, that details of their organisation were never sought during the research and that interviews took place at a time which was convenient to the interviewee and was suggested by them, not by the interviewer.

In terms of the substantive aspects of research ethics, as the research took place online and over the telephone (except for two interviews which took place face to face in offices within busy buildings) no physical risk was identified to participants or the researcher. The only psychological risk that was identified to participants was the potential for distress which may have been caused by discussion of their past experiences of disinvestment. In order to overcome this risk all participants were informed that they could withdraw from either part of the study at any stage, and the researcher listened closely for any signs of distress during the interviews. The researcher was prepared to bring the interviews to a close, or to change the line of questioning if any participant distress was noted.

All participants received an information sheet prior to taking part in the research, this is included as Appendix Two. This sheet gave details of the purpose of the research and the research design as well as providing information as to how to request further details and how to withdraw consent. Participants were informed that by logging in to the Q-study website they were giving consent for the information they provided to be used in the study; they were given the opportunity to withdraw their consent, and their information, by contacting the researcher. Participants in the interviews gave verbal consent to the interviews being recorded and transcribed and, again, were able to withdraw that consent following the data

collection. Participants were assured that all the information that they provided would be stored in line with University of Birmingham data management policy and that any information would be anonymised so that it could not be linked to any named individual or any specific organisation.

6.6 <u>Summary</u>

This chapter described the two stage-mixed methods approach taken to empirical data collection, and gives a rationale for the choices made. In addition to giving a detailed account of data collection, the chapter also explained how analysis of both the Q-Methodology and in-depth interview data was carried out and how rigour was ensured throughout the process. The following chapter details the results of this analysis.

Chapter 7- Results Part One - Whether and why the Public Should be involved in Disinvestment Decision Making

7.1 Introduction

Having given a comprehensive account of the methods used to collect data, the approach taken to participant sampling and the process for analysis of both the Q-Methodology and the qualitative data in the previous chapter, this chapter and the next present the findings from the research. In recognition of the interconnection between the Q-Methodology data collection and the in-depth interviews within the mixed-methods research plan, the first chapter will combine findings from the two phases of the research, presenting those that relate to Research Question One. The second results chapter will present findings in relation to Research Questions Two, Three and Four.

The first section of this chapter will detail the results of the Q-Methodology study, including giving details of the final sample of 55 participants, and the factors uncovered through the research. The second section will detail the make-up of the interview sample before using findings from the qualitative data to explore the motivations behind the perspectives uncovered in the Q-Methodology research.

7.2 Should the Public be Involved in Disinvestment Decision Making? Why?

Findings from both the Q-Methodology factor analysis and the in-depth semi-structured interviews suggest that respondents believe that the public should be involved, to some extent, in health disinvestment decision making.

7.2.1 Q-Methodology Findings

At this stage, the factor analysis presented is a face-value interpretation of the results of the Q-Study- links to the theory, literature review and empirical findings from the in-depth interviews will be made in the discussion chapter. The three factors derived through the Q-Methodology study are 'Advocates of Involvement', 'Cautious Supporters' and The 'Freedom of Choice' Group, each will be discussed in turn after details of the final sample have been presented.

In total 55 NHS professionals from a wide range of clinical and non-clinical backgrounds, working in organisations across England and Wales ranging from small-scale provider organisations (e.g. single GP practices) through to regional commissioning organisations and some national level government bodies took part in the Q-Methodology study. Q-sorts were completed online between 26th February and 2nd April 2013.

At the beginning of the study participants were asked to select the professional background and organisation type that they felt applied most closely to them; for background there were three clinical options- medical (e.g. doctor), nursing or allied health professional (e.g. paramedic) and one option for managers and non-executive directors. In terms of organisation types, commissioning organisations were those responsible for making spending decisions at a local-regional level (i.e. Clinical Commissioning Groups (CCGs)) and provider organisations were those whose main purpose was to provide direct health care e.g. GP practices or

hospitals. 'Other' organisations incorporated those that operated at a national level or those that did not fit neatly under a provider or commissioner umbrella e.g. public health, which has recently come under the remit of local government. An overall summary of the Q sample is given in table 7.1 with a more in-depth participant-level breakdown provided in Appendix Nine. As table 7.1 shows, all four of the broad professional backgrounds targeted in the sampling methodology were represented within the Q-Methodology sample, as well all three organisation types.

			Organisational Background			
			Commissioner	Provider	Other e.g. National Body	Total
Disinvestment Experience?	Yes	Clinician-AHP	0	5	0	5
		Clinician-Medical	3	7	0	10
		Clinician-Nursing	2	4	0	6
		Management/ N.E.D	13	2	3	18
		Total	**18**	**18**	**3**	**39**
	No	Clinician-AHP	1	4	0	5
		Clinician-Medical	0	5	1	6
		Clinician-Nursing	0	1	1	3
		Management/ N.E.D	2	1	0	3
		Total	**3**	**11**	**2**	**16**
	Total	Clinician-AHP	1	9	0	10
		Clinician-Medical	3	12	1	16
		Clinician-Nursing	2	5	1	8
		Management/ N.E.D	15	3	3	21
		Total	**21**	**29**	**5**	**55**

Table 7.1- Breakdown of participants in Q-Study by professional background, level of disinvestment experience and organisation

7.2.2 <u>Factor Summaries</u>

As part of the factor analysis process each of the factors will be analysed in light of the other factors that have been uncovered, thus teasing out where they are similar and where they disagree with each other. The following sections give in-depth analysis of each factor in turn, incorporating the qualitative data collected following the Q-sorting procedure where this aids description and analysis. Where direct quotations have been used these are shown in italics and where particular statements from the Q set have been used to exemplify an assertion the number of the statement and its position in the factor array is included in brackets following the assertion (statement number, +/- position).

Table 7.2 shows the position of each of the statements within the ideal Q-sort for each of the factors and Table 7.3 provides a brief summary of each viewpoint. Statements which distinguish one factor from the others are denoted with an asterisk (*) following the factor array position, those statements which are consensus statements across all the factors are denoted by the underlining of the factor array positions.

No	Statement	Factor 1	Factor 2	Factor 3
1	Some groups of people are hard to reach and may never get involved in decision making, so public involvement can't be representative.	0*	3	4
2	By participating in the process, the public are agreeing that there needs to be cuts which isn't true.	<u>-1</u>	<u>-1</u>	<u>0</u>
3	The public's views should be represented by elected officials e.g. MPs	0	-2	-1
4	The public pay for the NHS and they are better placed than doctors or managers to decide how to spend their money.	0	-4*	-1
5	The public should be involved in decisions on health care disinvestment because they know the needs of the local community.	1*	-2	-2
6	Individuals have more pressing personal concerns than decisions on health care disinvestment.	-1	1	0
7	The public don't trust public institutions and feel that they need to be involved in decision making to look after their interests.	<u>0</u>	<u>0</u>	<u>-1</u>
8	The public are put off becoming involved by the complex, technical nature of health care funding and the lack of information.	1	0*	2
9	The public are capable of over-looking their own self interest for the good of the community. Being involved can help build the community.	2*	-1	-2
10	Health professionals don't consider the impact on individuals when making decisions; public involvement allows individuals to express themselves.	<u>0</u>	<u>0</u>	<u>1</u>
11	The public must be involved as decision makers will take instructions from government, who don't represent the interests of the public.	1	-1	0
12	The public have different priorities to those people who run the health service. The public don't trust decision makers to represent their interests	0	2	1
13	Decision makers represent the best interests of the public so there is no need for public involvement.	<u>-3</u>	<u>-3</u>	<u>-3</u>
14	The public are too subjective to be involved. The public want everything and their views will change depending on their personal circumstances.	-2*	1*	0*
15	The public should be involved in decision making because health care is a vital public service and they have a democratic right to be. Health care staff and decision makers are not elected.	2	0	2

No	Statement	Factor 1	Factor 2	Factor 3
16	Whether the public are involved or not, decisions will always depend on what politicians want, so there is no point involving the public.	-2*	-1	2*
17	Public participation can make decision makers less remote and can help the public understand the decision making process.	3	3	1*
18	Public involvement can make difficult decisions easier to accept and it can give the process credibility.	3	4	0*
19	Public involvement gives citizens a sense of belonging and responsibility and can help to improve society.	3*	2	1
20	The public are too aware of existing perspectives and beliefs to give a fair view, and the media can bias their opinions.	-1*	1*	3*
21	Involving the public in decision making can lead to more cost effective health care and they could suggest alternative ways to make savings.	2*	1*	-3*
22	It is hard to show that involving the public is effective and influences the decisions that are made.	0*	0*	-3*
23	Involving the public will ensure that that resources are distributed fairly and 'unfashionable' services e.g. Mental health are not forgotten.	1*	-3*	-2*
24	Involving the public in decision making allows individuals to take more responsibility for their own health. They have a responsibility to contribute to decision making.	3	0	-1
25	Public involvement is pointless as it only achieves anything if the decision makers agree with what the public think.	-3*	-1	1
26	Involving a wide range of people (including the public) ensures that a range of knowledge and experience is taken into account when making decisions.	4	2	0*
27	The public are sensible enough, and now have enough knowledge of health services, to be able to contribute to rational decisions on disinvestment.	1	-2*	2
28	The public need to be aware of the consequences of the decisions they are making.	2	3	4*
29	Doctors know best, they know what different groups want, so they should decide for themselves how the budget is spent.	-4	-3	-4
30	Decision makers are self- interested and don't know what the priorities for public health care spending should be.	-1	-2	3*
31	The public don't know enough about health disinvestment	-2*	2*	0*

		Factor		
No	Statement	1	2	3
	to make decisions.			
32	Health service managers can't be trusted to make the right decisions. Public involvement is needed to understand and uphold the public's values.	0*	-2*	3*
33	Members of the community should have a choice whether they are involved in decisions or not.	1	2	3*
34	Decisions should be made on value for money, not public opinion. Involving the public makes the process more cumbersome.	-2	1*	-2
35	The public can't trust the information that is provided because statistics can be manipulated, so there is no point in getting involved.	-1	-1	0
36	Public participation gives a more transparent process which delivers fairer results and ensures that the consequences of decisions are thought through.	4*	1*	-1*
37	The media and interest groups represent the views of the public, and decision makers listen to these groups, so there is no need for public involvement.	-2*	-4	-4
38	Decision makers are shirking their responsibility to take difficult decisions if they involve the public.	-4	-3	-3
39	Efforts to involve the public are tokenistic. Public involvement won't change anything.	-3*	0	-1
40	The debate on disinvestment has to be made public otherwise it will be dominated by self-interested parties.	2	4	2
41	The public don't understand the need to prioritise and make health disinvestment decisions	-3*	0	0
42	Involving the public in decision making will bias decisions towards 'fashionable' services (e.g. away from mental health).	-1	3*	-2

Table 7.2- Factor Array Showing the Position of each Statement under each Factor

	Factor One- Advocates of Involvement	Factor Two- Cautious Supporters	Factor Three- Freedom of Choice Group
Should the public be involved?	Yes	Yes	Yes
What are the benefits of involvement?	Instrumental, educative, democratic	Instrumental, educative	Educative
What are the drawbacks?	No drawbacks identified	Difficulty in gaining representative sample, public preference for 'fashionable' services, influence of the media	Impossible to gain representative sample, difficulty in public remaining overlooking self-interest
Extent of involvement	Public should be involved alongside other stakeholders	Decisions should be collaborative, doctors and managers must be involved too	Broad-brush involvement, feeding public views into decision-making
What distinguishes this factor from others?	Steadfast view on benefits of involvement; the only factor which believed that the public could overlook their own self-interest.	Trust in managers to represent public views and backing of cost effectiveness as an approach to disinvestment decision making	Public should decide for themselves whether or not to become involved. Demonstrated wariness of the influence of politicians

Table 7.3 – Summary of Factor Viewpoints

Table 7.4 below shows the loadings of each individual Q-sort on to each factor and the proportion of the variance that is explained by each of the factors. Q-sorts which load significantly (p<0.001) are shown in italics and exemplars are denoted

with an x after their loading. Exemplars were identified and highlighted by the researcher using the formula detailed in section 6.2.6 (2.58 x (1/√n) =2.58 x (1/√42) =2.58 x 0.15 = 0.398). Respondents' Q sorts were flagged as exemplars if the factor loading for one factor was significant (greater than 0.40) and the factor loadings for the other two factors was not significant (less than 0.40) The autoflagging function of PQ Method was not used.

The column h shows the sum of squared factor loadings for each Q-sort across the three factors.

QSORT	F1	F2	F3	h
1	*0.70*	0.20	*0.44*	0.73
2	***0.83x***	0.21	0.30	0.82
3	*0.60*	*0.56*	0.00	0.67
4	0.29	*0.47*	*0.41*	0.47
5	0.39	***0.67x***	0.26	0.67
6	0.08	*0.52*	*0.55*	0.58
7	-0.24	***0.46x***	0.00	0.27
8	***0.75x***	0.32	-0.01	0.66
9	***0.73x***	0.19	0.03	0.58
10	***0.52x***	0.22	0.32	0.41
11	***0.78x***	0.08	0.27	0.69
12	0.36	***0.58x***	0.31	0.57
13	*0.65*	*0.44*	0.25	0.68
14	0.28	***0.61x***	0.00	0.44
15	***0.64x***	0.35	-0.14	0.55
16	*0.40*	*0.55*	0.08	0.47
17	***0.85x***	-0.07	0.28	0.81
18	***0.69x***	0.27	0.10	0.55
19	***0.56x***	0.34	0.06	0.43
20	***0.83x***	0.16	0.30	0.81
21	*0.40*	*0.56*	0.10	0.49
22	*0.52*	*0.52*	0.26	0.61
23	***0.83x***	0.23	0.20	0.78

QSORT	F1	F2	F3	h
24	-0.39	*0.52x*	-0.01	0.42
25	0.19	*0.68x*	0.19	0.54
26	*0.81x*	0.22	-0.01	0.70
27	*0.85x*	-0.09	0.13	0.75
28	0.16	*0.59*	*0.40*	0.54
29	*0.62*	*0.57*	0.13	0.74
30	0.19	*0.48*	*0.52*	0.54
31	*0.65*	0.26	*0.44*	0.69
32	*0.88x*	0.16	-0.02	0.81
33	*0.63*	0.21	*0.40*	0.60
34	*0.50x*	0.07	0.25	0.32
35	*0.70*	*0.41*	0.12	0.68
36	*0.45*	*0.53*	0.25	0.54
37	0.04	*0.67x*	0.08	0.46
38	*0.47*	*0.51*	0.35	0.60
39	-0.05	*0.49*	*0.60*	0.61
40	0.08	*0.57x*	0.35	0.46
41	*0.45*	*0.56*	0.05	0.52
42	0.22	0.05	0.27	0.13
43	*0.83x*	0.13	0.01	0.71
44	*0.79x*	0.16	0.19	0.69
45	*0.80x*	0.30	0.01	0.72
46	0.25	*0.50*	*0.48*	0.54
47	0.29	0.06	*0.60x*	0.45
48	*0.49x*	-0.28	0.10	0.33
49	*0.59*	*0.44*	0.10	0.55
50	0.27	*0.51x*	0.29	0.42
51	0.38	*0.51x*	0.39	0.56
52	*0.56*	*0.46*	0.16	0.55
53	0.06	*0.69x*	0.26	0.55
54	*0.83x*	0.04	0.30	0.78
55	-0.28	0.32	*0.47x*	0.40
Eigenvalue	17.35	9.79	4.46	31.60
% expl. Var.	32	18	8	58

Table 7.4 - Factor loadings for each participant on to each factor

7.2.3 Factor One- Advocates of Involvement

As is to be expected, and is often the case, far more individual Q-sorts loaded strongly onto the first factor to be extracted than on to subsequent factors (Watts and Stenner, 2012). In total, 20 of the 55 participants loaded strongly on to factor one- Advocates of Involvement (defined by having a loading of more than/ less than +/- 0.4) and were non-confounded (i.e. they loaded strongly on to only one factor). There was little commonality in the job roles and background of the factor exemplars; the majority (11) worked as clinicians in provider organisations and of these, seven worked as doctors or surgeons, three were allied health professionals (AHP) and one was a nurse. Six of the exemplars worked in commissioning organisations, four as managers and two as clinicians, and two worked in 'other' organisations at a national or local authority level. The remaining exemplar worked as a manager in a provider organisation.

Levels of involvement in, and experience of, disinvestment decision making varied greatly across the exemplars; of the 20 exemplars, seven had no experience whatsoever. All of the managers had some experience of disinvestment, this ranged from making proposals for disinvestment and providing data through to delivering service redesign. The clinicians had wider ranging experiences of disinvestment; with five of the 11 clinicians based in provider organisations having had no experience of disinvestment whatsoever, and the other six having had experiences ranging from being consulted on possible service changes to being involved in disinvestment as part of a national advisory board. Both of the clinical

commissioners had been involved in disinvestment as part of service review teams and the two other exemplars had no experience of disinvestment.

The factor array for Advocates of Involvement, demonstrating the statements which were placed at either extreme, was as follows:

Strongly Disagree			Strongly Agree
29.Doctors know best, they know what different groups want, so they should decide for themselves how the budget is spent.	13.Decision makers represent the best interests of the public so there is no need for public involvement.	24.Involving the public in decision making allows individuals to take more responsibility for their own health. They have a responsibility to contribute to decision making.	26.Involving a wide range of people (including the public) ensures that a range of knowledge and experience is taken into account when making decisions.
38.Decision makers are shirking their responsibility to take difficult decisions if they involve the public.	41.The public don't understand the need to prioritise and make health disinvestment decisions	19.Public involvement gives citizens a sense of belonging and responsibility and can help to improve society.	36.Public participation gives a more transparent process which delivers fairer results and ensures that the consequences of decisions are thought
	39.Efforts to involve the public are tokenistic. Public involvement won't change anything.	18.Public involvement can make difficult decisions easier to accept and it can give the process credibility.	
	25.Public involvement is pointless as it only achieves anything if the decision makers agree with what the public think.	17.Public participation can make decision makers less remote and can help the public understand the decision making process.	

Fig. 7.1- Extremes of the Ideal Q-Sort for Advocates of Involvement

The 'Advocates of involvement' viewed public participation in disinvestment decision making in an overwhelmingly positive light; if there were downsides to public involvement then these were not cited by those who subscribed to this point of view.

Advocates of involvement suggested that involving the public could deliver a variety of benefits, ranging from instrumental benefits e.g. making it *"easier for people to accept decisions that have been made in an open and transparent*

process" (Participant 19) (18, +3), to educational benefits, *"the more an individual is involved the more literate they will be"* (Participant 18) (17, +3). In addition to this, involving the public could also help to build *"a sense of shared ownership and responsibility and lead to a sense of empowerment and being part of a whole"* (Participant 20) (19, +3).

In relation to instrumental benefits, Advocates of Involvement also believed that public involvement could lead to improved decision making because the public *"know more what the man in the street wants, they are more in touch with the community"* (Participant 34) (5, +1) and because the public could ensure fair distribution of resources, even to 'unfashionable' services which were not promoted by the media or interest groups (23, +1). The cautious supporters (5, -2/ 23, -3) and the Freedom of Choice group (5, -2/ 23, -2) were both far more sceptical of these benefits of public involvement and they disagreed with both of these notions.

Advocates of involvement would consider that *"the more people are involved the fairer the decisions and the more transparent the process is"* (Participant 48) (36, +4), and that a fair process would be more likely to lead to a fair outcome. This suggests that, in their eyes, any processes which did not involve the public may be unjust, from both a procedural and a distributive justice perspective.

Whilst championing public participation in disinvestment decision making, advocates of involvement would suggest that the public should only be involved as

one stakeholder group amongst a number of interested parties (26, +4) and that *"good health care should be a partnership between clinicians, patients, managers and the wider community"* (Participant Two). The perspective suggests that these stakeholder groups could add a wealth of knowledge and experience which neither decision makers (13, -3), who *"operate in a centrally controlled system which is not democratically accountable"* (Participant Two), nor doctors (29, -4), could offer on their own. Advocates of involvement strongly disagreed that, by involving the public, decision makers would be hiding from their responsibilities to take decisions (38, -4). Indeed, they suggested that decision making was *"a shared responsibility"* (Participant 20) and that *"decision makers are taking responsibility for good governance by involving the public"* (Participant 32).

Despite this organisational responsibility, however, advocates of involvement did stress that *"individuals should start taking more responsibility for their own health"* (Participant 27) (24, +3) and should not expect decision makers to go out of their way to seek public views. Extending this 'responsibility' for personal health to incorporate taking personal responsibility for ensuring that available services meet each member of the public's own needs suggests a somewhat individualist view of public involvement. This view expressed by some participants was in contrast to the communitarian benefits espoused by advocates of involvement more widely and it did represent something of a tension within the perspective shared by this group of individuals.

In addition to a belief in the potential benefits of public involvement for

individuals and society, advocates of involvement had a strong belief that the

public had the skills, abilities and knowledge to contribute to decisions that were

being taken and were *"just as clever and wise as health managers"* (Participant

32) (41,-3). As well as believing that the public had the capability to contribute,

advocates of involvement also believed that decision makers had a genuine interest

in what the public had to say (39, -3) and that *"strong public opinion can affect

changes in decision makers"* (Participant Eight) and could sway their thinking (25,

-3).

Advocates of involvement agreed that the public were able to overlook their own

self-interest and *"can be trusted to make sensible decisions and choices"*

(Participant Nine) (9, 2) and they suggested that this was not hampered by being

too aware of existing perspectives (20, -1). This viewpoint was in contrast to both

the cautious supporters (9, -1 /20, 1) and the freedom of choice group (9, -2/20, 3)

who were more sceptical of the public's ability to view disinvestment decisions

impartially.

7.2.4 Factor Two- Cautious Supporters

Eleven non-confounded Q-sorts loaded strongly on to factor two- Cautious

Supporters. Similarly to factor one, there was little commonality in the

occupational backgrounds of these exemplars. Six of the exemplars worked as

managers- four from commissioner organisations and two from a provider. All of

the commissioners, and one of the provider managers who worked in a secondary

care organisation, had some experience of disinvestment. This experience ranged

from acting in an advisory capacity to decision making boards e.g. providing cost and activity information, through to actually leading disinvestment and service changes as a commissioning manager. The other provider manager worked as a practice manager in a GP surgery and had no experience of disinvestment.

The remaining five exemplars were all from clinical background and worked in provider organisations. Three of these clinicians were medical, one was an AHP and one was a nurse. All of these clinical exemplars, except one of the doctors, had some experience of disinvestment. This experience ranged from being involved in pathway re-development to being a clinical lead for a service, essentially with the final say over decisions.

The factor array for Cautious Supporters, demonstrating the statements which were placed at either extreme, was as follows:

Strongly Disagree	←	→	Strongly Agree
4.The public pay for the NHS and they are better placed than doctors or managers to decide how to spend their money.	13.Decision makers represent the best interests of the public so there is no need for public involvement.	17.Public participation can make decision makers less remote and can help the public understand the decision making process.	18.Public involvement can make difficult decisions easier to accept and it can give the process credibility.
37.The media and interest groups represent the views of the public, and decision makers listen to these groups, so there is no need for public involvement.	29.Doctors know best, they know what different groups want, so they should decide for themselves how the budget is spent.	42.Involving the public in decision making will bias decisions towards 'fashionable' services (e.g. away from mental health).	40.The debate on disinvestment has to be made public otherwise it will be dominated by self-interested parties.
	38.Decision makers are shirking their responsibility to take difficult decisions if they involve the public.	1.Some groups of people are hard to reach and may never get involved in decision making, so public involvement can't be representative.	
	23.Involving the public will ensure that that resources are distributed fairly and 'unfashionable' services e.g. Mental health are not forgotten.	28.The public need to be aware of the consequences of the decisions they are making.	

Fig. 7.2- Extremes of the Ideal Q-Sort for Cautious Supporters

Cautious supporters were broadly supportive of public involvement in

disinvestment decision making but their backing was not unequivocal and they did suggest that decision makers should approach involvement with some caution.

Cautious Supporters backed public involvement because of the instrumental benefits that it could deliver in making the public more accepting of decisions; *"informed consent creates an environment for logical, fair changes"* (Participant 12) (18, +4). In addition to this they also thought that the chances of public acceptance of decisions would increase if they knew the process and understood it (17, +3); this implies that cautious supporters had some recognition of the educative benefits of involvement as well as the instrumental. In order for the benefits of public involvement to be realised, Cautious Supporters recognised that it was necessary to open the debate up to the public (40, +4) and they realised that if the debate remained private then self-interested parties would have significant influence over decisions.

Whilst Cautious Supporters acknowledged the benefits of public involvement they also highlighted the fact that it was very difficult for involvement to be considered to be representative as *"it's the 'usual suspects' with the usual agenda that get involved whilst others (particularly in deprived areas) simply do not have a loud enough voice"* (Participant Seven)(1, +3). In addition to this, Cautious Supporters also warned that the public could be swayed towards a preference for 'fashionable' and high profile services- *"the public focus of questions etc is predominantly on acute hospital services"* (Participant 37) (42, +3), and involving the public would not have the effect of promoting under- represented fields (23, -3). This preference

could be caused by the media and interest groups who, they believed, did not represent the views of the public as a whole, and who *"print what makes money- not necessarily what is in the public interest"* (Participant 14) (37, -4).

Cautious supporters recognised that, whilst the public paid for the NHS, they were not in a better position than doctors or managers to decide how money should be spent; the public *"do not have the wider view of public interest, most, but not all, will be guided by what's important to them"* (Participant 14)(4, -4). Although the public were not better placed than managers or doctors to make decisions, neither of these groups was ideally placed to take decisions on their own either (13, -3/ 29, -3) and decision making should therefore be done in partnership. Health service managers *"are going to have their own biases"* (Participant 53) and *"doctors are professionals and experts in their own areas, but are not disinterested in the funding for their own services or special areas of interest"* (Participant 50). In light of this, the perspective suggested that decision makers had a responsibility to involve the public and, by doing so, were *"ensuring that everyone's views are listened to"* (Participant 25) (38, -3).

One of the statements that distinguished Cautious Supporters from the other two factors was statement 34; this suggests that the Cautious Supporters believed more strongly in the importance of economic evidence. This economic focus and emphasis on cost effectiveness implies that Cautious Supporters would take a more utilitarian view of disinvestment and believe that *"value for money is the way to select the most appropriate service"* (Participant 14) (34, +1). The Freedom of

Choice group (34, -2) and, perhaps unsurprisingly, the Advocates of Involvement (34, -2) felt that public opinion should take precedence over cost effectiveness analysis whereas the Cautious Supporters showed some agreement with the idea that value for money outweighed the views of the public.

The Cautious Supporters were sceptical about whether or not the public were well enough informed to make health disinvestment decisions (31, +2) and they suggested that health service managers, who they believed to be better informed, could be trusted to understand and uphold public values (32, -2). Conversely, the Advocates of Involvement felt that the public did have enough knowledge to contribute (31, -2) and were neutral about whether or not health service managers could be trusted (32, 0). The Freedom of Choice Group were neutral about whether the public were sufficiently well informed to contribute (31, 0) but, their distrust of health service managers (32, +3) suggested that, from their perspective, the only way to ensure that public values were understood and upheld was to involve them.

7.2.5 Factor Three- Freedom of Choice Group

Two Q-sorts loaded on Factor three: Freedom of Choice Group. Unlike the other two factors, there was a little commonality in the professional backgrounds of the exemplars, with both working as allied health professionals. Both exemplars were employed in provider organisations and both had experience of disinvestment having been clinical leads for their services. In these roles, both exemplars had been asked to consider how money could be saved in their areas and had been asked to select between disinvestment options which could affect the way that their

services were provided.

The researcher recognises that, as there are only two exemplars of the Freedom of Choice factor, and one of these (participant 55) also loads quite strongly (0.32) on to the Cautious Supporters factor, there is an argument to suggest that this third factor should not have been extracted and that a two factor solution should have been presented. Because of this, the researcher did consider extracting a two factor solution but, for a number of reasons, it was decided that the data collected and the views of the participants were best represented across three factors.

First, even if participant 55 also loads quite strongly on to factor two, its significant loading is on factor three and there is a considerable difference between the participant's loadings on to the two factors (0.15). In addition to meeting Brown (1980)'s criterion, the three factor solution also meets the other statistical requirements laid out prior to the commencement of the research. The third factor meets the Kaiser-Guttmann criterion (Kaiser, 1960; Guttman, 1954) (its eigenvalue is >4) and the overall solution accounts for 58% of the variance of the study- Kline (1994) suggests that the solution should account for at least 35%.

From a qualitative perspective, initial interpretation of the third factor offered a viewpoint which, in the researcher's opinion, was sufficiently rich and distinct from the other two factors to warrant inclusion. The Freedom of Choice Group also offered a view which was genuinely held by participants within the sample (as reflected by qualitative comments), made sense to the researcher and was operant.

In terms of theoretical justification, factor three was of interest to the researcher because it linked closely to the third proposition identified through the literature review: "The public should be involved in disinvestment decision making because they want to be involved." Initial interpretation, suggested that the Freedom of Choice Group could link with this proposition in suggesting that, if given the choice about whether or not they wished to be involved in decision making, the public would want to take part. This face-value synergy encouraged the researcher to extract the third factor and to investigate it further.

In addition to this, the inductive nature of the research encouraged the researcher to extract as many factors as possible, with the mixed methods research design allowing all factors to be further explored and interrogated in the second stage, regardless of the number of exemplars and strength of their loadings.

Given the commonality between the professional backgrounds of the two exemplars of the Freedom of Choice group it is possible that an additional round of purposive sampling could have identified additional sorts that load on the factor, for instance allied health professionals with experience of disinvestment. With hindsight, the researcher recognises that relying solely on snowball sampling to grow the P sample, and not conducting purposive sampling until the interview stage of the research, may have limited the strength of the three factor solution.

The factor array for Freedom of Choice Group, demonstrating the statements which were placed at either extreme, was as follows:

Strongly Disagree			Strongly Agree
29.Doctors know best, they know what different groups want, so they should decide for themselves how the budget is spent.	22.It is hard to show that involving the public is effective and influences the decisions that are made.	33.Members of the community should have a choice whether they are involved in decisions or not.	28.The public need to be aware of the consequences of the decisions they are making.
37.The media and interest groups represent the views of the public, and decision makers listen to these groups, so there is no need for public involvement.	21.Involving the public in decision making can lead to more cost effective healthcare and they could suggest alternative ways to make savings.	32.Health service managers can't be trusted to make the right decisions. Public involvement is needed to understand and uphold the public's values.	1.Some groups of people are hard to reach and may never get involved in decision making, so public involvement can't be representative.
	38.Decision makers are shirking their responsibility to take difficult decisions if they involve the public.	30.Decision makers are self- interested and don't know what the priorities for public healthcare spending should be.	
	13.Decision makers represent the best interests of the public so there is no need for public involvement.	20.The public are too aware of existing perspectives and beliefs to give a fair view, and the media can bias their opinions.	

Fig. 7.3- Extremes of the Ideal Q-Sort for the Freedom of Choice Group

Similarly to the Cautious Supporters, the Freedom of Choice group were broadly supportive of involving the public, who, they said, could *"act as a critical friend"* (Participant 47) in disinvestment decision making. In contrast to the Cautious Supporters, however, the Freedom of Choice group were champions of informed choice and felt that the public should be able to make an informed decision for themselves about whether or not they became involved in disinvestment decision making (28, +4/ 33, +3).

The Freedom of Choice Group accepted that *"it is impossible to engage with the whole community for various reasons"* (Participant 55) (1, +4), thus questioning whether public involvement could be representative. Despite this they did suggest that involvement should still be sought as health service managers and decision makers were self-interested (30, +3) and did not *"always have the (needs of the community) at the centre of their decision making processes"* (Participant 55) (32, +3/ 13, -3).

The Freedom of Choice Group advocated the involvement of the public and suggested that it could have *"both a knowledge building and influencing impact"* (Participant 47) (22, -3), but the perspective did not agree that public involvement could deliver innovation or more cost-effective solutions (21,-3). In light of this, it could be suggested that the Freedom of Choice group viewed public involvement as an end in itself and was indifferent to the instrumental and other benefits which it offered.

Similarly to other factors, the Freedom of Choice group had a distrust of the media and interest groups (37, -4) and, potentially due to this distrust, they questioned the public's ability to take all arguments and evidence into account fairly when involved in disinvestment decision making (20, +3). Despite their mistrust of the public, the Freedom of Choice Group suggested that *"doctors do not know best"* and that managers' decision making was *"based around money and wholly money"* (Participant 55) (29, -4/ 32, +3). The Freedom of Choice group suggested that decisions should be taken by a *"number of health care professionals"* (Participant 55) and that decision makers would not be shirking their responsibilities if they involved the public (38, -3).

Whilst advocating for public involvement, the Freedom of Choice Group suggested that political will could have a big impact on decisions that were taken and they agreed that, even with involvement, decisions would depend on what politicians wanted (16, +2). Both the Advocates of Involvement (16, -2) and the Cautious Supporters (16, -1) disagreed with this notion, suggesting that they were

more confident that involvement could have an impact even if the public and politicians disagreed with each other.

Whilst both the Advocates of Involvement (18, +3) and the Cautious Supporters (18, +4) agreed that involving the public could make difficult decisions easier to accept and could give the process credibility, the Freedom of Choice group remained neutral (18, 0) thus questioning some of the reported instrumental benefits of involvement. Similarly, the Freedom of Choice Group (36, -1) also disagreed with the Advocates of Involvement (36, +4) and the Cautious Supporters (36, +1) as to whether or not public involvement added transparency to the process. The Freedom of Choice Group perspective maintained that involving the public did not necessarily make the decision making process transparent; this may explain why they did not agree that a process with public involvement was always more credible than one without.

7.2.6 Comparing and Contrasting the Factors

Each of the three factors identified was unique and each was represented by at least two exemplars as well as having several distinguishing statements; this justifies the decision to extract three factors from the data. Whilst each factor was unique, however, there were several aspects of each perspective which were common across Advocates of Involvement, Cautious Supporters and the Freedom of Choice Group.

All three factors were supportive of the idea that the public should be involved in

disinvestment decision making and they disagreed that decision makers would be shirking their responsibility if they were to seek to involve them. Advocates of Involvement showed unreserved support, whereas Cautious Supporters and the Freedom of Choice Group did appreciate that there may be some drawbacks to involvement. Nevertheless, all perspectives agreed that the public should be involved. Given the strong support that all of the factors showed for public involvement it could actually be suggested that decision makers had a responsibility to involve the public and that this responsibility was an important aspect of their role.

This key distinction between the factors could be characterised by defining the Advocates of Involvement as taking a normative view on public involvement, envisioning what it ought or could be in an ideal world (Hands, 2012). This view is in contrast to the Cautious Supporters and Freedom of Choice group who appeared to take a more positive, or realist, view of public involvement, considering some of the risks it entailed and bearing in mind their own practical experiences of involvement. One example of this difference is in the Advocates of Involvement view of the public's ability to overcome self-interest; they seem to be far more trusting of the public, whereas the Cautious Supporters and Freedom of Choice Group give more credence to the potential risks.

All of the three factors disagreed that the media and interest groups represented the interests of the public, although the Cautious Supporters and Freedom of Choice Group disagreed more strongly than the advocates of involvement. It could be

suggested that the Advocates promoted public involvement fully and espoused all of its benefits so, in their view, the media and interest groups would have less of a say in decision making and, whether or not they represented the public view, would be less important. Both the Cautious Supporters and the Freedom of Choice Group suggested some caution around involving the public and disagreed more strongly with the suggestion that the media represented public interests. This was because they were concerned that the media may have more of an opportunity to influence decision makers in the absence of real public engagement.

The Freedom of Choice Group suggested that the public should be given full information before they decided for themselves whether or not to become involved in disinvestment decision making. Whilst agreeing that public involvement was a good thing, and should be encouraged, the Advocates of Involvement and the Cautious Supporters neither strongly agreed nor disagreed with the idea of choice; this implied that decision makers had a duty to involve the public whether or not they wanted to take part.

Each of the three factors highlighted potential benefits of public involvement. Cautious supporters and the Freedom of Choice Group recognised the instrumental benefits of public involvement, such as the ability of involvement to influence decision makers and the fact that involving the public could make difficult decisions seem more acceptable. In addition to these benefits, the Advocates of Involvement also suggested that involvement could deliver benefits in terms of helping individuals to feel part of a community, ensuring that decisions reflected

public views and introducing the public to the ways in which decisions were taken. In addition, the Advocates of Involvement also suggested that involvement could encourage individuals to become involved in decision making and to take responsibility for their own health care.

7.2.7 <u>Q-Study Summary</u>

This Q-study has shown that, amongst a sample of 55 NHS professionals, there was significant support for public involvement in disinvestment decision making. Despite this support, however, some scepticism as to the levels of benefit that could be achieved through public involvement was also shown and some of the potential drawbacks were highlighted alongside the advantages. In order to investigate further the reasons behind the views displayed in the Q study and to offer more in-depth insights into why participants felt that the public should be involved in disinvestment decision making, and what the implications of this could be for disinvestment practice, a series of semi-structured interviews was carried out with a purposive sample of the participants from the Q study.

7.3 <u>Semi-Structured In-Depth Interviews</u>

A total of 20 participants took part in the semi-structured interviews, these took place between 15th April and 24th June 2013. Interviews lasted between 25 minutes and 1 hour and 20 minutes, the median interview length was 41 minutes. The professional backgrounds of the participants, their experience of disinvestment and the Q-Methodology factor that they were an exemplar of (if any) is included in table 7.5- further information about each participant is included in Appendix Nine.

As is demonstrated, the sampling methodology ensured that a broad range of experiences in a number of different types of organisation was represented alongside a range of the views highlighted by the Q-Study. Using interviews as a means of data collection allowed the factors, and the influence that participants' professional and organisational backgrounds had on their views, to be explored in depth. Where direct quotes have been used to exemplify a theme these have been shown in italics and the participant's unique identifier, their professional background and the type of organisation within which they are employed have been included in brackets. In order to exemplify the sequential nature of the research and to allow for the views of particular participants to be tracked throughout the data collection, individual participants retain the same participant number for the interviews that they were assigned for the Q Methodology phase.

7.3.1 Thematic Analysis

Thematic analysis was carried out as described in the Methods Chapter. A full coding breakdown incorporating the 125 descriptive codes, 34 sub-codes and seven over-arching themes that were identified is included as Appendix seven. The coding structure also contains a brief description of each of the initial descriptive codes, identifies which of the research questions each code is most relevant to and gives an indication as to whether the code is sufficiently supported in its own right by the data.

			Organisational Background			
			Commissioner	Provider	Other e.g. National Body	Total
Professional Background and Perspective	Advocates of Involvement	Clinician- AHP	0	1	0	1
		Clinician- Medical	0	2	1	3
		Clinician- Nursing	0	1	1	2
		Management/ N.E.D	1	0	0	1
		Total	**1**	**4**	**2**	**7**
	Cautious Supporters	Clinician- AHP	0	1	0	1
		Clinician- Medical	1	0	0	1
		Clinician- Nursing	0	0	0	0
		Management/ N.E.D	1	0	0	1
		Total	**2**	**1**	**0**	**3**
	Freedom of Choice Group	Clinician- AHP	0	1	0	1
		Clinician- Medical	0	0	0	0
		Clinician- Nursing	0	0	0	0
		Management/ N.E.D	0	0	0	0
		Total	**0**	**1**	**0**	**1**
	Confounded	Clinician- AHP	0	1	0	1
		Clinician- Medical	0	2	0	2
		Clinician- Nursing	0	0	0	0
		Management/ N.E.D	5	0	1	6
		Total	**5**	**3**	**1**	**9**
	Total	Clinician- AHP	0	4	0	4
		Clinician- Medical	1	4	1	6
		Clinician- Nursing	0	1	1	2
		Management/ N.E.D	7	0	1	8
		Total	**8**	**9**	**3**	**20**

Table 7.5- Breakdown of Participants in In-depth Interviews

The remainder of this first results chapter will build on the Q-Methodology answer to research question one and explore further why participants felt that the public should be involved in disinvestment decision making. In agreement with the Q-Methodology findings, participants within the interview study broadly supported

the idea that the public should be involved in disinvestment decision making; every interviewee, initially at least, was supportive of public involvement, to some extent. The research highlighted a range of societal, educative and instrumental motivations for involving the public.

7.3.2 Societal, Educative and Democratic Motivations

Respondents evoked a number of societal arguments, suggesting that public involvement could help to bring communities together, to unite them in a common cause, particularly if decisions did not go in their favour:

> *".....as a process it was a guaranteed way to turn all of the locals against it, which they have done. It's been fantastically uniting for the area, I have to say!"* (Participant 49, Clinician- Medical, Provider).

Similarly, the involvement of the public in disinvestment decisions was viewed by the interviewees as a way of encouraging the community, as a whole, to work together, to take ownership of their services and to contribute to them.

In terms of education, public involvement was perceived by participants to offer multiple benefits; firstly, it was suggested that involving the public in disinvestment decision making could educate them as to what the possible options for service design were and what the consequences of these options were. It was also suggested that it may help to reassure the public of the quality of a new service e.g. a nurse led service. In addition, some participants suggested that involvement may educate the public on when and how services should be used

appropriately and responsibly: it was suggested by Participant 31, for instance, that public involvement could *"lead to better environments for patients and also a better understanding of what services can be used for- ED, primary care, pharmacy, they* {patients} *are still not using them to the fullest extent or some in the right ways"*. It was also suggested that the educative benefits of involvement could extend to the public gaining an understanding of why service changes needed to be made, as well as educating them on how decisions were taken and better enabling them to advocate for themselves.

Whilst levels of knowledge amongst many members of the public were thought by interviewees to be conducive with involvement in disinvestment decision making, the research does suggest that participants were wary of a significant minority who may be ill-informed or ignorant. The educative benefits of public involvement were thought to be particularly important and relevant for this group. One of the perceived symptoms of this lack of knowledge was a tendency to value some services more highly than others on the basis of how popular or high profile they were. If involvement in the process did not deliver the educative benefits that participants in the interviews expected, and involvement resulted in illogical or irrational outcomes, then this was considered to be a potential argument against public participation in disinvestment decision making.

"You can pretty much guess who it {public involvement} *would affect- it would affect STD* {Sexually Transmitted Disease} *clinics, patients that were IV drug users and alcohol abusers, smokers, obese people. All the things that people*

perceive 'oh they've brought it on themselves', they would start losing their services…. all the sorts of things that are in the media that are perceived to be something that they have brought upon themselves would be the services that you would see decline and that really worries me" (Participant 24, Clinician-AHP. Provider).

Regardless of the instrumental, societal and educative benefits of public involvement, a number of participants suggested that organisations might seek to involve the public in disinvestment decision making because the public pay for and use the NHS. The ability of public involvement to make decision making more transparent and ensure that decision makers were held accountable for the decisions that they made was seen by some participants to be a key democratic benefit:

"….the taxpayer's money is being used for the benefit of the public, it's a finite amount, and I think that there should be ways of getting greater public influence over how that money is spent, as a principle" (Participant 16, Management/ N.E.D, Commissioner).

7.3.3 Instrumental Motivations

Participants in the in-depth interview stage of the research suggested that knowledge of decision making processes may improve the credibility of both decision makers and decision making organisations in the eyes of the public. Involving citizens in decision making could, according to the interviewees, give

the public confidence that decisions were being made in their best interests and that proposed service changes represented an improvement in what was available to them:

> "….at the minute it all happens behind closed doors I suppose. So, yeah, by being more involved with it they might be more confident in it and the fact that they've been part of the process, yeah would help that" (Participant 27, Clinician- A.H.P, Provider).

Further instrumental benefits identified by the participants included the ability of public involvement to get citizens 'on side' and accepting of the decisions that were being taken:

> "…if you get better understanding you may get better co-operation with the final decision" (Participant Four- Management/ N.E.D, Commissioner).

Indeed, it was viewed by some participants as a missed opportunity if the public were not involved in decision making:

> "I think that if you don't get people on board with that decision, involve them with that decision, then you are going to lose out" (Participant 43, Clinician-Medical, Other).

Interviewees believed that involving the public, and gaining their acceptance, would increase the chances of successfully implementing disinvestment decisions because the public (and those working within the service) would be more likely to

abide by the decision that had been taken. Even in cases where decisions went against public opinion, the interviewees suggested that citizens would react more rationally and would be more willing to accept the outcome of the decision making process if they had been involved in it.

Findings from the interviews also showed a belief amongst participants that public involvement could make a real and genuine difference to decisions that were taken; it could help to make services more equitable by ensuring that minority views were heard and could improve the quality of services provided. As Participant 39 suggested, public involvement could *"help shape and deliver services that respond better to customers' needs"*. Participants believed that the public could be used as a source of information, and could offer innovative solutions to disinvestment problems; they know what they value and could offer a different perspective on how best to use limited funds.

Interviewees felt that delivery of these innovative solutions could require the integration of services, or the establishment of new care pathways meaning that public involvement may force collaboration between previously separate groups of clinicians. As Participant 16 suggested, *"I think that* {by involving the public} *you might get a challenge to rather deeply-embedded clinical silo thinking."* Interviewees felt that the public took a 'bigger picture' view of health care delivery, seeing through organisational and service-level boundaries and challenging decision makers to work collaboratively to improve quality and deliver innovation. Participants also suggested that this may, in turn, help to improve

organisational efficiency.

7.3.4 Public Capability

Interviewees suggested that the public could make a valuable and worthwhile contribution to decision making. The interviewees believed the public to be knowledgeable and able to overlook their own self-interest in order to contribute to wider decisions:

> *"I do think that people have the ability to be objective. People are always affected by their own personal circumstances or what is affecting their family but they are grown up and I think that they are aware of things on a slightly more complicated level"* (Participant 43, Clinician- Medical, Other).

> *"If we can put things in plain language then most people can get their heads round the issues and that's my personal reflection on interactions with the public when I've been information giving"* (Participant 39, Management/ N.E.D, Commissioner).

In the opinion of the majority of interviewees, even before the public had been involved in decision making processes, they had enough awareness and understanding to realise that disinvestment in health services was necessary; they were capable and ready to contribute to these tough decisions.

Whilst the motivations for involving the public aligned with the Q-Methodology findings, particularly the Advocates of Involvement factor, the semi-structured

interviews also highlighted a number of potential arguments for minimising public involvement in decision making. Whilst the essence of the qualitative findings was that participants were in favour of public involvement and that any arguments against were outweighed by the motivations for involvement, it is important to highlight them in order to add further depth to the factors identified through the Q-Methodology study. In particular, the arguments made against public involvement in disinvestment decision making give further explanation of the Cautious Supporters perspective. They are also of interest in light of the Advocates of Involvement factor, which showed minimal recognition of any disadvantages to public involvement. Section 7.4.1 focuses on the interview responses of the exemplars of the Advocates of Involvement factor and offers some explanations as to why this factor did not appear within the interview data.

7.4 <u>Arguments for Reduced Involvement</u>

The first argument that participants made against public involvement was that it often made little difference to the final decisions that were taken and that those in power paid little attention to public views:

> *"....one of the things that I find a bit frustrating about these types of consultations is that the decision has already been made and I think the public know that"* (Participant 24, Clinician- AHP, Provider).

With limited scope for public involvement to actually change decisions, it was felt by the interviewees that there was a risk that any involvement process would

appear to be tokenistic and, particularly if expectations were artificially raised, could potentially risk eroding public trust in decision making organisations. According to Participant 38, *"minimal involvement and almost tokenistic attempts are worse than doing nothing at all. The trouble is that you have that knock-on effect";* as a result of this, the findings from the interviews suggested that public involvement may be best avoided in circumstances where it had little potential to impact decisions.

Given the suggestion that tokenistic public involvement should be avoided, the design of public engagement processes became of paramount importance but this, according to the participants, was not an easy thing to get right. Firstly it was suggested by interviewees that there was significant difficulty in gaining a representative sample of the public- there were, according to the participants, groups within society who remained hard to reach and this could lead to involvement exercises that involved homogenous groups and the same individuals every time. Participant 30's response to a question regarding groups that may have been missing from public involvement exercises that they had been involved in, and Participant 24's comments exemplify this well- *"we don't have any representation…..actually if I twist it round and tell you the ones that we do have. We have retired, middle-class, white females"* (Participant 30, Management/ N.E.D, Commissioner).

> *"Public consultations always seem to me to involve white, middle class people*
>
> *who have the means to participate in the NHS by providing themselves with a*

taxi or providing themselves with a relative who's got a car or whatever…."

(Participant 24, Clinician- AHP, Provider).

Despite this call for further representation, some participants did caution that wider public involvement had led to disagreements between citizens and groups of individuals from different areas: rather than helping to build communities, it was suggested by some participants that involvement and openness may actually have contributed to divisions. This further emphasised the need to give careful consideration to the design of any process before seeking involvement.

Although believing that the public had the knowledge and ability to contribute to disinvestment decision making, there was some concern amongst participants that they may find difficulty in appreciating the opportunity cost of the decision that they were making. Participants were unclear as to whether this difficulty came as a result of a lack of knowledge, or a lack of public willingness to accept trade-offs but they did feel that organisations and health professionals had a responsibility to guide public participants through the process and ensure that the opportunity cost of decisions was taken into account.

"I think there is a need to slowly manoeuvre the public into that territory of understanding that, unless you are prepared to pay a lot more tax, or make some stark choices around less public spending in other areas of public services there are choices to be made" (Participant 39- Management/ N.E.D, Commissioner).

The influence of interest groups was also highlighted by interviewees as a reason for giving careful consideration to processes and a potential argument against involving the public in disinvestment decision making. These groups were felt to be self-interested and too invested in decisions- their involvement was viewed by participants as a possible threat to the public's ability to weigh up all the arguments and evidence and reach a reasoned decision. It was also suggested by interviewees that this ability could be further threatened if the public lacked knowledge and could be easily swayed.

If this were the case it could, according to the participants, potentially undermine the impartiality of the process and could increase the possibility of public involvement becoming tokenistic. Key to effective public involvement was deemed, by the interviewees, to be involving the 'right' people- a representative sample of the local community, not just those who *"shout the loudest"* (Participant 55, Clinician- A.H.P, Provider).

Participants in the interviews suggested that designing and carrying out effective public involvement could be time consuming and resource intensive. In the case of disinvestment, participants highlighted the problem that this time and resource may not be available, and that the need to make decisions quickly may negate the opportunity to involve the public in anything more than a tokenistic way. Where tokenistic involvement was hard to avoid, interviewees suggested that it may be preferable to minimise wide public involvement efforts.

7.4.1 Absence of Advocates of Involvement in the Interview Data

Given the strong support for public involvement demonstrated by the Advocates of Involvement factor in the Q Methodology study, it is an interesting finding that all of the interviewees, including the exemplars of the 'advocates' factor, identified some arguments against involving the public. Whilst no Q-sort correlated completely with the first factor (the strongest loading was participant 32 (0.88)), and the factor did not therefore represent any individual's view entirely, it is still an unexpected finding that all the exemplars contradicted the factor, to some extent, in their interviews.

In addition to the themes outlined in the previous section, further analysis of the interviews completed by the Advocates of Involvement exemplars also identified three additional arguments against public involvement specific to this subset of the sample. This analysis also gave some indications as to why the advocates may have displayed a less supportive view of public involvement in the interviews than they did in the Q study.

First, in contrast to most of the rest of the interviewees, Participant Nine drew a clear distinction between patients and the public, and suggested that, in some circumstances, the public should not be involved in disinvestment decision making because they could not empathise with the patient's perspective. If they had never used a service before then they could not understand what particular services entailed and whether or not services were delivering a high standard of care for

patients.

> *"....if it's the general population, sometimes their perception of the service is*
> *different to if you are actually involved in it or receiving it and then you*
> *understand the complexity more......We have had public's championing keeping*
> *services open when, in actual fact, that is advocating for unsafe provision"*
> (Participant nine, Clinician- Nursing, Other).

Despite not necessarily having first-hand experience of services, or knowledge of service quality and effectiveness, some of the advocates felt that the public held particularly strong views about disinvestment based solely on a service's reputation. Even when faced with expert opinion and clear evidence which challenged these views, they remained firmly held within the community. As a result they could, if the public were given a significant say in decision making, unduly influence the outcome of a decision making process and prevent disinvestment taking place.

> *".....if something has a very strong reputation or if there is a very strong*
> *community group influence then sometimes their voice can be so strong that it*
> *can go against whether or not a service is really good. So, for example, if*
> *something is not proven to be effective but a group very strongly wants to keep*
> *it open, it's almost impossible in some ways to decommission it"* (Participant
> 17, Clinician- Nursing, Provider).

Lastly, analysis of the advocates of involvement interviewee data suggested that

this group of participants were wary of public involvement because of the multitude of opinions that existed within the community. Whilst it was recognised that involvement efforts should not be tokenistic and should not *"make your services less equitable"* (Participant 43- Clinician- Medical, Other) by focusing involvement on small sections of society, it was also suggested that *"...sometimes you can get 100 different opinions of the 100 people that you've got there because people will have their own axes to grind and personal agendas etc"* (Participant 11- Clinician- Medical, Provider). The challenge of incorporating this vast range of views could make effective involvement a very difficult task and could, as suggested previously, make it a time and resource-intensive exercise.

Analysis of the advocates of involvement interview data suggested that one of the reasons the main reasons that there may have been a difference in the views expressed between the Q-study and the interviews was that the interviews encouraged participants to think more about public involvement in practice. Where the Q Methodology study asked participants to consider whether or not the public should be involved in disinvestment decision making, the interviews forced participants to consider their own experiences. This made the advocates of involvement take a more practical, pragmatic view of public involvement and consider their own role and responsibilities. Participant 17, for example, was supportive of public involvement, but recognised that they had a responsibility to represent the views of their employer, even if this was at odds with the public, and their own personal view.

"...if I went to a meeting I am speaking not as myself, but as an employee of an organisation and I've got their mission statement and anything I say I can only say with their authority" (Participant 17, Clinician- Nursing, Provider).

In this case, Participant 17 highlights that there may be a trade-off between the view that they are obliged to take by their organisation and that of the public (and their own personal view). By encouraging public involvement, Participant 17 could be compromising themself and could be letting themself in for conflict, both internally and with members of the public.

Similarly, Participants 23 and 27 who both supported public involvement, highlighted conflict in their own experiences of discussing disinvestment with members of the public. Participant 23 described *"....a call to arms to say 'they're shutting our service,'"* and Participant 27 recalled an instance where, following a disinvestment in a neighbouring service, they *"..... had a patient come into clinic the other week and he was literally shouting at me..."* (Participant 27- Clinician-A.H.P, Provider). Both of these instances further demonstrate the difference between the theoretical desirability of public involvement and the practical challenges that it poses. The responses of the advocates of involvement would suggest that they viewed public involvement theoretically in the Q Methodology study but took a more realist perspective in the interviews.

The interviews also asked participants to consider how they would involve the public, encouraging participants to justify and expand on their answers. This

change of focus, from 'whether?' to 'how?', made some of the advocates of involvement give more consideration to the practical implications of what they were advocating, and in some cases to reduce their level of support. Participant 43, for instance, was supportive of involvement but recognised, when asked to consider how they might involve the public, that it may be an easier task in theory than in practice and that some organisations may try to avoid it.

> *"....you shy away from doing it because you don't feel confident and it's*
> *difficult"* (Participant 43- Clinician- Medical, Other).

These explanations use the data to provide some rationale for the inconsistency between the interview findings and the Advocates of Involvement factor, but the researcher believes that the research process itself may also account for this finding. Further possible explanations, including the timing of the stages of the research, are explored in the Discussion chapter, section 9.4.4.

7.5 <u>Summary</u>

The findings from both the Q-Methodology study and the semi-structured interviews begin to suggest that, according to the participants, there is a role for the public in disinvestment decision making. Arguments for and against public involvement were identified in both stages of the research but the balance of opinion was in favour of the public having a role in decision making. The key, as far as the participants were concerned, was to ensure that an effective public involvement process was designed before seeking input. This call from the

interviewees to remain cautious whilst still being supportive of public involvement adds further weight to the second factor identified in the Q-Methodology study.

It is difficult to determine what an ideal public involvement process might look like but amongst the key considerations would be the extent to which the public should be involved and the amount of influence they should be afforded, the stage within the decision making process that they should become involved and the types of decision that they are best suited to contributing to. These questions were examined during the semi-structured interviews and analysis of the findings relating to them will be presented in the next chapter.

Chapter 8- Results Part Two- Extent and Timing of Public Involvement in Different Types of Disinvestment Decision

8.1 Introduction

Having established through the Q-Methodology findings and the first section of qualitative data analysis that participants in the research were supportive of the public playing a part in disinvestment decision making, and being involved in decisions around service change, it is important to consider what this 'involvement' might entail. The first section of this chapter will build upon the last chapter by focusing on the findings from the thematic analysis of the interview data relating to the second research question- the extent to which the public should be involved in disinvestment decision making. The chapter will then go on to consider findings from the interviews in relation to the third and fourth research questions- the stage at which the public should become involved and the types of decision that the public should become involved in.

8.2 To what Extent Should the Public be Involved in Disinvestment Decision Making?

8.2.1 'Consultation' as Involvement

When asked to draw upon their own experiences of disinvestment and the extent to which the public were involved, participants often conflated the terms 'consultation' and 'involvement'; the two words were used interchangeably and were often viewed as meaning the same thing.

"I think that a high level of involvement is needed in that for similar reasons to

the second scenario. I think that you should make sure people aware and

consultation should definitely occur so that people are able to discuss their

concerns and also be made aware that they are still getting a good service"

(Participant 23- Clinician- Medical, Provider).

'Consultation' with the public had come to be seen as the norm by most of the participants but, amongst them, there was no unified understanding as to what consultation actually entailed. Within their experiences the participants quoted a range of approaches:

"Sometimes it's just their {the public's} *opinion that's sought and sometimes*

they might be part of the decision making process and we have examples of both

of those usages in our current organisation" (Participant nine, Clinician-

Nursing, Other).

"I've had quite a significant recent involvement with consultation, so in the way

of actually publicly held meetings with public representation and representation

of findings with time allowed for members of the public to actually voice their

own views on things. That's the one thing that I have had an awful lot of

involvement with recently. Alongside that use of consultation type

questionnaires being sent out to targeted members, users from the point of view

of the services we provide and to question potential changes to services and

reconfiguration of services" (Participant 13- Clinician- Medical, Provider).

Within the interviews participants used the term consultation to refer to large scale

public meetings, surveys, information sharing through online or printed media, and campaigns that combined all three of these techniques. Each of these approaches gave the public a different level of influence and enabled them to be involved to a different extent. Across all of these forms of consultation, however, the power to make final decisions, and even to involve the public in the first place, consistently remained with the decision making organisation.

The range of experiences and understandings led some participants to remain sceptical about the power of consultation to effectively incorporate public views into disinvestment decision making, leading Participant 31 to suggest that "*a lot of public consultation is superficial*" and for Participants 24 and Four to further question its validity.

> "*I think that consultations tend to have lost their integrity a little bit because the public perceive that there's no point to it because the decision has already been made by the people who manage the money*" (Participant 24- Clinician- A.H.P, Provider).

> "*You get everybody into a huge room and then people talk for quite a long time and everybody ticks the box to say that they've had a really great day, and then nothing much changes*" (Participant Four- Management/ N.E.D, Commissioner).

The term consultation was linked by participants to a legal duty to involve the public in decision making. It was implied by participant 43 that this statutory

obligation often resulted in organisations involving the public in decision making because it was something they had to do, rather than something that they felt could be beneficial to the decision making process.

> *"Then you have this consultation about things - significant changes and that is more about our duty to consult, so I think that at the moment public involvement is something which is done by organisations- commissioning organisations or management organisations, or those organising health care or other services, as part of their statutory duty or a requirement of the organisation it is not done to maximise the benefit from involving the public or to delegate responsibility to the public"* (Participant 43- Clinician- Medical, Other).

The suggestion from interviewees that organisations may involve the public in order to meet statutory requirements, rather than necessarily to aid decision making, could result from the feeling that effective public involvement, and involvement which gave the public a greater extent of influence, was far easier in theory than in practice. Those participants with experience of public involvement suggested that *"as a principle….the public should be involved in the design of the services and in changes to those services.* {But} *I think that, in practice, that's a terribly difficult thing to achieve"* (Participant 16, Management/ N.E.D, Commissioner). Because of this difficulty, a number of participants expressed the view that the NHS was lagging behind where it should be in terms of public involvement and there was a suggestion that it was something that the NHS struggled significantly with.

".....it's {public involvement's} *a real area for development, it's something that I am really interested in but I feel a bit inadequate about doing it. I don't feel as confident about is as in other areas of my practice. I think that you have to lose control. Something that you don't feel comfortable with, as a health professional, as a doctor, it's a question of losing a bit of control and seeing what happens sometimes it's not necessarily a bad thing"* (Participant 43- Clinician- Medical, Other).

As suggested in the first results chapter, in the experience of some of the participants, public involvement in NHS decision making, often referred to as consultation in the interviews, had become somewhat flawed or tokenistic. In the experience of Participant Two this had even led to an active refusal to recognise the legitimacy of one involvement exercise.

"I might be being cynical here, if a decision has been made to do something along those lines {disinvestment} *then that decision is already there. Involving the public, as part of that decision.....is normally a bit of a tick box again. I tend to think that with any change like that someone, somewhere has already decided what the outcome is going to be and it's very rare that the public will..... have a great deal of influence on that decision because it has already been made"* (Participant 30- Management/ N.E.D, Commissioner).

"I remember reading it and thinking that you could write a questionnaire to get the answers that you wanted. I can't remember exactly how the questions were

phrased but….they were very weighted towards getting the answers they wanted. I remember actually it was quite blatant, it wasn't shrouded at all. I remember thinking at the time that it wasn't really worth handing them out because the answer had already been given" (Participant 23- Clinician- Medical, Provider).

8.2.2 <u>Patients/ Public and Other Stakeholders</u>

Within the language used by participants another key conflation was between the terms public involvement and patient involvement; in some cases it was not clear whether participants were referring to patients, the general public or both. During the interviews the terms were used by some participants interchangeably and, despite the researcher seeking clarification, they continued to refer to the two concepts as the same thing.

"I suppose starting at the most basic level public involvement is the one to one patient interaction" (Participant 23- Clinician- Medical, Provider).

"That's a difficult one really because I am talking about patients and you are talking about the wider view…see I'm going to talk about patients as opposed to public again now" (Participant 30- Management/ N.E.D, Commissioner).

In the experience of some of the participants it seemed that patients and the wider public were involved in the same decision making processes, potentially at the same time, and it was difficult to distinguish between the two groups:

"We put patient engagement in at the earliest opportunity that we can, it's still needs to go in earlier than that but the point is that we don't make solutions and then go out and consult on them, we involve them in what those solutions could look like…" (Participant 54- Management/ N.E.D, Commissioner).

This demonstrates another key theme within the research findings- that participants considered there to be a number of other important stakeholder voices and considerations that should be incorporated into the disinvestment decision making process alongside the public view.

"…..in these sort of things {disinvestment decisions} *I think it's really important to involve the multiple stakeholders and the key people are the people using the service, the people providing the service and the people responsible for divvying out the money that pays for the services"* (Participant 11- Clinician-Medical, Provider).

Incorporating these voices alongside the public could, it was suggested, potentially, lead to the public being involved in disinvestment decision making to a lesser extent and to their influence being diluted.

8.2.2.1 Related Services, Quality and Equity of care

One of the alternative considerations highlighted by participants was the impact that disinvestment could have on related or substitute services. If, for instance, a proposed disinvestment would force patients to access an alternative service that did not have the capacity to cope with increased demand then the managers and

staff of the alternative service would have a legitimate case for opposing the disinvestment:

"Yeah, obviously if you are looking at downgrading a hospital you would be looking at other hospitals taking the strain. You would have to have the evidence" (Participant Six- Clinician- A.H.P, Provider).

In addition to other related NHS services, participants suggested that those groups who may oppose disinvestment on the grounds of unmanaged substitution and 'knock-on effects' could include charities, the police and local authorities.

"I think that the voluntary sector should be involved because most of the time, when services are decommissioned in health it is picked up by voluntary sector organisations, so I think that they are crucial to be in the middle." (Participant Seventeen, Management/ N.E.D, Provider)

'Multi-organisation' decision making was a phrase that was used by Participant 54 and it encapsulates the majority of views on the ways that the disinvestment debate should be structured to incorporate wider considerations:

"I suppose, for me, when I'm thinking very blue sky is that we make decisions as multi-organisation. Not just the health council/ hospital but actually we start to bring in the other aspects that affect our community as well so things like the Police. I think that it's actually about understanding the social needs of people rather than just the health needs because they fit hand in hand for me"

(Participant 54- Management/ N.E.D, Commissioner).

"Well, the first thing is I would identify the range of stakeholders and the public arrangements. The one thing I would do is that I would be clear on the range of stakeholders and what their needs were to allow them to properly engage"
(Participant 38- Management/ N.E.D, Commissioner).

Several participants suggested that a thorough stakeholder mapping exercise should be carried out before disinvestment is considered. This exercise would identify all interested parties and allow them to contribute to option formulation and ensure that any potential adverse impacts of the disinvestment on their organisation were fully explored.

"...first of all we would look at the stakeholder maps....We involved them {stakeholders} *from the beginning and it wasn't just patients but it was stakeholder groups, people that would be affected by the rollout and making sure we were inclusive e.g. mental health"* (Participant 54- Management/ N.E.D, Commissioner).

"....what you need to do is to do an analysis of all the individuals who are going to be involved or hit by it {disinvestment}*...it's sort of scoping all the players, all the stakeholders and being clear in your own mind about the differential impact of what you are proposing on each and every one of them"* (Participant 22- Management/ N.E.D, Commissioner).

Other considerations that participants highlighted as significant and suggested should be incorporated into discussions at the option formulation stage included equity of service and quality of care. It was considered vital for any disinvestment decision not to impact unduly on any groups within society or geographical areas- a full independent impact assessment would be required to ensure this. Similarly, it was suggested that the views of carers and patients should be incorporated if there was a perception that the proposed disinvestment would have a detrimental effect on the quality of care provided or the patient experience.

> *"I think that the benefit that I would like to achieve* {from disinvestment} *is having better quality services, more equitable services, and ones which give a better experience for users of services"* (Participant 43- Clinician- Medical, Other).

> *".....they need to do an Equality Impact Assessment as well to say what impact that is having on the community as with any other service"* (Participant Seventeen, Management/ N.E.D, Provider).

8.2.2.2 <u>Staff, Media and Elected Representatives</u>

Another key stakeholder group identified by participants for inclusion in disinvestment decision making was staff working within affected services. Staff were considered to have in-depth knowledge of services that may outweigh, or add to, the kind of evidence provided by academia and organisations such as NICE:

> *"Sometimes we* {the staff} *know better. Well 'the research evidence isn't there,'*

well there isn't the research evidence there but anecdotally and clinically we

feel like it really benefits patients" (Participant 55- Clinician- A.H.P, Provider).

In addition to having intimate knowledge of how services work, participants also felt that staff, in the same way as patients, could be directly affected by disinvestment decisions. They could potentially be asked to work in different ways, switch locations or even be made redundant and, as such, there was a feeling amongst some participants in the research that staff views should hold significant weight in decision making.

> *"I think this issue of staff is quite huge when it comes to disinvestment decisions*
>
> *because, as you know, the NHS is the biggest employer in this country, third or*
>
> *fourth in the world, so if a service is disinvested in it might have quite a heavy*
>
> *impact on the local community if lots of people are going to lose their jobs or*
>
> *have doubts about their jobs. I think staff and trade unions need to be*
>
> *involved"* (Participant 22- Management/ N.E.D, Commissioner).

Two other key stakeholder groups with significant roles to play in disinvestment decision making were identified in the research- the media and politicians. Having initially identified the media's role in disinvestment decision making as being one of providing information to the public, participants then noted the possibility that this information could be skewed to suit a particular agenda and suggested that the best way to prevent this was to ensure that they were party to discussions early in the process:

"…it may be a good idea, if it's a sort of significant change which is going to be controversial, to involve the media and to try and make the process transparent, to deliver facts in a press release about the changes and how people are going to be involved and do that from an early stage" (Participant 43- Clinician-Medical, Other).

"There might be a better way of leveraging local papers, local radio, journalists etc. to engage different groups of people. I might go back and add them to my group of people who ought to be involved" (Participant 23-Clinician- Medical, Provider).

Despite favouring engagement with the media, wariness of their potential to sway public opinion remained, and some participants continued to highlight the potentially damaging effect that they could have on the decision making process if the public were not given the whole picture:

"I think it can be quite damaging in some respects if they {the public} *don't have all of the information so they are not necessarily making informed decisions on what they are doing and they are only picking up on pieces and that could be from the media, that could be from newspapers, TV and the likes"* (Participant 30- Management/ N.E.D, Commissioner).

The impact of the public only receiving selected information from the media could, participants suggested, also be exacerbated by local politicians. As such, the possibility of the public developing a biased view was seen as a potential

justification for lessening the extent of both groups' influence over decision making.

> *"....there was an election coming up and that was significant at the time because the politicians got involved in misinforming the public and I'm not quite sure where their facts came from"* (Participant Nine, Clinician- Nursing, Other).

As elected officials, there was no doubt amongst interviewees of the legitimacy of local MPs and councillors being involved in disinvestment decision making, but participants in the research suggested that they could, potentially, have an undue influence over the process, preventing service changes unnecessarily and lessening the extent to which other groups could impact upon decision making. In some cases, political opposition to disinvestment was seen to be irrational, or unjustifiable, and against the best interests of the public:

> *"I think that there is a fear amongst local politicians that if they support the closure, or argue that the downgrading may actually have benefits for the population, people won't buy that and they will get kicked out basically at the next election"* (Participant 43- Clinician- Medical, Other).

Despite the legitimacy that participants ascribed to the voice of elected representatives, in some cases direct public involvement in disinvestment decision making was encouraged by interviewees because they felt that elected officials lacked popular support and because some, it was suggested, had their own agendas

to follow.

"I am now of the opinion that any kind of constructive public involvement i.e. citizens wanting to get involved is a good thing because not enough people are involved in politics as a whole" (Participant Twelve, Clinician- Medical, Commissioner).

"...there are a few councillors out there who have personal interests and then you get those who are genuine people, and I have met both " (Participant 38- Management/ N.E.D, Commissioner).

Findings from the research suggest that the most effective way to ensure political support, and potentially public support linked to this, would be to ensure political engagement as early as possible in the process. Delaying the involvement of local politicians was seen to facilitate their rejection of plans and/or denouncement of the need for disinvestment.

Regardless of whether or not politicians supported the specific decisions that were being taken there was, according to the participants in the study, a need for them to be more open and honest with the public, and to encourage NHS organisations to do likewise. Participants felt that it was important for all parties to be clear that disinvestment was necessary in order to continue to meet demand for services.

"I'm not sure all the time that they {decision makers and politicians} *are that open and honest and I think that's what.....I think it's the culture in the NHS*

that's wrong and I think that comes top down, you know, from government"

(Participant 55- Clinician- A.H.P, Provider)

".....the public aren't going to know that the government are cutting £2million from your budget this year so you can't run the services as you are. That's the other thing- I would like organisations to be able to be honest and transparent about that, instead of trying to protect themselves so that they get the next job up the ladder or whatever" (Participant 49, Clinician- Medical, Provider).

8.3 At what Stage in the Disinvestment Decision Making Process Should the Public Become Involved?

As was discussed previously, the word consultation was often used by participants as an umbrella term to describe public involvement, but there was no unified understanding of what it entailed or meant. This section will consider participants' conceptualisations of public involvement and will pay specific attention to the stage in the disinvestment decision making process at which they felt it should occur.

8.3.1 Early Involvement and Option Formulation

The first, and most fundamental finding relating to this question is that participants felt that it was important for the public to be involved in decision making as early as possible. It was felt that current practice was often to involve the public too late and that they may not be given the opportunity to adequately shape decisions that were taken, as Participant 39 said, *"....there is a need to involve people much earlier on in the process, because otherwise, if you don't, people will feel that the*

consultation is a sham." Participants felt that there was a need for transparency and to share as much information as possible with the public *"from the word go, right when the plans are in their germinal phases"* (Participant 12, Clinician-Medical, Commissioner).

This early sharing of information was felt by some participants to be an opportunity for the public to actually decide upon what the options for disinvestment could or should be. This was particularly true at the system (macro) or economy-wide level where participants suggested that the public could be involved in fundamental decisions about how much funding the NHS received and whether or not they would be willing to pay more tax to reduce the need for disinvestment.

> *"It's difficult in this scenario* {decision about Emergency Department closure} *because, we run with your interpretation of my suggestion and actually we involve people much, much, much earlier on with choices around 'do I pay more income tax or not?'"* (Participant 39- Management/ N.E.D, Commissioner)

Regarding option formulation for actual service changes at the system level, such as Emergency department reconfiguration, it was felt that this could be carried out in public, with public input from the outset and the public not just being given information but being *"actually involved in the solution and what that solution might look like"* (Participant 54- Management/ N.E.D, Commissioner).

Participants were less keen for the public to be given the freedom to influence disinvestment options for decisions relating to individual services or individual patient groups. For these micro and meso level decisions it was felt to be most appropriate for the public to be presented with a set of pre-defined choices and asked for their opinions on which they preferred. Allowing the public to devise service options was considered to be impractical because of the knowledge required and the sheer number of decisions being taken.

> *"In an ideal world you would delegate a lot more responsibility and have a lot more public involvement and let people shape services a lot more but there are actually challenges in doing that and I can understand why it's not done at the moment"* (Participant 43- Clinician- Medical, Other).

> *"You could say that you want to produce a range of options, 'these are the options that we are considering, what do you think of these?' You could take a step back and actually involve the public in actually developing the options but it just gets very messy if you have too much involvement early on* "(Participant Six- Clinician- A.H.P, Provider).

Key to the success of this approach was seen to be ensuring that the choices that were presented were clear, realistic and honest:

> *"I suppose the biggest challenge for me in these kinds of scenarios, and I think there is a need to involve the public, is how well and how clearly the choices that exist can be articulated and understood"* (Participant 39- Management/

N.E.D, Commissioner).

In cases when options were limited it was deemed most appropriate for decision makers *"to put the case to them* {the public} *and say, 'this is what is being planned'"* (Participant 16, Management/ N.E.D, Commissioner). In this case involvement would be limited to an information sharing and justification exercise on the part of the decision making organisation, with the public offered the opportunity to respond to a decision that had already been reached.

> *"You can't have everything and there is a reason why this decision is being made. So yes, I think that the public should be informed and allowed to respond to that decision"* (Participant 43- Clinician- Medical, Other)

Having been presented with options (whether they were involved in devising them or not) the public could, according to the findings from the research play a part in making the final decision- *"I see no reason….that you shouldn't still involve the local public in making ultimate decisions"* (Participant 13- Clinician- Medical, Provider). There was no suggestion from the participants that full decision making power should be devolved to the public but the interviewees did suggest that, where the purpose of involvement was more than just information sharing and justification, the public could have the opportunity to influence decision making at all stages, right up to the point when a disinvestment decision was taken.

8.3.2 Information, Knowledge and Opportunity Cost

Whether the public became involved at the stage where options had been devised

(as suggested by participants for micro and meso level decisions) or right from the outset when there were no clear options under consideration, information would, according to the interviewees, be key to the success of the process. Ensuring that the public were furnished with accurate, understandable information and evidence was seen by participants to be vital in giving them the opportunity to form an opinion on disinvestment and take part in decision making.

> *"I think that you are going to have break it down into plain English, you can't hide behind medical or economic terms. I think if you are face to face with the public then you have to put it into the lexicon that they are using and that's important because it allows you to make decisions from a different level"* (Participant 23- Clinician- Medical, Provider).

> *"I think that given the right information, provided that there's no censoring of the information, in my experience and how we've been involved, yes I think that they are perfectly capable"* (Participant Nine, Clinician- Nursing, Other).

Responsibility for provision of this information to the public could, to some extent, fall to academic bodies or organisations such as NICE, but participants in this research suggested that the organisations making disinvestment decisions held the key responsibility.

Participants suggested that it was down to these organisations to *"work with people in a way that distils quite complex information into an accessible way that allows the broad spectrum of the public to understand that there are choices"*

(Participant 39- Management/ N.E.D, Commissioner). It was felt that professionals working in the affected services would be best placed to provide accurate information and evidence because they know what patients value and have the best knowledge of how their services work. Some participants were concerned that staff may have been unwilling to engage with a process relating directly to disinvestment in their service, but the findings from the research suggest that they still held a responsibility to ensure that decisions were being taken on up to date, accurate information.

> "...sometimes they {the public} are misinformed but that can be traced back to
> us, that is still our role and responsibility to talk things through.....we've got to
> make sure that they do have the right information when we are talking to them
> and that they understand it and they feel that they can ask questions"
> (Participant 31- Management/ N.E.D, Other).

According to participants in the research it was the responsibility of NHS organisations (as well as politicians and the media as discussed earlier) to ensure that the public were fully informed of what their options were and what the limitations of the health service were:

> "....the man in the street has got to be better informed via the links we make
> with him and through general public education campaigns actually"
> (Participant Four- Management/ N.E.D, Commissioner)

> "The devil in the detail is how does an organisation take back to the public in a

way that makes the involvement meaningful? Some of the proposals will be
quite complex and technical in terms of medical and clinical data and, whilst
this is going to sound terribly condescending, there is a challenge to
organisations to present that information to the public in a way that they can
absorb it" (Participant 16, Management/ N.E.D, Commissioner).

By providing full and frank information and giving the public the opportunity to participate, participants suggested that decision making organisations could ensure that they were being honest about their resource constraints, were taking decisions in a transparent way and were giving the public the best possible chance to understand opportunity cost:

"My naive approach now is that actually if you can honestly explain the
reasons why things are happening or the benefits of them happening then you
will get a better response and I'm very keen on getting more public involvement
rather than less" (Participant 49, Clinician- Medical, Provider).

This honesty and trust in the public to understand and take difficult decisions was seen to be vital in enabling them to participate early in the decision making process; without it participants suggested that they would struggle to be involved to any greater extent than passing comments on proposals that had already been finalised.

8.4 What Types of Decision Should the Public be Involved in?

Whilst the qualitative and Q-Methodology findings showed support for public

involvement, to some extent, in all decision making, the form and purpose of the involvement being advocated for depends, according to participants, on the type, scale and nature of the disinvestment decision in question. Participants took a pragmatic view of public involvement, recognising the time and financial commitments associated with it, as well as the lack of public appetite, and suggested that full public involvement incorporating wide engagement and public participation in option formulation should be restricted to the biggest decisions.

8.4.1 The Emotive Nature of Disinvestment

Interviewees suggested that public involvement was more critical in disinvestment decision making than it was in other decisions on health spending. Participants in the research highlighted the emotional nature of decisions to decommission services and reported a number of examples where failure to involve the public properly had caused anger and resentment amongst local citizens. One such example was described as a 'hands around the hospital' (Participant Nine, Clinician- Nursing, Other) demonstration where members of the public surrounded a maternity unit in an attempt to prevent its closure, another was a 'candle lit vigil' (Participant Eleven- Clinician- Medical, Provider) also aimed at preventing a maternity unit from being downgraded.

The emotion related to disinvestment decisions was a recurring theme throughout the interviews and it was considered to be particularly significant in instances where visible, tangible changes to services were being made such as the closure of A&E departments:

"If you took {Hospital A} A&E, people's lives had been saved there, people have had their kids born there, maybe they were born there and it's so precious…" (Participant 22- Management/ N.E.D, Commissioner).

Removal of services such as A&E departments could, interviewees felt, leave the public feeling vulnerable and could have an impact on all members of society- it could also raise the interest of the media and politicians which would further heighten tensions.

"….there's an attachment, there's a real strong attachment to having an A&E close by that's always been there because that's where you have attended and that's where family members have attended. It may be regardless of the quality of the service that you get there, there's just something about having it in the locality" (Participant 43- Clinician- Medical, Other).

As a result of this, participants suggested that these kinds of tangible disinvestment decisions which have a broad impact and rouse significant emotion are the types of decision in which wide and full public involvement should be prioritised. The findings from the study also suggested, however, that these types of decision were potentially the ones where public involvement is currently suppressed or avoided:

"I think that people would be more nervous of it because they would say that it's highly emotive" (Participant 31- Management/ N.E.D, Other).

The emotion attached to disinvestment decision making was, however, found to

be no excuse for failing to involve the public; *"I don't think that you can use 'highly emotive' as a 'get out of jail free card'"* (Participant 31- Management/ N.E.D, Other).

8.4.2 Less Contentious Decisions

Whilst participants suggested that highly emotive, tangible decisions which affected large numbers of citizens necessitated full involvement which gave the public the opportunity to contribute to option formulation, they also suggested that minimal public involvement was acceptable in slightly less contentious decisions. Where, for instance, the mode of delivery of a service was being altered or the setting of a particular service was changed from hospital to community, it was suggested that public involvement could be reduced to a process of education to convince service users of the benefits of the change:

> *"The question is do you involve them {the public} in the decision? Or, do you convince them it's a good idea?...I would find it hard to argue that it wasn't a good idea, therefore why would you need to involve the public? Which is awful, so maybe it's a different type of public involvement that's needed here, in terms of what is public involvement? Is it taking the public with you or is it them co-designing?"* (Participant 31- Management/ N.E.D, Other).

In this case it was assumed that the clinical and cost effectiveness of the proposed service change, and the quality and patient safety benefits, had already been proven. It was also assumed that the impact upon service users would be minimal

and, because of this, there was little justification to seek wide public involvement.

Clinical and cost effectiveness was a recurring theme throughout the interviews. In cases where a proposed service change had been independently analysed e.g. by academics who worked outside of the health service or by NICE, and was found to be more, or at least as, clinically or cost effective as the existing service then the interviewees often perceived wide public involvement to be unnecessary (depending on the scale/ emotion of the decision).

> *"If it's done on national guidelines, for example if the service has been peer reviewed or it's apparent that there's a policy, or procedure or NICE guidelines and if the patient, at the end, receives the same quality of service and there's no change outcome then I'm not sure exactly how much user involvement will add"* (Participant 17, Clinician- Nursing, Provider).

In cases where public opinion contradicts cost and clinical effectiveness evidence, participants suggested that the evidence should take precedence and the role of public involvement could be reduced to one of education and information sharing. This finding suggests that the health professionals in the study placed higher value on effectiveness evidence than they did on public views or values. As the public and service users did not take part in this study it is difficult to say whether they would necessarily share this view.

8.4.3 Scale of Decision

The scale of the decision, the costs involved and the number of patients (or

potential patients) that would be affected, not necessarily the level of decision (i.e. macro/meso/micro) itself, was another key variable in participants' level of support for public involvement.

"I would just think you have to put it into context of the cost of the proposed intervention, or decommissioning, or whatever the decision is, against the broader cost of the engagement and, in reality, whether it would make any difference" (Participant 38- Management/ N.E.D, Commissioner).

"....if you are spending large amounts of money, say if you've got a project that you want to deliver, for a relatively small amount of money and you are spending your money on activities trying to involve the public then....it has to be proportionate to what you are doing, or what your service is or what your change is." (Participant 43- Clinician- Medical, Other)

Where a proposed service change or disinvestment was deemed to impact on a significant proportion of society and to affect the majority of citizens equally it was suggested that it was more important to seek wide public input right from the outset of the decision making process:

"There is something about the size of a change, and the focus on that change and is it something that is generic for the whole population or is it for a specific health issue for a specific subset of the population?" (Participant 16, Management/ N.E.D, Commissioner).

"Again, that's a slightly broader issue....because there will be more people who will have a view and there are more people that it could potentially have an impact on. So I think, yes, it's absolutely critical to involve the public"
(Participant 39- Management/ N.E.D, Commissioner).

"I think that the public should be fully involved in making that decision. In some ways, because that decision would affect a greater number of people..."
(Participant 55- Clinician- A.H.P, Provider)

Where proposed disinvestments affected a smaller number of people e.g. a change to a specific service, interviewees suggested that engagement (i.e. involvement in option formulation and discussions around pre-defined options) with those affected directly should be prioritised over wider public engagement. In this instance participants would advocate involvement restricted either to informing the general public of the decision that had been taken, or giving them the opportunity to provide feedback on a limited number of options, later in the decision making process,.

"The practical solution, I suspect, putting my managers hat on now, is that we would have to be pragmatic on that one {a decision affecting a small number of patients} and therefore I suspect we would need to keep it {involvement} relatively small i.e. not to involve as many people as potentially we possibly could" (Participant 13- Clinician- Medical, Provider).

"You are talking about the utilisation of a very niche service, for a very small

number of people and I think there patient involvement is kind of more useful

than public involvement" (Participant 12, Clinician- Medical, Commissioner).

Where disinvestment decisions affected only a small group of individuals but the potential financial impact of the decision was significant, participants suggested that affected patients and staff should be involved in decision making alongside a small number of members of the wider public. An example of where this kind of decision may be necessary could be in the provision of expensive drugs to treat rare diseases: *"There's no way that sort of decision can be made without public involvement but it has to be a balanced public involvement"* (Participant 11- Clinician- Medical, Provider) i.e. the public should be involved alongside patients.

In this case the decision would be a straight decision as to whether to continue to provide funding for treatment or not, there would be limited scope for any involvement in option formulation but the findings from the research would still advocate public involvement because the potential financial impact of the decision would be significant. In this, and the previous example, the involvement of service users and carers in the decision making process was advocated because of their unique knowledge of the effects that particular conditions can have on sufferers and the impact that disinvestment in particular services or treatments can have. It was suggested by participants that, for the most part, the general public do not possess this intimate knowledge.

"I think that's an example where it will affect people under the service, I think

some members of the public won't even know what {service x} is and so I do think again it's a range of these who are involved and informed. But, because {service x} is quite a broad area there will be an element then of local clinics, so your first group is the people who use the existing service which is broken down to local communities." (Participant 38- Management/ N.E.D, Commissioner)

8.5 <u>Scope and Scale</u>

The findings relating to the extent to which the public should be involved in decision making, the types of decision that they should be involved in, and the stage at which they should become involved have been summarised in a matrix. The matrix, Figure 8.1, is entitled 'The Scope-Scale Matrix Showing Extent of Public Involvement' and reflects the impact that the scope (nature) of a disinvestment decision and its scale (the number of people affected) have on the way in which the public should be involved. For clarity, the matrix title will be condensed to The Scope-Scale Matrix for the remainder of this thesis.

The Scope-Scale matrix was developed through comparison of emerging themes relating to extent, stage and nature of public involvement in different types of decisions. Having identified that scope and scale of decisions were recurring themes within discussion of the stage at which the public should become involved and the extent of that involvement, the researcher then conducted an in-depth analysis of specific participant experiences of involvement and participant responses to the scenario based questions in the interviews. This analysis

demonstrated the types of public involvement that the participants considered to be appropriate in different decisions, it also gave an indication of what the ideal type of public involvement might be, and gave real-life examples of what might be practically possible. Although there was not consensus amongst all participants that particular extents and stages of involvement were always appropriate for particular decisions, the thematic analysis did identify strong support amongst interviewees.

The Scope-scale Matrix summarises the emerging findings, begins to offer guidance and recommendations to decision makers, and gives an indication of the implications of the findings for disinvestment decision-making practice. These are explored in further depth in the Discussion chapter.

Full Withdrawal, Noticeable Change e.g. Maternity Unit	Public involvement limited to feedback on specific options	Full, wide public involvement in decisions around specific options	Full, wide public involvement in decisions around specific options	Full, wide public involvement at the option formulation stage
Scope	Patient involvement, first then public involved at ratification/ informing stage	Public involvement limited to feedback on specific options	Patient involvement, first then public involved at ratification/ informing stage	Full, wide public involvement in decisions around specific options
Marginal Change to Service Delivery e.g. change of delivery mode	Few Patients Affected/ Limited Financial Impact	Many Patients Affected/ Limited Financial Impact	Few Patients Affected/ Significant Financial Impact	Many Patients Affected/ Significant Financial Impact

Scale of Decision

Fig. 8.1- The Scope-Scale Matrix Showing Extent of Public Involvement

8.6 Interviewee Recommendations for Improved Practice

In addition to the emerging themes which related directly to the types of decision

in which the public should become involved, and the extent and stage of this involvement, a number of other relevant themes were uncovered by the thematic analysis. These themes related to improvements that participants felt could and should be made to existing practice.

8.6.1 Use of Existing Structures

Despite their misgivings about current practices, participants were reticent to seek new approaches to public involvement. Findings from the research suggested that many of the participants were willing to continue using existing structures for involving the public including Healthwatch England (a government-run national body that seeks to act as a consumer champion for health and care in England), existing community groups and NICE (the National Institute for Health and Care Excellence) as long as the public and NHS organisations sought to engage more effectively with them.

Findings suggested that participants felt that the public should be encouraged to contribute to decision making through the existing structures rather than seeking to find new ways to have their voices heard. They felt that publicising the work of existing organisations, and showing what could be achieved by the public engaging with them, would be the best way to ensure that public voices could be effectively incorporated into disinvestment decision making:

> *"...the more that people can involve themselves in things like Link* {Local Involvement networks} *and Healthwatch the better, and that's a good way of*

being informed about the decisions" (Participant 31- Management/ N.E.D, Other).

8.6.2 Overcoming Apathy

Some participants in the research suggested that, regardless of the involvement process, decision makers may find difficulty in attracting public participants because of apathy in society and a lack of willingness to take part in decision making. As Participant 24 suggested, *"everywhere there is a general sense of apathy, both on the part of the public and the staff about the health service".* Recognising this lack of interest in participation, and working to overcome it, was seen by participants as an important part of health care organisations' role in decision making. Participants offered a number of explanations for the public's lack of willingness to participate and a number of recommendations as to how organisations could work to overcome apathy.

The perceived lack of interest and willingness to take part in decision-making was, in large part, put down by participants to a feeling that, regardless of their opinions, the public could do little to influence decision making:

> *"Well you think 'why bother? It's not going to make any difference, they've already made their minds up.' You know, it's those kinds of phrases that you hear* {from the public} *all the time"* (Participant 39- Management/ N.E.D, Commissioner).

Despite this, participants suggested that the public should take more responsibility

for their own services and that they should do more to seek information and hold decision makers to account. According to the interviewees, if the public had been given a fair opportunity to contribute to decision making and had chosen not to then they could have little cause for complaint if a disinvestment decision went against them. If the public continue to lack willingness to participate in decision making then the extent of their involvement and input could, according to participants, only ever be limited:

> *"We are not of that society where we will force people to be involved without their consent"* (Participant 12, Clinician- Medical, Commissioner).

Regardless of perceived public apathy, findings from the research still suggested that organisations had a duty to do more to encourage wider public involvement. Participants in the study made calls for those making decisions to make public involvement processes clear, transparent and simple, and to make them as accessible as possible to as wide a range of citizens as possible. Participant 16, for example, made one such plea; *"we, as the NHS as a whole, can only get there* {making effective decisions} *if we are doing what we are supposed to be doing and making it comfortable and safe for people to be able to want to have their say."*

Providing materials and information in a range of languages, holding events at weekends and evenings and situating them within different communities were all put forward by participants as possible ways to increase engagement. In order to

encourage participation it was also suggested that the outcomes of public involvement and the difference that the public have made could be publicised and that organisations could consider providing incentives to participants in the form of small payments, covering expenses or providing refreshments.

Within organisations clinical staff were viewed by participants as a key resource in encouraging public participation in decision making. At the most fundamental level, it was noted that staff interact with patients and the public on a day to day basis and are often the first port of call for feedback on any service changes. Whilst participants suggested that there was still an important role for structured patient and public involvement in the NHS, there was also a call for clinicians to play more of a part in gauging public opinion:

> *"I really believe that there should be someone, that each trust should have a lead person for patient and public involvement but I also believe as clinicians, we're all responsible"* (Participant 27- Clinician- A.H.P, Provider).

In addition to seeking informal feedback, it was also suggested that clinicians could encourage patients and the public to participate- they could inform them of potential service changes and instruct them as to how best to contribute to the debate.

Within the interviews there were a number of examples of clinical staff encouraging patients and the public to provide feedback and to contribute to decision making. In some instances this involvement was encouraged because

"patients are a stronger lever than health care professionals" (Participant 12, Clinician- Medical, Commissioner) and were more likely to be listened to by senior managers.

Depending on the decision, participants suggested that staff may encourage the public to disagree with proposals or they could help to convince them that proposed service changes would be beneficial. In one case, a participant even suggested that they had influenced members of the public completing an opinion survey so as to try to ensure that the ongoing service change consultation found in their favour. In other instances participants reported encouraging members of the public to contribute to decision making forums but then being informed that senior management felt that their input was unwelcome or inappropriate.

> *"We actually had one of our volunteers put their view forward to one of our chief executives….Literally we were told that that was inappropriate and we were told that the volunteers shouldn't be going and we were like 'well they should!' But we were told that they shouldn't be going to the open forum"*
> (Participant 27- Clinician- A.H.P, Provider).

8.7 <u>Conclusion</u>

This chapter detailed the findings of the study in relation to research questions two, three and four, showing that participants felt that the public should be involved in disinvestment decision making as early as possible alongside other stakeholders. The extent of public involvement should depend on the scale and nature of the

decision, with the public being involved in larger scale more emotive disinvestment decisions at the option formulation stage, and being involved to the extent of being informed of the outcome of decision making in smaller scale less contentious decisions.

Having detailed the findings of the study they are now considered in light of the existing knowledge detailed in the earlier chapters, and the contribution that they make to the literature is identified. The following chapter will help to position this study within the existing literature as well as considering its implications for disinvestment research, policy and practice, and critically analysing the strengths and weaknesses of the approach taken.

Chapter 9- Discussion

9.1 Introduction

This chapter will draw together and summarise the findings from both stages of the empirical research in relation to the research questions. These findings will then be reflected upon in light of the existing theoretical and empirical literature presented in the background and literature review sections. The final section of the chapter will provide personal and methodological reflection and will give the researcher the opportunity to critically assess the strengths and weaknesses of the approach taken to the research.

9.2 Support for Public Involvement

Findings from the literature review, the Q-Methodology study and the in-depth interviews all showed strong support for public involvement in health disinvestment decision making. The benefits of involvement highlighted by the empirical research fell into three broad categories- instrumental, educative and societal. In addition to this, it was suggested that organisations should involve the public because they had a legal obligation to do so.

Whilst some arguments against involving the public in disinvestment decision making were identified in the empirical findings, including reasons that organisations had some control over and some that they did not, the conclusion from the empirical research is that participants perceived the advantages to outweigh any potential disadvantages.

9.3 <u>Stage and Extent of Involvement in Decisions</u>

Findings from the research showed a clear link between the initial research questions two, three and four. The findings suggested that it was too simple to conclude that there were some types of decision that the public should be involved in and some that they should not. Respondents believed that the public should be involved in most disinvestment decisions, but what differentiated the decisions was the extent of loss that the public were likely to feel and how contentious the decisions were perceived to be. This came to affect the stage at which participants felt that the public should become involved and the extent of influence that they should have.

Where disinvestment decisions affected a greater number of individuals, or where their scope extended to full withdrawal of services and tangible, noticeable loss, participants suggested that the public should be involved to a greater extent in decision making. The extent of this involvement could range from full, wide public involvement with citizens playing a part in the formulation of disinvestment options (in decisions of greater scope and scale) through to involvement at the decision ratification stage (in less contentious decisions). The findings relating to these questions are summarised in the Scope-scale Matrix in Fig. 8.1.

9.4 <u>Reflecting on Findings</u>

9.4.1 <u>Reasons to Support Public Involvement</u>

A range of motivations for public involvement, initially categorised under the Williams et al. (2012) framework as democratic, instrumental or educative, were

outlined in the background chapters. All of these categories were represented within the empirical findings but amongst the participants the instrumental benefits were mentioned most frequently and were explored in more depth by the interviewees.

This observation suggests that the respondents were most driven to involve the public in disinvestment decision making by the outcomes of that process e.g. better decisions being made. Previous research has shown that physicians challenge the evidence used to make disinvestment decisions, and suggest that their experiences and the wider decision making context should be taken into account (Hodgetts *et al.*, 2012). By foregrounding the instrumental benefits of public involvement, and highlighting the different opinions, experiences and knowledge that the public can offer, the participants in this research may have been exhibiting a similar perspective. Instead of applying the logic demonstrated in Hodgetts et al.'s (2012) study to physicians, however, they could have been extending it to the public voice.

The suggestion that some participants in the research may have favoured instrumental benefits is a particular concern, however, when considered in relation to the democratic motivations for involving the public. Research shows that physicians are willing to disregard evidence used in disinvestment decision making if it does not support their view or does not reflect their experiences; some consider themselves to be the arbiters of whether or not evidence is worthy of consideration (Hodgetts *et al.*, 2012; Watt *et al.*, 2012b). This literature, and the

focus of some participants in this study on the outcomes of public involvement rather than necessarily on the democratic benefits, suggest that, whilst advocating for the public to be involved in disinvestment decision making, participants (or the physicians at least) may be willing to overlook their views if they are not in line with their own. As clinicians have a unique and powerful position within the process (Mitton *et al.*, 2003), and can de-rail disinvestment decision making by not changing their practice and applying new rules, for example, decision makers may opt to side with them if they disagreed with the public view, and this could have implications for the fairness of the whole decision making process.

One of the key instrumental benefits highlighted in the empirical findings was the ability of the public to offer innovative and different solutions to disinvestment problems. This finding is significant because it demonstrates the belief amongst participants that the public have a unique view. When considered alongside the literature this presents a difficulty for decision makers. Recent Q-Methodology studies (Mason *et al.*, 2011; Baker *et al.*, 2014; VanExel *et al.*, 2015) have shown that a wide range of perspectives on how best to distribute scarce health resources exist within the public. The public may offer different views to other stakeholders but there is a plurality of views in evidence amongst citizens themselves. In order to overcome this difficulty, decision makers should find the most effective means available to capture the spectrum of public views and incorporate these into disinvestment decision making.

The literature review and empirical research also highlighted a separate set of

motivations which were not fully represented within the Williams et al. (2012) framework. These motivations, referred to in the findings as societal benefits of public involvement included the potential for participation to bring communities together and to encourage citizens to take ownership of public services. Whilst it may be suggested that these benefits are adequately described under the instrumental banner, the researcher would argue that they are sufficiently distinct to warrant their own categorisation and that there is a requirement for the theory to be developed further.

Commonly occurring in both the literature and the empirical findings was the suggestion that involving the public in decision making was the 'right' thing to do and that, because the NHS is publicly funded, decision makers had a moral duty to seek public input. In addition to this, organisations had a legal obligation to consult with citizens when making disinvestment decisions (Bowie *et al.*, 1995; Edgar, 1998b; Dolan *et al.*, 1999; Mossialos and King, 1999; Gallego *et al.*, 2007). This duty could, according to the empirical and literature review findings, stem from the funding model in the NHS or from the notion that health care is a conditional good (Landwehr, 2013), a vital interest (Clark and Weale, 2012) and a basic human right (Fleck, 1994). This legal duty could also, potentially, have had a bearing on the extent to which the public had been involved in decision making in the experience of the participants- this is explored further later in this chapter.

9.4.2 <u>Arguments Against Involvement</u>

Whilst the Q-Methodology study identified three perspectives amongst

participants- Advocates of Involvement, Cautious Supporters and Freedom of Choice group- only two of these points of view were in evidence within the interview findings. In the interview findings, the unequivocal support for public involvement in disinvestment, demonstrated by the Advocates of Involvement was not present. Participants in the interviews highlighted potential drawbacks, as well as motivations, thus questioning whether its benefits were necessarily axiomatic (Mullen, 1999). All interviewees recognised some potential arguments against involvement and a number highlighted arguments which suggested that members of the public should be given every opportunity to take part in decision making but that, ultimately, whether or not to participate should be their choice.

The reasons for caution identified by participants can be categorised into two groups- those that the decision making organisation could have some influence over (internal) and those that were completely external to the organisation (external). For instance, the arguments that public involvement does not make a difference to the outcome of decision making and that it is difficult to gain a representative public sample could both, potentially, be overcome by the decision making organisation itself and, as such, would be considered to be internal.

One of the more common internal arguments uncovered in both the empirical research and the literature was that the public lacked the information and the knowledge to participate effectively in disinvestment decision making (Knox and McAlister, 1995). This is considered to be internal because the findings also suggested that it should be the decision-making organisation's responsibility to

provide the right level of information.

Despite this organisational responsibility, the empirical and literature review findings clearly identified the educational benefits of involvement (Rowe and Shepherd, 2002; Irvin and Stansbury, 2004; Williams *et al.*, 2012) and, as such, it is important to consider the experiential learning that can be derived from participating in public involvement exercises. In light of the findings, it could be suggested that the level of public knowledge should not have an effect on the extent to which they are able to become involved in decision making. The more the public are involved in decision making, the more they could learn, and the narrower any knowledge gaps could become i.e. they should be given the opportunity to take part regardless of their initial level of knowledge. The effect that experiential learning has on levels of public understanding and knowledge remains an area for further investigation

Some of the arguments made in the literature against public involvement, such as the public lacking the ability to overlook self-interest (Bruni *et al.*, 2008) and the potential that public involvement could sway decisions in an illogical or irrational way (Nelson, 1994), would be more difficult for decision making organisations to overcome on their own. This illogical swaying of decisions could, according to the research findings come as a result of a public preference for more high profile or fashionable services (Bowling *et al.*, 1993) and it may have the effect of causing disinvestment decisions to be made using decibels (Mitton and Donaldson, 2002; Bate and Mitton, 2006).

A view expressed by respondents, and in the literature, was that the public had difficulty in grasping the concept of opportunity cost (Campbell, 1995; Bradley *et al.*, 1999; Lees *et al.*, 2002; Arvidsson *et al.*, 2009). If this were to be considered as an argument against involving the public in disinvestment decision making then it could be categorised as either internal or external. If filling the gaps in public knowledge to enable them to grasp opportunity cost was viewed as an organisational responsibility (e.g. if providing the necessary information and education would help to enable the public to understand it) then it would be considered to be internal. If it were viewed as the responsibility of individual citizens themselves then it would be external.

The assumption made by respondents that the public had difficulty in grasping the concept of opportunity cost presents a particular quandary for those responsible for making priority setting and disinvestment decisions. Given that many decisions are still taken using non-criteria based processes which do not take into account opportunity cost (Dionne *et al.*, 2008), why is it so important for the public to be able to understand and accept the trade-offs of the decisions that they are making? The only way that this argument against public involvement could seemingly stand up would be if decision makers consistently used processes which did incorporate the notion of opportunity cost, such as Programme Budgeting and Marginal Analysis (PBMA) (Mitton and Donaldson, 2004b). Disqualifying the public from participation in disinvestment decisions on the basis of a failing which is inherent within many commonly used approaches to decision making is seemingly unfair

and could limit the procedural justice of the process.

9.4.3 Public Inclination to be Involved

Regardless of arguments in favour and against involvement, both the literature (Richardson *et al.*, 1992; Rosén, 2006; Bruni *et al.*, 2007) and the empirical findings suggested that the public may have limited desire to participate. No definitive explanation for this was put forward but it was suggested that, in some cases, they may have felt that they could not genuinely influence decisions that were being taken (Meetoo, 2013), and, in others, they may have become jaded by the number of decisions that they were being asked to contribute to (Edgar, 1998b). Further investigation is required to fill this knowledge gap and provide a more conclusive understanding.

As was described in the Introduction and Methods chapters, the researcher had first-hand experience of difficulty in engaging the public when carrying out the empirical research detailed in this thesis. Despite dedicating a number of months to public recruitment and offering to enter participants into a prize draw, the researcher was unable to attract sufficient numbers.

Had the public recruitment been successful then it would have been possible to draw firmer conclusions as to the extent that the public should be involved in disinvestment decision making and the types of decision that they should be involved in. As the only participants in the study, health professionals were asked to not only give their views on whether or not they thought that the public should

be involved and whether they were capable of being involved, but also whether they thought that the public had the desire to be involved or whether they thought that the public were happy for others to make decisions on their behalf.

The public themselves were given no right to reply to the research findings and it was not possible to compare and contrast the views of the public with those of health professionals, or to test the conclusions. Had there been a public group they may have disagreed with the conclusions and may, for instance, have suggested that they had the desire to be involved fully in all disinvestment decisions. Alternatively they may have added weight to what was found. Regardless of this, the findings from this research, and the normative recommendations made as a result, are only substantiated in relation to a health professional perspective

The lack of a public sample is recognised as a substantial limitation of the study by the researcher, but it also presents a significant opportunity for future research and provides a platform on which to base further enquiry. This study could be repeated in its entirety with a public sample, or specific conclusions could be tested, for instance by conducting a large scale survey or questionnaire to assess the extent to which scope and scale are significant factors in whether or not the public feel that they should be involved in disinvestment decision making.

Work by Edwards et al. (2002) has shown that the odds of receiving a response to a postal questionnaire double when financial incentives are offered to participants. When this finding is considered alongside the experiences of the researcher, the

implication for future research involving the public is that a significant budget will be required and that incentives should be offered to participants. With this in mind, the expansion of this research could require national level funding in order to ensure that it is completed well and that the work presented in this thesis is built on effectively.

In practice, organisations making disinvestment decisions are likely to be financially restricted (Mitton *et al.*, 2014) and may not have access to national level funding. They may also have less time, desire and motivation to reach a diverse sample than the researcher did. The fact that, despite this time and motivation, the researcher was still unable to recruit sufficient public participants could, potentially, provide an explanation as to why the health professionals reported tokenistic consultation still to be prevalent and why decision makers reportedly found difficulty in reaching some groups in society.

Whether or not the public lacked interest in participating in disinvestment decision making, the qualitative research findings suggested that organisations should make concerted efforts to encourage as many citizens as possible from different backgrounds, cultures and communities to participate. When combined with the Q-Methodology finding that the public should have freedom of choice, the implication for disinvestment practice is that organisations should make reasonable adjustments to encourage this wide participation. Examples of these adjustments may include offering information in a range of languages, scheduling engagement events on evenings and weekends and offering incentives or expenses as has been

done in previous involvement exercises e.g. Bowie (1995).

9.4.4 Participant Reflection and Understanding of Key Terms

There are a number of possible explanations as to why the participants in the interviews, which included seven exemplars of the Advocates of Involvement factor, would demonstrate a more critical view of public involvement in the second phase of the research than they had in the first. One of these is that the Q-Methodology participants had been given at least two weeks to reflect on their views on public involvement in disinvestment before taking part in the interviews; they may have recalled more experiences or spoken to colleagues about the research during this period.

Between the two phases of data collection participants learned, through e-mail contact thanking them for their participation, that the researcher had previously worked in the health service. This knowledge may have given participants the confidence to give their opinions on public involvement more openly and freely- they may have come to see the researcher as 'one of them'. When completing the Q-Methodology study, some of the participants may have given a more corporate view of public involvement, reflecting the publicly stated, supportive, views of senior NHS managers and politicians. Having learned that the researcher had previous NHS experience, they may have felt more able to trust them with views that contradicted those above them within the organisation.

The design of the study itself, and the choice of methods used, may also offer

some explanation as to why participants' views seemed to change between the first and second stages of the study. It is possible that interviews, as a more in-depth research method, are conducive to more critical exploration of a topic than a survey or ranking-based method. In this case, the researcher was able to ask participants to expand on, explain and contextualise their answers during the interviews, but was not able to do so in the Q-Methodology study (Adams and Cox, 2008). In this way, the choice of data collection method may have had some direct influence over the responses generated.

Another possible explanation is the participants' conflation of patient and public involvement. If, when taking part in the Q study, the Advocates of Involvement had understood patient and public involvement to be the same thing, then their perspective could have been that there were no disadvantages to patient involvement, not necessarily public involvement. As Lomas (1997) notes, members of the public can take three positions in health decision making, either taxpayer or collective community decision maker, or as patients. The way in which participants viewed the public position in decision making may have affected their view on the extent to which they should be involved. The interview findings, and the requirement for the researcher to clarify understanding during the interviews, imply that some participants may have viewed the public as patients, rather than as taxpayers or community decision makers. If this was the case then the advocates of involvement may, potentially, have displayed less caution in their support for involvement than they would if they had adopted the perspective that they were

instructed to.

This, along with a realisation that public involvement can mean more than a legally mandated consultation period (see later in the discussion), may have diluted some of the support demonstrated by participants in the Q-methodology study. Further research into health professionals' perceptions of who, or what, the public are could be enlightening. Similarly, a repetition of this study, positioning the in-depth interviews first, followed by the Q-Methodology study, may demonstrate the impact that the two week reflection period had on participants and the extent to which taking part in the interviews changed their expectations and understandings of public involvement.

9.5 <u>Early Involvement</u>

The suggestion in the findings that the public should become involved in disinvestment decision making as early as possible, becoming involved in decisions around levels of funding for the NHS at the economy-wide level, for instance, was also previously reported by Gold (2005). She found members of the public to have strong views about overall government prioritisation, focusing in particular on the use of public funds for defence rather than health care. This preference for early involvement is borne out by a section of the literature which promotes methods used to elicit values (such as DCEs (Green and Gerard, 2009; Watson *et al.*, 2011)). These methods could be ideal for decisions for more emotive, tangible decisions taken on a larger scale as they imply a preference for public involvement which takes place before any specific options are discussed.

The only support within the empirical findings for involving the public at the final decision making stage came when using involvement as a mechanism for educating the public after decisions were taken; this was considered to be acceptable where clinical effectiveness had been proven and where few patients were affected. In these less contentious instances it was thought to be preferable for decision makers to act on behalf of the public, in a role described by Coast (2001) as the citizen-agent role. In her work, Coast (2001) found that the public were happy to defer to doctors and other experts, trusting them to make priority setting decisions which required specific expertise and knowledge.

Coast's (2001) findings are supported by the findings from this research, which suggest that health professionals recognise their role as agents in the disinvestment process and believe that, in certain circumstances, it is appropriate for them to take decisions on behalf of the public. When considered in light of the other findings from this research it could be suggested that this willingness to act as an agent results from a feeling that the public do not always want to participate in decision making. It could also be explained by participants believing that the public have difficulty in appreciating opportunity cost, or failing to trust them to be able to overlook self-interest and make informed decisions for themselves. Taking these findings into account it could be suggested that participants felt that there were, at times, some instrumental benefits to not involving the public in decision making, and that better decisions were reached as a result. Advocates of public involvement, and the democratic, educative and societal benefits that it can deliver,

would, however, dispute this claim and they may suggest that failure of health professionals to involve the public in disinvestment decision making would represent a return to paternalistic decision making in the NHS (Barnes, 1999; Baggott, 2005).

9.5.1 Scale of Decision and Extent of Involvement

The empirical findings from the study suggested that the public should be involved to a greater extent in disinvestment decisions that affected a larger number of patients or had greater resource release implications; this is referred to as the 'scale' of the decision. In the existing priority setting literature, types of decision are often distinguished by the level at which they are taken e.g. macro (health system level), meso (service level) or micro (patient level) (Klein, 1993; Litva et al., 2002), rather than the scale of the decision as it is defined here.

Scale and level of decisions initially seem to be closely linked i.e. decisions taken at the health system level would often directly affect more patients than those taken at the service level and would have greater resource implications. In light of this, the findings from this study seem to support existing research on public involvement in priority setting which suggests that the public have less desire to be involved as decisions move down the macro-meso-micro continuum towards patient level decision making (Wiseman *et al.*, 2003; Wiseman, 2005; Theodorou *et al.*, 2010).

Given that this study focuses on disinvestment, however, rather than priority

setting more generally, the similarity between the sets of findings should be qualified. As was hypothesized using Prospect Theory earlier in the thesis (Kahneman and Tversky, 1979), the public themselves are more inclined to become involved in disinvestment decision making than priority setting. As such, it is not possible to say that a member of the public's desire to become involved in a priority setting decision at the meso level, for instance, will be the same as their desire to become involved in a meso level disinvestment decision. The differing nature of the decisions means that although the similarities in the findings are noteworthy, the existing work cannot necessarily be used to substantiate the findings from this research.

It is also too great a leap to make to say that scale and level of decision making are always equivalent. It could, for instance, be the case that a decision taken at the patient level to disinvest in a particular treatment and make it unavailable directly affects a large number of patients also suffering from the same condition. In this instance, the existing literature would view the decision as micro level and would suggest a limited role for the public in decision-making, but the findings from this study would view the decision as large scale (because of the number of patients affected) and would suggest that the public should be involved to a significant extent.

The empirical findings from this research challenge the priority setting literature and suggest that, when making disinvestment decisions, scale, and not necessarily level, of decision should be the measure by which decision makers gauge the

extent to which the public should become involved. This suggests a need for further research and theoretical refinement where decisions involve disinvestment.

9.5.2 Prospect Theory- Tangible Losses and Risk Aversion

The earlier chapters used Prospect Theory (Kahneman and Tversky, 1979) to hypothesize the distinctions between disinvestment decision making and priority setting decision making. It was suggested that the public would be more willing to become involved if they felt that services were at risk and would be more likely to take an active part and 'gamble' if there was a risk of full withdrawal (Daniels *et al.*, 2013). Findings from this study reinforce the theoretical framework and, as well as highlighting the importance of scale, suggest that the public should have a bigger part to play where the scope of proposed service change extends to tangible, noticeable losses i.e. where services are taken away all together. Where marginal changes are made to services i.e. with priority setting, both Prospect Theory and the empirical findings suggest that the role of the public could be reduced in terms of the extent of influence that they have over the final decision.

The notion of contentiousness of decisions, referring to how noticeable, tangible and emotive they were- their scope- recurred throughout the qualitative findings and it was suggested that more contentious decisions warranted greater public involvement. Although contentiousness may be hard to measure, one way to identify some of the more contentious disinvestment decisions would be to assess them against the framework put forward by Schmidt (2012). In this case, the research findings would suggest that those decisions which are absolute or cost-

based disinvestments i.e. where on the grounds of clinical effectiveness, or the need for savings, services are withdrawn entirely, are more contentious and should therefore incorporate greater public involvement than those which are relative. Whilst disinvestment, in general, was considered in the literature to be a wicked issue (Grint, 2005; Dickinson *et al.*, 2011), requiring new approaches to decision making and leadership (Cooper and Starkey, 2010), the findings from this research would suggest that some disinvestment decisions i.e. absolute and cost-based are more controversial, emotive and potentially more difficult to make and lead than others.

Although the gap in the literature relating to the distinctions between disinvestment decision making and more established priority setting practice has been addressed in part by this PhD there is still scope for further development and empirical investigation.

9.6 <u>Assessing Levels of Public Influence</u>

The Scope-scale Matrix outlined in Fig 8.1 provides a basis for discussion as to the different stages and extents of involvement that the findings suggested the public should have in different types of disinvestment decision. In order to assess the distinctions in levels of influence between the different approaches to public involvement put forward by the participants, and how they differ from current practice, as described in the literature, and by participants, they will be assessed against Arnstein's Ladder (1969).

One approach to public involvement which was frequently advanced in the literature was the involvement of lay members on priority setting boards (Ayres, 1996; Goold, 1996; Hofmann, 2013). When assessed against Arnstein's Ladder, public input into these boards could be viewed in a number of ways and matched against a number of rungs. If, at the bottom end for instance, the role of these lay individuals was to 'rubber-stamp' decisions that had already been taken and/or approve pre-defined assessment criteria (i.e. in PBMA where criteria are used to score different disinvestment options) then this would be categorised as manipulation or therapy.

The empirical research findings suggest that, in the eyes of the respondents, for less contentious, smaller scale disinvestment decisions, involving the public to the manipulation or therapy extent, allowing them to ratify decisions, would be appropriate. Whilst this ratification role would also be in place for larger scale decisions, alongside earlier participation setting the scope of disinvestment and devising options, it would be the only opportunity for the public to influence smaller scale decision making. As such, this form of involvement could be viewed as tokenistic unless the public were given a veto over decisions.

Despite viewing tokenism in a negative light, the findings from this study would support informing the public in smaller scale/ scope decisions, recognising that, because of the resource implications of involvement and the low levels of public interest, it would be more effective to concentrate wider, earlier involvement efforts on larger scale/ scope decisions.

For larger scale, wider scope decisions, the findings from the research would support the public being involved to the extent of partnership (Arnstein, 1969). In this partnership the public would have a genuine influence over what decision-making criteria were, how they were weighted and what final decisions were reached alongside other stakeholders. In this arrangement, lay members could be given equal responsibility alongside professionals on a priority setting board, or the views of the public (collected through DCEs/surveys, for example) could be incorporated into decision making and given equal weight alongside the views of others. The key to this partnership, in terms of maximising the instrumental benefits of involvement e.g. making decisions which are based on a range of knowledge and experiences and are likely to be broadly accepted, would be that citizens (and other stakeholders) be given an equal say in decision making alongside senior managers and clinicians. Also key to this would be finding the most effective means by which to gain the insights of each group of stakeholders and to incorporate these insights equally into decision making.

For decisions taken at the economy-wide scale and resulting in visible, full withdrawal of services, the research suggests that the public should be given the opportunity to influence the parameters of the priority setting exercise and to opt to widen health disinvestment decision making to incorporate wider areas of public spending. When mapped against Arnstein's ladder this form of involvement would probably be considered to be partnership. This partnership would require genuine shared responsibility between the public, decision makers and other stakeholders,

but if the public were given the opportunity to set parameters on their own (i.e. through a referendum), without the influence of those in power, then it could even be considered to be citizen control.

9.6.1 Practical Experience of Public Involvement in Priority Setting

Whilst in theory it is feasible that a high level of public and stakeholder influence and autonomy (e.g. citizen control) could be delivered in health services, the evidence from the literature review suggests that, in practice, the top rung of Arnstein's ladder has rarely, if ever, actually been reached in health priority setting. The empirical findings from the study also suggest that it is still a long way from occurring in NHS disinvestment decision making, and that targeting genuine partnership might prove to be more achievable.

In their analysis of public consultation within the NHS, Harrison and Mort (1998) noted that public engagement had, at times, become a means of managers legitimating decisions that had been taken. They also suggested that specified individuals within organisations were often tasked with raising interest in public consultation amongst their colleagues, and that it was common for the will of the public to be overruled by decision makers. These observations are echoed in the findings from this research which showed that, in some instances, consultation was seen as a chore for decision makers and that, at times, they had little interest in engagement with the public. In these instances the bare minimum involvement was often carried out as a result.

Setting in stone a minimum, legal level of required public involvement and obliging organisations to consult the public seems, in practice, to have had the effect of narrowing public involvement. Within the empirical findings it was rare to hear of an experience in which public involvement went beyond the degrees of tokenism that Arnstein identified. Whilst the researcher would not advocate removing the legal requirement at this stage, it is suggested that further experimental research be carried out to assess the extent to which legal obligation limits public involvement. If thorough evaluation shows that organisations with no set minimum obligation to engage with the public actually involve them to a greater extent in decision making, and deliver the benefits of involvement in the process, then the legal duty could be relaxed in the future.

Whilst Arnstein's ladder has proved helpful in conceptualising and comparing the different levels of involvement in current practice and those proposed based on the empirical findings, the researcher is in agreement with Tritter and McCallum's (2006) criticism that it may be missing rungs (see Chapter Three for further details). Rather than criticising Arnstein's Ladder (1969) for not taking into account intensity and scale of involvement, and not giving the public the opportunity to frame the problems (Tritter and McCallum, 2006), however, the empirical findings suggest that, for health care decision making, it fails to adequately cover the range of approaches to consultation that are employed in practice. In order to make it more practical and applicable to modern health care, the theory should be developed to recognise that, in practice, most involvement in

decision making takes place between the informing and consultation rungs (Charles and DeMaio, 1993; Church *et al.*, 2002). In light of this, additional rungs should be incorporated between these levels and it should be recognised that some consultations devolve a greater level of power to citizens than others. Given the range of approaches to public involvement that the participants termed consultation it may even be appropriate for future theoretical development to move away from the term all together.

9.6.2 Experiences of Involvement

Similarly, the findings from the study demonstrated a significant gap between the literature and practice relating to methods. Within the literature is was noted that recent years had seen a move towards more deliberative methods (Mitton *et al.*, 2009) such as citizen juries (Lenaghan *et al.*, 1996), 21st century town meetings (Williams *et al.*, 2014) and the CHAT technique (Goold *et al.*, 2005), but these approaches were rarely raised in interview by respondents.

As was noted in the findings, the participants in the study had come to conflate consultation with public involvement. Understandings of consultation may have ranged from informing through to giving the public the opportunity to feedback on proposed plans, but none of the participants' experiences resembled the level of involvement espoused in the literature by proponents of deliberative engagement like Richardson (1997) and Abelson (2003a). Deliberative engagement can be used by decision makers to seek answer to specific priority setting questions or to seek overall guidance (Lenaghan *et al.*, 1996) but, regardless of its purpose and

regardless of the extent of influence that the public actually have over the final decision (Pickard, 1998), it differs from the consultation discussed by participants in the empirical research in two key ways. First, deliberative involvement seeks to build consensus amongst the public and encourages citizens to work together to answer a particular question e.g. which services should be disinvested in, or to devise potential options. Consultation, at best, offers individual members of the public the opportunity to have a say on pre-defined options e.g. a plan to disinvest in particular health services, and put their own point across (Harrison and Mort, 1998), and, at worst, offers them no chance to express their views at all. Deliberative involvement seeks to use discussion and deliberation amongst the public to allow them the opportunity to consider all sides of an argument before making a judgement. Consultation, by encouraging citizens to have a say as individuals, does little to encourage the public to work together, consider the evidence and reflect on each other's perspectives.

The second key difference is that, with the consultation discussed by participants, there was usually a preferred option i.e. an outcome that had already been reached by decision makers/ an outcome that they hoped would be reached. The deliberative methods discussed in the literature suggested a more open-minded approach whereby decision makers were more willing to take note of the ideas that emerged from the public involvement exercise and to incorporate them.

The main implication of the identified theory/ practice gap is that some of the benefits of public participation identified in the research and literature may not be

realised in practice. The involvement approaches familiar to the participants may deliver instrumental benefits, but any educative benefits will be limited to what the public can learn from being informed of the decision. Similarly, the opaque nature of decision making and the lack of public opportunity to influence outcomes will limit democratic benefits, and the absence of interaction between community members will prevent any societal benefits from being realised.

In order to bridge the gap further work should be carried out to educate decision makers as to the range of public involvement methods that are available and the benefits of using deliberative approaches to seek consensus. There is a growing literature on the use of deliberative methods to involve the public in priority setting but the findings from this study give the impression that further focus should be placed on knowledge transfer and that efforts should be made to follow-up deliberative engagement exercises to ensure that they become more widespread, common practice within organisations.

9.7 <u>Implications for Decision-Making Frameworks</u>

Chapter Two detailed a number of approaches that have been applied in practice to make disinvestment decisions. These extant models and approaches will now be critically analysed in light of the insights generated by the research in order to identify further implications of the findings and give tentative recommendations for future research and practice.

9.7.1 <u>Needs Assessment and Core Services Approaches</u>

The needs assessment approach to disinvestment decision making uses epidemiological data to make decisions regarding the targeting of funding. Those areas e.g. diseases not deemed to be have the highest need may not receive funding, and services or treatments could be disinvested in. The nature of needs assessment implies that it is best suited to macro level decisions across services and disease areas, taken on a large scale, and potentially with a significant scope. The findings from this research would suggest that wide public involvement should take place at the outset of decision making, setting criteria as to how need should be measured and contributing to option formulation. This approach would offer the instrumental benefits of ensuring that decisions reflected public views and would increase the likelihood of public acceptance of decisions.

The core services approach to disinvestment also takes decisions at a macro level on a large scale, setting priorities across the health economy and using criteria to decide which services will be invested in and which will be disinvested in. The findings from this research would support the approach taken in Oregon (Kitzhaber, 1993), and would advocate wide public involvement at the stage where decision-making criteria and values are set; as in Oregon, this transparency would help to deliver democratic benefits. There would, however, be some divergence between the Oregon process and the findings from this research at the decision ratification stage. Instead of giving managers and clinicians the sole responsibility of checking and signing off the final list of core services, as in Oregon, the

findings from this research would advocate the public playing a key role at this stage as well.

9.7.2 Economic Evaluation and Health Technology Assessment (HTA)

One way in which public views could be incorporated into decision making could be to factor societal values into Quality Adjusted Life Years (QALY) calculations (Baker *et al.*, 2010). The literature has shown that the public value some QALY gains more highly than others (Pennington *et al.*, 2013) and that for instance, they may value a short period of high quality life more than an extended period of low quality life. This involvement at the value-setting stage would, according to the findings from this research, be particularly appropriate for large scale, larger scope disinvestment and would give the public the opportunity to influence decision making before options had been formulated. Involving the public at this stage would offer the instrumental benefit of ensuring that the right decisions were made in their eyes.

QALY calculations form part of the evidence base used in health technology assessment (Baker *et al.*, 2010). If these calculations incorporated public views and were weighted so as to give the public a voice in disinvestment decision making this approach could, according to the findings from this research, be particularly appropriate for decisions of a larger scale and scope. In addition to this, the findings from the research would advocate public involvement alongside other stakeholders as part of the multi-disciplinary team (MDT) or committee appraising the evidence. This call was amongst a number of recommendations made by

Abelson et al. (2007) who sought to make public involvement in HTA more consistent; more recent literature has suggested that HTA decision makers are still searching for this consistency (Gauvin *et al.*, 2010). Involving the public as part of the MDT would offer the democratic benefit of making the decision making process more transparent, it would help to educate public members of the board on how clinical and cost effectiveness are measured, and could offer the instrumental benefit of making disinvestment decisions more acceptable to the public.

For smaller scale, less contentious disinvestment decisions taken using HTA, the findings from the research would advocate a more limited role for the public. In practice this could mean incorporating the values of patients, but not the public, into cost effectiveness calculations, and including patient representation within the MDT. In these decisions, public involvement could, according to the findings, occur at a late stage in the process and be restricted to being informed of the outcome of the decision making process.

9.7.3 <u>PBMA and Multi Criteria Decision Analysis (MCDA)</u>

The PBMA framework has previously been modified to increase its applicability to disinvestment decision making (Mortimer, 2010; Schmidt, 2012) but the findings from this empirical research suggest that further modifications should be made in order to ensure that adequate provision is made for public involvement. At the first stage of the process, for instance, the findings from this research would suggest that the public and other stakeholders should be involved in setting the scale and the scope of the exercise, particularly for economy-wide decisions which

may incorporate wider government spending.

The current PBMA process involves forming an advisory board at stage three, then that board devising criteria against which the marginal costs and benefits of services will be judged at stage four. Published PBMA guidance suggests that the advisory board could contain some lay representation alongside senior clinical and management decision makers (Mitton and Donaldson, 2004a). In encouraging the formation of a priority setting board to incorporate stakeholder values, the PBMA process is in line with a sizeable proportion of the literature uncovered through the in-depth review (Ayres, 1996; Goold, 1996; Hofmann, 2013), but it is not necessarily in line with the findings from the empirical research. These findings promoted participation in disinvestment decision making, open, particularly in the case of larger scale decisions, to all groups within society rather than restricted to limited lay members.

Another potential criticism of the advisory board in the PBMA process is that it could be viewed as a mediating institution, with the role of interpreting public views before they can be incorporated into decision making, and therefore not necessarily directly representing public opinion. Whilst Tenbensel (2002) argues that these mediating institutions are potentially the most feasible way in which to involve the public and are necessarily opaque, others have called for more clarity on the specific role of the public in priority setting decision making (Martin *et al.*, 2002a) and the difference that their input can make (Mullen, 1999), and have called for them to take a more central role (Smith and Wales, 2000).

The empirical research offered few insights into alternatives to involving the public as part of the PBMA advisory board. The literature review does, however, provide a wider range of options and ideas. DCEs (Green and Gerard, 2009; Watson *et al.*, 2011), or large scale surveys asking the public to prioritise lists of services (Bowling, 1996; Lees *et al.*, 2002), for example, could offer potential ways to elicit views and values from a wider public sample than could be involved in person on priority setting boards. The benefits of these approaches may, however, be limited to the instrumental motivations identified in the findings from the research. As suggested earlier, in order to realise the educative, democratic and societal benefits of public involvement, deliberative approaches such as the CHAT technique (Goold et al., 2005), 21st century town meeting (Williams et al., 2014) or deliberative polling (Goodin and Dryzek, 2006; Fishkin et al., 2010) could be more effective options.

The implication from this research for disinvestment practice is that, where decisions affect large numbers of patients, the values of the wider public should be sought before the priority setting board meets to set criteria. If wider views are sought before the board is constituted then they could potentially be incorporated into criteria discussions without the need for lay involvement at all.

The fifth step in the PBMA process is to score the different services against the criteria identified by the advisory board, and to assess the resource implications of making marginal changes to service levels. This a technical step in the process but the public could be involved to the extent of checking or ratifying the decisions

reached after scoring. It is possible that this checking could offer the instrumental benefits of reducing the risk of irrational outcomes of the decision making process (such as those identified by Nelson (1994) and during the first iteration of the Oregon priority setting exercise (Kitzhaber, 1993; Redden, 1999)) and could ensure that the public values incorporated into the criteria are properly reflected in the outcomes. According to the empirical findings, involvement at this stage in the priority setting process could take place in addition to involvement as part of an advisory board for larger scale decisions, but, for micro level decisions made at limited scale it could be sufficient involvement in itself.

Alternatively, MCDA could be incorporated into the PBMA process (Peacock *et al.*, 2009) and could be used to draw together the range of criteria that had been devised at step four, and to assess and compare the options against these criteria. The findings from this research would suggest that, for large scale decisions, the public should be involved in setting the criteria, as was suggested for the broader PBMA process, and being part of the MCDA scoring panel. Additionally, the criteria used could incorporate a measure of how publicly acceptable each of the options was, with data collected through a survey, for example. For smaller scale decisions with narrower scope, the research would support the public being given the opportunity to interrogate the scoring of each option against the criteria, and being fully informed as to how the criteria and weights were devised and how the decision as to the preferred option for disinvestment was reached.

9.8 <u>Accountability for Reasonableness (A4R) and Disinvestment</u>

Regardless of the methods or approach used, a priority setting decision-making process can, according to Daniels and Sabin (1997; 2000; 2008), only be considered to be legitimate if it meets the four A4R Conditions- Publicity, Relevance, Appeals and Revision and Enforcement.

Despite numerous applications (Martin *et al.*, 2003; Mielke *et al.*, 2003; Maluka *et al.*, 2010), the A4R framework has previously been criticised for its lack of clarity on the role of the public (Friedman, 2008) and other stakeholders (Gibson *et al.*, 2005b) in priority setting. The findings from this research suggest that similar criticisms, particular regarding the role of the public, would also apply if A4R were to be used to assess a disinvestment decision making process; the publicity and relevance conditions require particular attention.

The publicity condition states that all decisions relating to the limiting of care (and disinvestment in services), and the rationale behind these decisions, should be made available to stakeholders. The findings from this research suggest that, for larger scale and scope disinvestment decisions, this condition would not be sufficient to deliver a fair process. The condition implies that informing the public (and other stakeholders) of decisions that have been taken, and how those decisions were reached is enough to ensure procedural justice. The findings from this research support public involvement in decisions at an early stage, and encourage citizens to be able to set criteria and score different options, as well as

ratifying the final outcomes. The involvement supported by participants in this research for larger scale and scope decisions goes far beyond what is called for by the publicity condition.

Daniels and Sabin's framework (1997; 2000; 2008) suggests that decisions should be taken with relevance to the organisational context in mind and that they should be relevant in the eyes of 'fair minded people'. The framework is not clear, however, on how relevant a priority setting decision should be; for instance, what constitutes a fair minded person and how many fair minded people should the decision be relevant in the eyes of? The findings from this research support the relevance condition in principle but also offer some clarity as to how decision makers can ensure that their disinvestment processes are fair and that decisions are taken with relevance in mind.

The findings support early involvement of the public in large scale and scope decisions, and giving them a central role in setting the boundaries of the disinvestment process. In order for disinvestment decisions to be procedurally just, the findings from this research would suggest that the A4R relevance condition be expanded to require decision makers to demonstrate that an assessment of the scope and scale of decision has been carried out and that stakeholders have been involved in decision making accordingly. The research would also suggest that the condition should require decision makers to demonstrate the stage at which the public were involved and the extent and outcomes of that involvement.

9.9 Stakeholder Claims

As was suggested earlier, the findings from the research support the involvement of other interested parties in disinvestment decision making alongside the public. A wide range of stakeholders were identified and they were each considered by the participants to have a legitimate say in decision making. All of the internal and external stakeholders identified by Patrick and Erickson (1993) and presented in Chapter Three were highlighted by the interviewees. The findings from the research did, however, challenge some of Patrick and Erickson's (1993) stakeholder groupings and did identify some stakeholders that were not considered in their original work; these challenges and additional stakeholders will be presented below. Mitchell et al.'s (1997) criteria of power, legitimacy and urgency will be used to assess the strength of the claims of the newly identified groups over the disinvestment decision making process, and to show why they may have a legitimate interest in decision making.

9.9.1.1 Internal Stakeholders

The internal stakeholders i.e. those that operated within the decision making organisation, that Patrick and Erickson (1993) identified consisted of managers and clinicians. Whilst the roles of these two groups are clearly distinct, they were banded together by many of the participants and simply described as staff. This finding is potentially a reflection on the mixed clinical/ managerial group that took part in the research or of a change in the nature of relations between the two groups which have previously been characterised by mutual suspicion (Edwards,

2003) and destructive antagonism (Degeling *et al.*, 2003). The finding could also potentially be explained by the managerial responsibilities held by a number of the practicing clinicians that took part in the study, or by the participants' awareness of the researcher's NHS management background and the possibility that they were less critical of managers as a result.

In this case the line between manager and clinician was clearly blurred and the findings suggest that Patrick and Erickson's (1993) distinction between the two groups may not be necessary or helpful in analysis of the stakeholders involved in disinvestment decision making.

9.9.1.2 External Stakeholders

In terms of the external stakeholders identified by Patrick and Erickson (1993), interest groups, politicians/ government officials, patients/ services users and their families, and the public were all identified by participants in the research as having a legitimate interest in disinvestment decision making.

One external stakeholder that was not recognised within the original framework was the media, including local and national newspapers and television channels. The media, similarly to elected officials, were viewed by participants in the study as having a vital role to play in disseminating information and shaping the public discourse about the requirement for disinvestment and the possible options (Hodgetts *et al.*, 2014). Potentially because the media are unelected and do not fund or use health services, their views were seen to lack legitimacy in the decision

making process (Robinson *et al.*, 2012), but their power to de-rail disinvestment decision making by turning the public and patients against plans was seen by participants to give them a significant claim. This strength of this claim was viewed by participants to necessitate an urgent response to media concerns and enquiries (Mitchell *et al.*, 1997). It is understandable that Patrick and Erickson (1993) may not have considered the media to have an important claim as a stakeholder but the findings from this research suggest that, in practice, they should be considered alongside all of the other internal and external claims identified and should be incorporated in to any stakeholder mapping exercise for disinvestment decision making.

9.10 <u>Limitations and Reflections</u>

Having presented the findings from the empirical study over the previous two chapters, and linked them back to the literature in this discussion section, it is now important to recognise any potential limitations within the approach taken to the research. These limitations will help to highlight and explain any inconsistency within the data, and also help to provide methodological direction for future research, thus adding to the recommendations/ implications for policy, research and practice. Throughout this section, Lincoln and Guba's (1985) measures of trustworthiness- credibility, transferability, dependability and confirmability (as introduced in the Methodology chapter) will be used as a frame to assess the rigour of the approach and findings.

9.10.1 <u>Sampling</u>

First, owing to the relatively small P sample, the outputs from Q-Methodology are not generalisable to the wider population (Amin, 2000) and it is only the factors that are of interest- not the proportion of individuals within the study who identify with each factor. This limitation reduces the transferability of the findings (Lincoln and Guba, 1985) i.e. they are not applicable to wider contexts.

In addition to this, whilst the wide-ranging P and Q samples used in the study did ensure that as many perspectives as possible were uncovered, it is recognised that Q-methodology could not ensure that all possible attitudes to public involvement in disinvestment were highlighted (McKeown and Thomas, 1988). The public themselves are one group whose perspectives are not fairly reflected by the factor solution. A repeat of the Q-Methodology study aimed specifically at citizens, and with sufficient budget to offer incentives in order to encourage participation, would add significantly to the findings from this study and would allow for direct comparison to be made between the views of those working within the NHS and those whose taxes fund it.

By targeting participants from a range of geographical areas and clinical/ non-clinical backgrounds the aim was to deliver as diverse a sample as possible to take part in both stages of the empirical research. This is particularly important in small scale qualitative studies (Allmark, 2004), and by sampling in this way it was hoped to ensure a broad range of views was represented in both the Q factor solution and

the qualitative data. By making this sampling choice it was hoped that the transferability of the findings (Lincoln and Guba, 1985) would be increased because the sample would contain a greater range of experiences of a number of wider contexts.

Similarly, snowball sampling, employed successfully in a number of previous Q studies (Steelman and Maguire, 1999) and other qualitative work on public participation (Barnes *et al.*, 2003), was used to ensure that individuals who could offer the most information, and challenge or supplement the theory, were selected and were able to contribute (Baker *et al.*, 2006). Whilst, in most cases, this was successful, and the approach delivered varied perspectives and experiences, it is recognised that some participants may have recommended others with similar views and backgrounds to themselves (Heckathorn, 2002), and that the breadth of the sample may not always have been increased.

Criticisms could also be made of the sample size at the in-depth interview stage of the study. As the sample was restricted to 20 key informants (when data saturation was reached) the findings from this stage of the study are not generalizable beyond the participants that took part either. As this project was exploratory in nature, and its purpose was to begin to map out health professionals' views on public involvement and to start to develop theory, providing understanding and not prediction (Denzin, 2009), this was not viewed as a major deficiency by the researcher.

The decision taken to invite all of the target population to take part in the Q-Methodology study could leave the research open to the criticism that the participants were 'self-selecting' (Lieu and Dewan, 2010) and that their only reason for taking part in the research was that they already held a particular view on disinvestment and/or public involvement. Similarly, the interviewees all put themselves forward to participate in the second stage of the research- this could mean that only those Q-Methodology participants who had strong positive or negative views on public involvement were interviewed. This self-selection may have affected the findings by removing the input of participants who had no strong views; it may have made the benefits and drawbacks of public involvement seem more pronounced and may have made the differences of opinion within the population seem more stark than they actually were. Had a non-self-selecting sample participated in both stages of the research then it is possible that more middle-ground views would have been represented and this may have affected the findings which emerged.

The researcher recognises that this self-selection could hamper the internal and external validity (Fletcher and Fletcher, 2012) of both the Q- Methodology and the interview findings, but it is felt that the nature of the study reduces the significance of this limitation.

It is recognised that others judge research quality on the basis of scientific principles, such as external validity (Denzin, 2009), and therefore future research could look to employ a more quantitative methodology seeking a much larger, and

more statistically representative, sample. In this case, however, the findings from the study, and the contribution that the research makes, justify the qualitative methodology and the approach to sampling.

9.10.2 Choice of Methods

Q-Methodology was selected as the first empirical data collection phase of the two-stage sequential procedures mixed methods research design (Creswell, 2003). The in-depth literature review reported a range of perspectives and subjective points of view as to whether or not the public should be involved in disinvestment decision making (Bruni *et al.*, 2008) and it was recognised that the first stage in the empirical data collection should take account of this. Q-Methodology allowed for the vast range of participant views to be synthesised into three analysable factors and was the ideal way to sort through the nuances and provide data which allowed for comparisons between the ways that different individuals viewed the research questions. The structured, documented approach to the Q-Methodology study also ensured that it could be repeated in order to confirm findings and give them increased credibility as an accurate reflection of the beliefs of the participants. This enabled the first section of the study to meet Lincoln and Guba's confirmability and credibility measures of trustworthiness (1985) and provided an ideal frame around which to begin to question the participants in more depth.

Having identified the interpretive epistemological position as the most appropriate way to tackle the research questions, a number of qualitative approaches to data collection, including interviews, observation and focus groups, were considered as

options with which to follow up the Q-Methodology study.

Interviews were selected over observation because they allowed for a specific focus (in this case on public involvement rather than on disinvestment as a whole) and because, in addition to identifying opinions, thoughts and behaviours, they allowed for underlying reasons and explanations for these to be explored (Bryman, 2008). Whilst interviews and focus groups share much in common, interviews were chosen because they allowed the participants to be more open and forthcoming than they may have been in a focus group situation, and because of the logistical difficulties that would have been encountered in trying arrange places, dates and times for focus groups (Adams and Cox, 2008).

The sequential procedures mixed methods approach to research enabled valuable insights to be gained. In sequencing the interviews after the Q study, the interviewees had all had a chance to reflect on public involvement in disinvestment decision making ahead of speaking to the interviewer. The approach taken allowed the interviewer to investigate further why the views displayed by the Q findings were held, how they may have been constructed and what their implications were for disinvestment decision making practice. The interviews also allowed the researcher to investigate the factors fully; in this case, investigation of the Freedom of Choice perspective and the way that manifested itself in practice given the perceived low levels of public interest in disinvestment decision making was particularly enlightening. On reflection, interviews were an ideal method with which to follow up Q-Methodology and, as Onwuegbuzie and Leech (2005)

suggested, the two methods combined well because they promoted each other's strengths whilst countering each other's weaknesses.

9.10.3 <u>Trustworthiness</u>

Although considered to be a strength of good qualitative research (Krefting, 1991), the central role that the researcher plays in data collection and the closeness of the researcher to the informants and the data can also be viewed as a potential disadvantage (Mays and Pope, 1995). Having identified a number of methodological limitations this section will reflect on the role of the researcher in data collection for this project, the effects that the researcher's background and position may have had on the approach taken to research and the methods used for data collection, as well as on the way in which the data was analysed (Malterud, 2001).

Given the central role that the researcher plays in qualitative research it is accepted that more positivist, quantitative measures of research quality (e.g. validity, reliability and replicability) are not appropriate. As such, Lincoln and Guba's (1985) 'Measures of Trustworthiness' (as introduced in Chapter Five) will be used to assess the quality of this research, to highlight potential issues with the approach taken and to explain how the researcher sought to minimise the effects of these.

The decision to allow participants in the Q study to take part online using 'Poet Q' was taken so as to enable participants to take part at a time convenient to them (Duffy *et al.*, 2005) and to take part in an environment of their choosing. It is felt

by the researcher that the PoetQ software (Jeffares *et al.*, 2012) may have helped to maximise response rates because it offered this convenience; although this theory was not explicitly investigated in this case, it is observed in other studies (McCabe, 2004; Kiernan, 2005). In addition to this, the online option reduced costs (Cobanoglu *et al.*, 2001; Kaplowitz *et al.*, 2004), and helped to reduce the potential for participants to be led by the researcher (Duffy *et al.*, 2005) because each participant received exactly the same instructions on the screen and was not subjected to any verbal or non-verbal prompts. This not only increased the dependability of the findings but also their confirmability (Lincoln and Guba, 1985). Despite this, the researcher recognises that the use of PoetQ (Jeffares *et al.*, 2012) may have been a barrier to participation for potential participants without internet access or those without IT skills or confidence. It may also have been a barrier to those with visual impairment or those for whom English is not their first language and it may have therefore added an unintentional bias into the sample. Whilst offering exactly the same instructions to participants, PoetQ did not offer equality of opportunity to participate for all potential participants; this is recognised as a limitation of the study.

Although much of the Q literature remains focussed on face to face studies, online applications for completion of Q-Methodology studies have now been used successfully on a number of occasions (Donaldson *et al.*, 2010a; Westwood and Griffiths, 2010; Gruber, 2011; Jeffares and Skelcher, 2011; Dickinson *et al.*, 2013). Aside from the limitations highlighted previously, other potential

drawbacks of using the online technology rather than asking participants to complete the Q-sorts face to face could include participants failing to understand the requirements of the process, being unable to check their comprehension of the statements, and the researcher being unable to take account of non-verbal cues when conducting qualitative data collection following the Q-sort- all of these could have impacted upon the credibility of the findings (Lincoln and Guba, 1985). Having taken all of these considerations into account, however, and received informal feedback on the research process from the participants, the researcher would suggest that the benefits of using online Q-sorting outweighed the potential drawbacks, and that an implication for future Q-Methodology research practice from this study could be that online applications become increasingly considered.

Similarly to the Q-sorts, 18 of the 20 interviews took place from distance and were carried out by telephone (the other two were face to face at the request of the participant). Conducting the majority of the interviews by phone did mean that physical non-verbal communication such as hand gestures, facial expressions and posture were unable to be noted and the researcher was unable act upon such cues. Despite this, other non-verbal communication such as pauses, silence and laughter were able to be taken into account (Graneheim and Lundman, 2004), and these, added to the logistical advantages of telephone interviewing e.g. cost and flexibility of timing, justified the decision not to insist upon face to face interviews.

Within this project, the data from the interviews was socially constructed and was

created as a result of the interaction between the researcher and the participants; as such the researcher was central to the research process and their involvement will have influenced what was said by participants (Dickson-Swift *et al.*, 2007). As a past manager within the English NHS the researcher was able to engage the participants in conversation. This may have helped in understanding and appreciating participants' experiences and perspectives, and may have made the researcher more empathetic to the pressures faced by the participants thus encouraging them to be more forthcoming. Although it is recognised that much rapport building comes from visual cues such as body language, dress and proximity (Duncombe and Jessop, 2002), this shared knowledge, and the communication by e-mail ahead of the interviews, allowed the researcher to build a relationship with the participants despite the lack of face-to-face contact.

The researcher recognised that, because of their previous experience, they may have come into the research with some preconceptions about public involvement in disinvestment decision making. In order to instil rigour and trustworthiness in the research process, the researcher sought not to lead participants towards their preconceived views, using the Q sample matrix (Table 6.1) to allow even representation of the entire concourse within the Q sample, and focusing in the interviews on what each individual participant was saying, what their experiences were, and encouraging them to share information freely (Mullings, 1999). The researcher gave no positive or negative reinforcement when responding to participants' comments and followed good interview practice by avoiding leading

questions (DiCicco-Bloom and Crabtree, 2006). When interacting with participants the researcher minimised any mention of their own experience and, where it was necessary to mention experiences in order to build rapport and encourage participants to be more forthcoming, discussion was restricted to the facts of the situation and not their opinions on the approach that was taken to disinvestment and/ or public involvement.

By taking this approach to the interview process, using the coding matrix to refine the Q-sample, following Watts and Stenner's (2012) crib sheet approach to analysis of the Q data and taking a consistent approach to the coding and analysis of the qualitative data (as outlined in the Methods chapter) the researcher aimed to make the findings of the research as trustworthy as possible by meeting Lincoln and Guba's (1985) measures of confirmability and credibility.

9.10.4 Personal Reflections

It is important in qualitative enquiry to demonstrate reflexivity in relation to data collection, synthesis, analysis, and write up. This section looks back upon the research process and offers reflections on the interactions and relationship between the researcher and participants, and critically examining how the researcher and their views developed over time. Consideration will be given to any assumptions that the researcher made throughout the process, any preconceptions that the researcher entered the process with and how this 'conceptual baggage' may have affected the outcomes of the project as it is presented in this thesis.

Having previously worked in the NHS and had experience of disinvestment decision making, the researcher recognises that they embarked on the research with a pre-conceived idea about how disinvestment decisions should, or should not, be made. The researcher believed that a structured, criteria-based process should be followed, and this belief was strengthened by knowledge gained whilst conducting the literature view. The researcher also believed that disinvestment was necessary and that it was not feasible for NHS organisations to avoid the need for difficult decisions to be made. Conducting the research reinforced this belief, but it also made clear to the researcher that not all members of NHS staff shared it and that not all NHS organisations were as advanced in making disinvestment decisions as the researcher might have expected. The fact that 16 of the 55 Q-study participants claimed to have no experience of disinvestment exemplified this and came as some surprise to the researcher.

From past experience, the researcher believed public involvement in all decisions relating to health spending to be desirable but this belief was challenged by the findings from the research. The findings relating to scope and scale of disinvestment decisions made the researcher realise that it should not be a taken for granted assumption that the public should always be involved in decision making. The findings also encouraged the researcher to think that an assessment should be made by decision makers to identify who the 'public' are, the purpose of involving them in decision making and the extent of influence that they should have. This represented a significant change in the thinking of the researcher before

and after the project.

The researcher was conscious of the effect that their experience may have had on the research process and took steps to limit this e.g. by piloting the Q study before involving study participants. However, the researcher recognises that their preconceptions may still have had a subconscious effect. Despite using a matrix to ensure that the whole of the concourse was represented by the Q sample, it is possible, for instance, that the researcher favoured statements that were in agreement with their view and that the wording of the statement showed those sentiments with which the researcher agreed in a more positive light. Likewise, despite using a coding structure to analyse the qualitative data, the researcher may have sub-consciously favoured those themes with which they agreed most and may have favoured the evidence which backed these themes up. The researcher may also have interpreted the Q factors in a way which supported their underlying beliefs, although the possibility of this was reduced by following Watts and Stenner's (2012) crib sheet approach to analysis. The researcher may also have favoured literature which agreed with their perspective and assumptions for inclusion in the synthesis, the possibility of this will have been reduced by the use of the data extraction form (see appendix ten) and the clear inclusion/ exclusion criteria.

The central role that the researcher plays in qualitative research means that their underlying assumptions and preconceived ideas could impact upon the research process, the findings and the way that these are presented. In this case the

researcher attempted to minimise the effects of assumptions and ideas by following a structured process and taking actions, where possible, to reduce any subconscious favouritism. Despite these mitigating actions, the researcher is cognisant of the role that their 'conceptual baggage' may have played in the research process and, as such, has been as transparent as possible about their previous experiences and underlying beliefs relating to public involvement in disinvestment decision making.

9.10.5 <u>Reflections on the Interviews</u>

Interviews varied significantly in length, with some being more than twice the length of others. This variation can be explained by two factors; first the experience of the participants- those participants with more years of service and experience in different roles had a greater number of examples to draw upon and often spoke for longer in the interviews. Second, the backgrounds of participants- those participants with management or commissioning responsibility tended to have more experience of disinvestment and the interviews with these individuals often lasted longer than those participants with purely clinical backgrounds. Similarly, those participants with management roles often seemed more familiar with public involvement, as opposed to patient involvement, and were able to draw upon examples more readily.

At no stage during the research did any of the interviewees demonstrate any obvious inhibition or unwillingness to talk about all aspects of their roles and activities. It was clear that in some cases respondents saw the research as an

opportunity to share their frustrations at the ways in which they had witnessed disinvestment decisions being taken, and to consider what they, and their organisations, may have learned from these experiences.

As expected, due to the nature of the interview sample, the semi-structured approach was more effective with some participants than others. Those participants that were more forthcoming and more confident seemed to revel in the freedom that the approach offered them. Those participants who seemed less confident, or had less experience of disinvestment, required more input from the interviewer and these individuals may have been better suited to more structured interviews. In terms of refining the questions, the idea to request feedback from the first six participants was effective and it helped to ensure that the researcher covered as much relevant ground as possible in the following interviews. One subtle change that was made to the interview format following feedback was to investigate participants' understanding of the difference between patient and public involvement more thoroughly.

In most of the interviews the participants were able to recall examples of disinvestment that they had witnessed or been involved in, but it was necessary for the researcher to probe some of the participants more deeply than others. On reflection, the researcher recognises that this approach could have damaged the rapport between them and the interviewee and that asking participants to recall potentially difficult times in their careers could have been distressing. Fortunately there was no noticeable loss of rapport or distress caused but if the researcher was

to repeat this series of interviews then this is something that they would give careful consideration to.

Overall, the researcher was left with an impression that the interviewees were articulate, intelligent professionals who were committed to their work and were committed to providing the best possible care for their patients. For the most part there was an acceptance amongst the interviewees that disinvestment in health services was necessary but in many cases it was clear that the prospect of service change was not relished. Because of this, and the possibility that interviewees may not agree with the course of action taken by their seniors or by their organisation, the researcher was aware that there may be some participant reservations. Assurances of anonymity and research ethics were therefore employed to encourage interviewees to be forthcoming and to speak freely about their experiences and views.

9.11 <u>Summary</u>

This chapter has drawn together the empirical findings from both stages of the mixed methods study and drawn upon the existing literature and theory to contextualise them in answers to the research questions. The findings and literature have been presented in such a way as to show how the study bridges gaps in existing knowledge and contributes to the literature e.g. in seeking the views of health professionals and investigating disinvestment specifically, and to demonstrate the implications for policy, research and practice. The potential limitations of the study have also been presented alongside an assessment of its

rigour and trustworthiness, and reflections of the role of the researcher in the data collection process.

The key conclusions from the thesis as a whole will be summarised in the final Conclusion chapter alongside the implications of the study, recommendations and next steps resulting from it.

Chapter 10- Conclusion

10.1 Introduction

Having drawn together the findings from both stages of the empirical research in the previous chapter and contextualised these using the existing literature, this chapter will summarise the thesis as a whole. In concluding the thesis it will identify how the study contributes to the literature and where gaps remain, and will summarise its implications for policy, research, theory and practice. Lastly the conclusion will apply the findings to the current NHS context, as detailed in the introduction, and give a series of recommendations and next steps.

10.2 Overall Summary

This thesis began by contextualising the environment within which the empirical research was carried out, highlighting the need for disinvestment and priority setting as a result of rising global health care costs and slowing health spending. The thesis then introduced a number of criteria and non-criteria based ways in which priorities are set by decision makers in practice, before using Prospect Theory to construct a theoretical framework explaining why disinvestment decision making is an aspect of the priority setting process worthy of research in its own right. The third chapter then considered the priority setting/ decision making process in more depth, paying particular attention to the different stakeholders within the process, focussing especially on the public and proposing four research questions.

Having introduced the public as a stakeholder with a particular interest in

disinvestment, the next chapter detailed an in-depth literature review, using four propositions to demonstrate the range of views expressed on public involvement and identify the gaps within the existing literature. The four propositions examined the benefits of involvement, the range of methods available to involve the public, the public's willingness to be involved and whether or not professionals were able to adequately represent public views.

After identifying the gaps in the literature relating to public involvement in priority setting and disinvestment, chapters Five and Six considered the kinds of data that would be needed to answer the research questions and the methods that could be used to answer these questions. The constructionist ontological and interpretive epistemological positions adopted by the researcher were explained and examined before a mixed-methods research design was proposed. The design, incorporating a Q-Methodology phase involving 55 health professional participants, followed by a series of 20 in-depth interviews with a purposive sample of the Q-Methodology participants, was then put forward. Chapters Seven and Eight detailed the findings from both stages of the research (these are detailed below) and Chapter Nine provided a discussion which brought together the findings from both stages of the research, comparing and contrasting these with the existing literature and highlighting the implications of the study.

10.3 Key Considerations for Decision Makers

Findings in relation to the research questions were summarised in the discussion chapter. In short, the empirical research and literature review supported public

involvement in disinvestment decision making and suggested that the extent of involvement and stage at which the public should become involved in decision making depended on the number of patients affected and the nature of the decision. These factors were described as scope and scale respectively.

10.4 <u>Contribution</u>

The background chapters and literature review identified a number of gaps in the literature; the first of these gaps was the dearth of empirical research and theoretical literature relating specifically to disinvestment. This lack of existing literature necessitated the exploratory approach, and the fact that both stages of data collection investigated disinvestment decision making processes in particular, rather than priority setting more generally, ensured that the findings from this study filled a significant knowledge gap. The congruence between the findings from this study and Kahneman and Tversky's Prospect Theory (1979) give justification for the decision to research disinvestment in its own right. The findings lay the foundation for further empirical investigation into disinvestment decision making; this is one of the study's most significant scholarly contributions.

The second gap identified was the lack of empirical data relating to the views of frontline health professionals and managers. Previous studies into public involvement in priority setting had focussed on the views of the public themselves, senior managers or, on occasion, General Practitioners. By becoming the first study to seek the views of such a wide range of health professionals from different backgrounds, the reported work fills a significant gap in the literature and

contributes the views of this substantial stakeholder, with a unique perspective, to the existing knowledge.

Another gap in the literature that was identified was the stage at which the public should become involved. The priority setting literature clarified that there was a role for the public in decision making, and the public involvement literature offered a number of methods which allowed the public varying degrees of influence over this decision making but there was no theoretical or empirical investigation into the different stages at which the public could become involved; this study is the first to specifically investigate this. The reported empirical research contributes to the literature by identifying three different stages at which the public could become involved in disinvestment decision making (option formulation, decisions between specific options or decision ratification) and by highlighting the different types of disinvestment decision in which they should be involved at these stages.

The literature review identified a number of theoretical and empirical items relating to public involvement in priority setting but the literature was not definitive; a number of articles specifically noted the need for further research. When this need is considered alongside the, already noted, dearth of disinvestment-specific research it is clear that another significant gap in the literature must exist around public involvement in disinvestment. This is the most significant gap that this research bridges, and where its contribution to the existing theoretical, empirical and practice-based literature is greatest.

Despite a growing number of applications, Q-Methodology remains a relatively little-known approach to research and this study makes a significant contribution to the existing body of literature. Q-Methodology has been applied to Health Economics and priority setting problems in the past but this is the first study that has focused solely on disinvestment. In terms of the Q-Methodology literature, this study not only makes a contribution because of its subject matter but also because of the approach taken. First the study adds to the limited number of examples of online applications of Q-Methodology. The success of the data collection demonstrates the potential that technology has to widen participation in Q-Methodology, collecting data from across geographical boundaries quickly, easily and cheaply, and adds further weight to arguments in favour of increasing the number of online applications.

The mixed-methods sequential procedures approach taken to the research is not unique but it is uncommon, and the successful staging of in-depth interviews in follow up to the initial Q-Methodology study should encourage others to take a similar approach. In the majority of Q-Methodology studies qualitative data collection extends only as far as asking participants why they sorted the statements in the way that they did; there is no opportunity for in-depth examination of how the participants' views could, or should, impact upon practice. By purposively selecting participants from the initial P sample to take part in the interviews and ensuring that exemplars of each identified factor were included, this study was able to go into greater depth, and offer more practical applications of the findings, than

most other reported Q-studies. This sets the reported study apart and is another of its major scholarly contributions.

10.5 <u>Implications and Recommendations for Policy and Practice</u>

This thesis has a number of implications for public involvement policy where disinvestment decisions are being made. First, the findings suggest that if the legal obligation for organisations to consult the public over disinvestments is to remain in place then the government should seek to clarify what this consultation should entail and what its intended aims and outcomes should be.

In addition to this, government policy on decision making processes for disinvestment should be clarified and guidance should be offered to organisations as to the different frameworks that are available. In particular, the findings suggest that policy should encourage processes which take account of opportunity cost. If the decision making processes used in practice continue to make disinvestment decisions in isolation, without comparing the costs and benefits of different options, then it would be unreasonable for the public's perceived inability to prioritise (i.e. their lack of understanding of opportunity cost) to be used as a reason not to involve them

The findings from this thesis imply that where, in practice, disinvestment decisions affect larger numbers of people, have significant financial implications and/or are considered to be more tangible decision makers should seek public involvement earlier in the decision making process. The thesis also suggests that the public

should be given an opportunity to influence these decision to a greater extent.

The benefits of using a range of approaches to public involvement, including using deliberative methods to seek consensus, were not clear to participants. This implies that efforts should be made to educate decision makers as to the range of public involvement approaches that are available beyond what is currently used in practice. Making efforts to extend the use of deliberative methods, such as those identified in the earlier chapters, will give decision makers the opportunity to carefully consider the purpose of their involvement and to find the most effective means of engaging the public. This could have a positive impact on disinvestment decision making practice.

Another implication from this research for decision making practice is that organisations should make reasonable adjustments and genuine efforts to increase levels of public involvement. The literature review and empirical findings suggest that approaches such as offering information in a range of languages, scheduling engagement events on evenings and weekends, and offering incentives or expenses could help to increase rates of participation.

10.6 Implications and Recommendations for Research and Theory

In addition to the implications for policy and practice, the thesis has a number of implications for research and highlights several gaps in knowledge which could be filled with further empirical enquiry. First, within the participant sample there was a lack of clarity as to who or what the public were. Further research aimed at

building on the Lomas (1997) framework could help to clarify and define the different ways that the public are conceived by health professionals.

Reflections on the research process suggested that the participants' understanding of disinvestment and public involvement may have altered between the two legs of the study. A repetition of this study, positioning the in-depth interviews first, followed by the Q-Methodology study, may demonstrate the impact that the two week reflection period had and could add further weight to the findings from both stages.

Both the literature review and the empirical research suggested that public involvement could deliver educational benefits, but there was little empirical evidence to substantiate this. Further research aiming to quantify and clarify these educational benefits, as well as investigating the different levels of learning that can be derived by the public through being involved to different extents could help to inform future public involvement practice

The findings from the empirical research, supported by Prospect Theory (Kahneman and Tversky, 1979), suggest that the public have a greater desire to be involved in disinvestment decision making than in setting priorities for additional spending. The findings also suggest that some disinvestment decisions may warrant more public involvement than others. Further research into the psychological effects of disinvestment and the attachments that the public and service users have to tangible, visible services should be carried out in order to

provide further theoretical clarity and understanding.

The literature review and empirical findings suggest that hard to reach groups within society, and a lack of willingness amongst some individuals to participate, could be impediments to disinvestment decision makers securing representative public samples. The implication of this for research is that further in-depth qualitative research should be carried out to establish why some members of the public are unwilling or unable to take part in decision making. The knowledge gained from this research could then help to inform public involvement practice and allow decision makers to find the most effective ways to increase participation across society and ensure the representativeness of engagement exercises.

From a theory perspective, this study has a number of implications. The first of these is that existing theory relating the benefits of public involvement e.g. the Williams et al. (2012) framework, should be expanded to comprehensively capture the societal benefits identified by this study. Similar theoretical adjustments should be made to Arnstein's Ladder (1969). In terms of disinvestment practice, the ladder assumes that too great a degree of citizen control is possible. The findings also suggest that it is not practical to categorise all consultation under one rung of the ladder. Theoretical development of Arnstein's Ladder could be carried out to recognise the different levels of consultation evident in public involvement practice and the limited evidence of citizen control.

The theoretical distinction between disinvestment and priority setting made using

Prospect Theory (Kahneman and Tversky, 1979) in the earlier chapters is supported by the empirical findings. Further theoretical development should, however, be conducted to strengthen this distinction, adding to the limited disinvestment literature and encouraging further empirical and theoretical work focussing purely on the disinvestment aspect of priority setting.

The existing public involvement theory relating to levels of decision and desired levels of public involvement e.g. Litva et al. (2002), Wiseman et al. (2003), Theodorodou et al. (2010) is supported by the research findings, but there is some divergence. This study suggests that the extent to which the public should be involved is not solely dependent on the level of decision making, but also on the scale and scope of decisions. The scope-scale matrix helps to demonstrate this and supplements the existing theory but further theoretical advancement could be achieved if research seeking the views of the public on their own involvement in disinvestment decision making were carried out.

10.7 Next Steps

The introduction to this thesis highlighted the challenge that former Chief Executive Sir David Nicholson set the NHS in 2009 to save £20bn per year by 2014, and the subsequent Five Year Review by Simon Stevens which laid out the need for further annual savings of £22bn by 2020/21. The fact that, despite the efficiency savings made since the 'Nicholson Challenge', there remains a significant budgetary shortfall demonstrates that the need for disinvestment in the NHS is as pressing as ever and that the challenge must be faced by decision

makers. Given the growth in health costs across the world (also detailed in the introduction), and the global nature of the priority setting literature examined throughout this thesis, the same can also be said for many other health systems across the world and the findings are applicable internationally.

The findings from the empirical research detailed in this thesis and the literature review demonstrated strong support for the public to be involved in the making of these disinvestment decisions, alongside other stakeholders, as early as possible. The findings challenge decision makers to seek more than token, minimal involvement and to carefully consider the types of decision that they are making and what the optimum level of involvement might be. The findings encourage those with decision-making power to see the benefits that public involvement can bring rather than the drawbacks, and encourage them to promote a more open, honest dialogue between themselves and the public that pay for, and use, their services. Without this shared understanding of the problems faced by health services and shared responsibility for tackling them, the challenge of disinvestment will continue to become more daunting, and those making decisions will be viewed with increasing suspicion by the public.

The findings from this research offer no support for the course of action taken by the UK Secretary of State for Health following the failed implementation of disinvestment decisions at South London Hospitals NHS Trust. In adding Clause 119 to the Care Act (Care Act, 2014), Mr Hunt has attempted to give decision makers the freedom to make disinvestment decisions across a health economy

without the requirement, or opportunity for local citizens to have a say. Although this clause has yet to be legally tested, it is possible that it would allow for large scale and scope decisions to be taken with the public only being involved to the extent of receiving information following the decision. The findings from this research suggest that the health professionals that took part would advocate for significant changes to be made to this clause, or for it to be repealed all together, so as to ensure that full, early public involvement can be carried out and that the benefits of this involvement can be realised.

In order to continue to push the field forward and to enable decision makers to make more effective decisions, further empirical research should be conducted to develop the evidence base relating to public involvement in disinvestment practice; qualitative methods such as case study research or further in-depth interviews could prove to be enlightening. Research emphasis should also be placed on the application of established public involvement approaches, such as deliberative methods, to disinvestment decision making to establish why they have yet to be adopted more widely. Lastly, further development of the scope-scale matrix, to provide clearer definitions and to establish exactly what makes some disinvestment decisions more wicked or difficult than others, could provide further guidance as to the decisions in which the public should play a bigger role.

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Appendices

Appendix One - Participant Information Sheet

Health Services Management Centre

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Participant Information Sheet- Public Participation in Disinvestment Decision Making

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being carried out and what it will involve. Please take a few minutes to read the following information carefully and discuss it with others if you wish. Feel free to contact us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Most publicly funded health systems around the world are currently facing a shortfall in their funding caused by rising costs and demand. In order to continue to deliver high quality health care in this climate it has become necessary for decision makers to look at existing services and assess the amount of funding that is being allocated to them. In some cases it has been decided to reduce the levels of availability of some services or even to remove them; this is known as disinvestment.

The purpose of this study is to explore what the role of the public in making these decisions should be.

Why have I been chosen?

You have been chosen to take part in this study because of your unique perspective as both a member of the public and as a professional working with or within the NHS. In order to get a wide range of views, participants from a number of different geographical areas and a range of professional backgrounds have been selected and approached to take part. Your name and contact details have been sourced from data held centrally by the Health Services Management

Centre due to your enrolment on one of our programs, or have been passed to us by a previous participant in the research who felt that you may be interested in taking part.

You are free to either take part or to decline to take part. If you do decide to take part you will be asked to sign a consent form, which you can keep, or to give your consent online.

If you decide to take part you are free to withdraw at any time and without giving a reason. The data collection phase will last until 31st December 2013 and it will be possible to destroy any data that you have provided up to this time; unfortunately it will not be possible for the data that you have provided to be withdrawn from the study after this time. If you wish to withdraw from the research you will be able to do so as soon as you let me know (see contact details at the end of this document).

What will happen to me if I take part?

The study has two phases. The first is a survey in which you will be asked to rank statements relating to public involvement in order of how much you agree with them; this will help us to find out what participants feelings and attitudes are and will allow us to establish what the different shared points of view on public involvement are. You will be able to carry out this exercise on-line or face-to-face if this is preferred. This will take around 30 minutes.

After the results of the first phase have been analysed a number of interviews will take place; you will be asked if you would like to take part in this further research during the survey. The purpose of these interviews will be to establish why you, as participants, think what you think and to get some more information from you as to how you think that disinvestment decisions should be made. Both the survey and the interviews are entirely voluntary and you can take part in just phase one of the study if you wish.

Will information be kept confidential?

Your responses to the survey will be assigned a unique identification number and will remain completely anonymous and will not be traceable back to you.

Digital recordings of interviews will be securely stored until the end of the study, when they will be deleted. In line with the University of Birmingham's code of conduct for research, interview transcripts will be destroyed ten years after publication of the study's findings. The transcripts will not identify participants by name.

What will happen to the results of the research study?

The results of the research study will form a significant part of my PhD thesis which will be published and will be available through the University of Birmingham library. Findings from the

study will also inform future research and practice in the field of public participation in disinvestment decision making

Who is organising and funding the research?

The research is being organised and sponsored by the University of Birmingham. I am the sole researcher in this project and my PhD studies are funded by a scholarship provided by the University of Birmingham. My supervisor is Dr Iestyn Williams.

What indemnity arrangements are in place?

This study is covered by the University of Birmingham's insurance policy for negligent harm. The study is not covered for non-negligent harm, as this is not included in the University of Birmingham's standard insurance policy.

How can I get further information?

Please contact Tom Daniels for further information.

Thank you for your help.

Appendix Two- Example Interview Schedule

<u>Introduction</u>

1. Tell me about where you work and what your current role is

2. What is your experience of public involvement and public involvement methods?

3. What do you believe public involvement to be?

4. Do you have any experience of disinvestment? If yes, what was the public's involvement in decision making?

<u>Scenarios</u>

Now I am going to give you three different scenarios and I would like you to think about the role of public involvement in each of these scenarios.

i) a national decision by NICE to decrease the number of IVF cycles available for couples on the NHS

ii) downgrading a local A&E department to an urgent care centre

iii) a decision to replace consultant led outpatient Dermatology clinics with community based Clinical Nurse Specialist Clinics

For each of these scenarios:

5. What role should the public have?

6. How should we involve the public and at what stage?

7. How much influence should the public have over the final decision?

<u>Supplementary Questions</u>

8. What are the benefits of public involvement?

9. Are there any disadvantages to involving the public?

10. Is it a problem that some groups are hard to reach?

11. Who else should be involved in the decision making process? E.g. other than the public and decision makers?

12. Whose responsibility is public involvement?

13. Is there anything else that you would like to add?

Appendix Three - Example Interview Transcript (Participant 43)

<u>Interviewer</u>

OK, so first of all, are you happy for me to record the interview? And have you received and read the information sheet? If you have any questions then just let me know.

<u>Participant 43</u>

Yes, no problem.

<u>Interviewer</u>

Right, excellent. OK, well we'll crack on then. So the interview today, we are just trying to build a little bit on some of the findings from the online survey that you have already done. We are just trying to get a little bit more in-depth qualitative information on top of that ranking exercise. So the first thing is, can you just tell me a little bit about yourself and where you currently work and what your current role is?

<u>Participant 43</u>

OK, so I am a medical doctor, a trainee in Public Health, coming towards the end of my training. So part way towards being a consultant in Public Health and currently based in Council A's Public Health team. Public Health teams have recently moved from the NHS into local authorities and we have various roles basically around improving the health of the local population, ensuring that there are good quality health services by working with Clinical Commissioning Groups and things like protecting our population from things like infectious diseases and other hazards through vaccination programmes for example.

<u>Interviewer</u>

OK, and do you specialise in a particular area of Public Health?

<u>Participant 43</u>

No, I'm just a generalist; I would probably like to work in a local authority setting in the future. I mean most people in Public Health are generalists. There are some that specialise in health protection but the majority kind of have a general grounding.

<u>Interviewer</u>

Have you noticed any big changes since you went to the council? What have the biggest changes to your role been?

<u>Participant 43</u>

I don't think from my experience in Primary Care Trusts, which was the sort of equivalent setting before, I don't think there are huge changes in the role that we have, There are differences in the setting of the council- the council works in a slightly different way, it's very much focussed on customers and providing value for money, whereas I guess in health it's more about quality of care and that would be the focus. I mean it's the same thing but maybe slightly different terminology. There's also good opportunities in the council and the local authority to work with people from within the council who deal with things that are related health, for example social services, adult social services, children's social services, but also areas like planning and transport policy which also have quite an impact on health.

Interviewer

So for you then, the move from the NHS into the council, it made a bit of sense to you?

Participant 43

There's definitely some advantages but I think that the upheaval in itself....I mean because I'm in training I have the security of my training contract for five years. I haven't felt the kind of upheaval in terms of job insecurity, changes in structure, changes in relationships which I think has definitely been a downside. But I think that there are opportunities for Public Health working in the local authority as well.

Interviewer

OK, so what I think I would like you to draw on really, in the course of the interview is your own experiences and, as well, other things that you have seen as an employee of the NHS and now as an employee of the council. It's interesting what you mentioned there about customers and value for money and these sorts of things, and I think that's the kind of the way that I am coming from with some of the questions. So first of all can you tell me about any experience that you have had of public involvement at all and any methods that have been used to involve the public in decision making?

Participant 43

OK, well I've got some experience, some direct and some just from the organisations that I have worked in. Obviously when I was in Primary Care Trusts, if we were devising strategies or changing the way that the care was delivered we had a duty to at least consult the public about these changes, and quite often that was all that was done. There would be somebody saying 'this is what we are doing, what do you think about it?' There would do things like...not surveys, but they would let people know and then they would have a channel through which they could respond to the consultation. I think there have been attempts, in some of the bits of work that I have been linked to, to do a little bit more in terms of engagement and kind of moving up that ladder of engagement and getting people more involved in choices and giving people options, for example, of how services should be delivered.

I haven't actually been involved directly in instances where we have delegated responsibility but I know my colleagues who work in Service A teams, I think they're quite good at engaging their service users and almost giving them budgets, giving them responsibility to deliver some kinds of services, all be it small scale services. For example user groups, facilitating those groups, facilitating support for service users, so they would actually be given a budget and then they would have to find a venue and then have to find how the services would be delivered. As I said, in the main, any consultation or engagement that is done is normally done at quite a low level and is, kind of, 'this is what we are doing, what do you think about it?'

Interviewer

In that kind of consultation there, where we are basically informing the public of what we are doing, do you think that the responses that people give has any impact whatsoever on the decisions that are taken?

Participant 43

I think it can do. I think in the main a lot of decisions have already been made and there isn't much influence. The questions are often asked in a way so that they don't influence...you know, so that they don't influence the decision being made. So, for example, there might be instances of a drive within the NHS to deliver more services out in the community, so the question that may be asked in consultation could be 'do you think that more services should be delivered in the community closer to home?' Most people are going to say 'yes' to that question. I think that the questions are often asked in a way that they aren't open necessarily and don't allow people to give their full views but that's not always the case. Of course, if people have strong views then their response which is clearly opposed to what is suggested will be taken on board.

Interviewer

OK, can you give me an idea then, I know that it sounds an obvious question, but, in a nutshell, what do you believe public involvement to be?

Participant 43

What do I believe it is or what do I believe it should be?

Interviewer

OK, well if there's a difference, first of all say what you believe it is now and then what you think it ought to be.

Participant 43

I think at the moment there is public involvement but quite often it is done through quite rigid and official channels. For example, you had what were called the LINKS, the Local Involvement Networks, which have now evolved into Healthwatch and you might have representatives from

that organisation on a strategy group or a steering board so there would be that kind of involvement at that level but I don't know how representative that is of public views...it's obviously better than nothing. Then you have this consultation about things- significant changes and that is more about our duty to consult, so I think that at the moment public involvement is something which is done by organisations- commissioning organisations or management organisations, or those organising health care or other services, as part of their statutory duty or a requirement of the organisation it is not done to maximise the benefit from involving the public or to delegate responsibility to the public.

Interviewer

And do you think that's what it should be?

Participant 43

I think we should aspire to do something more than that definitely. In an ideal world you would delegate a lot more responsibility and have a lot more public involvement and let people shape services a lot more but there are actually challenges in doing that and I can understand why it's not done at the moment. For me, yes, public involvement should be at all stages of the commissioning cycle, all stages of the decision making process- so, in terms of indentifying needs for services or gaps in services, identifying where the strengths are in communities and services that are already delivered and then going forward to actually planning and delivering those services. I think we should be delegating responsibility to the public and public groups and service user groups where possible, and always trying to maintain quality of services. As I said, for example the Service A Team who I work with, or having been involved in their projects, they have done that to a greater or lesser extent and I think they have had good outcomes from what they have done.

Interviewer

OK, now I know that on your online survey you said that you hadn't had any direct experience of disinvestment, or what we would call disinvestment, but do you have any experience at all from the organisations that you have worked with where services have been changed or altered? Disinvestment generally means cuts but it might also mean service changes where the public may or may not have been involved. Do you have any experience of that at all?

Participant 43

I think one which I have not really been directly involved in, is one called consultation A, which is a big programme of reorganisation of hospitals and hospital services in Area A. So, you know, it's quite high profile and from senior NHS management there is obviously a drive to rationalise the services and close acute services in some of the hospitals in Area A and concentrate those A&E services in more specialised centres. There was a big public consultation for that and it was sold very much in terms of 'we need to improve quality of care' and by specialising or having specialised centres for emergency care....for example it's worked for stroke, it's worked for heart

attacks and it's something that we need to do for A&E. I think that behind that there is obviously a huge driver for financial savings as well. People were given huge consultation documents and then people were given various options and all of the options were that we were going to close one or another, at least one of the A&Es across Area A, and then there was a preferred option from the managers/ commissioners or whatever.

Interviewer

You used an interesting term there, you used the word 'sold'. It sounds to me like with that particular process that a decision had already been taken and that it was a question of trying to convince people that it was the right decision, is that the case?

Participant 43

That's my perception as well. It's very political because I think that there's this famous David Nicholson challenge to save however many billion pounds in the NHS and I don't know where this decision came from. I presume it was somebody quite high up in the NHS who said 'we have too many acute hospitals in Area A, we need less, we need to save money and we have to have a consultation about it.'

Interviewer

OK, so we are going to come on now to three examples and I would like you think, in an ideal world, in an idealistic way, what the role of the public should be in each of these scenarios and how we could maybe involve the public. So the first example is a decision that has been taken by NICE to decrease the number of IVF cycles that are available on the NHS. At the moment I think that it's three cycles that they will pay for and they are going to drop it down to two. So in that kind of decision there, at a national level, what kind of involvement do you think that the public should have?

Participant 43

I think it's difficult. I think that the public should be involved but I think there has to be some honesty to start off with about why you are making decisions like that in the first place. You have to have honesty about, you know, funds are limited and we think that this is something that should be done because of.....You need to have a transparent process, and yes you can involve the public but you have to be clear that there are choices that have to be made and there are constraints. You can't have everything and there is a reason why this decision is being made. So yes, I think that the public should be informed and allowed to respond to that decision.

Interviewer

OK, that sounds to me like a late involvement, after the experts have decided, after the experts have reached a decision.

Participant 43

Well I would assume that if it's from NICE that they actually do have some patient involvement and that ideally, yes, they should be involved at all stages of the process, but the scenario suggests that the decision has already been made. But yes, in that decision making process you would want to involve the public as much as possible but in the context of 'look, we are going to have to review what we can do in terms of support for people and fertility services and maybe put that in the wider context of maternity services etc.' Yeah, ideally involve people at all stages, I mean that discussion has never really been had at a public level. People are aware that the NHS is facing constraints but decisions about what should be funded and what shouldn't be funded are often not put in that context. Obviously we have NICE which is quite convenient, or it's good in a way, because you have a transparent process for making those decisions and I think there is some public involvement there. But, in terms of the wider context, I don't think that the public are necessarily aware of that. There is this fear, isn't there, that if you involve the public in these decisions then there is obviously going to be opposition from everyone who has a particular interest in a particular condition. So if you're talking about hip replacements or rationing who has access to hip replacements or cataract surgery then you are going to get people who are affected by that condition responding to consultations or getting involved and saying 'this really shouldn't be happening.' Actually if you had a grown up conversation saying that funds are limited and we can't do everything then we might get a bit further with things.

Interviewer

Do you think that the public have a difficulty in being objective?

Participant 43

It is difficult to describe the public as one group because I think that you do have particular groups of patients or public involvement groups that represent maybe people with a certain condition and they have to advocate for people with that condition but I think that if you are talking about people as a whole I do think that people have the ability to be objective. People are always affected by their own personal circumstances or what is affecting their family but they are grown up and I think that they are aware of things on a slightly more complicated level. I suppose that you are right in a way, that having something like NICE, a structure that has this transparent process, or appears transparent, or should be transparent, making those kind of decisions is attractive because it takes away that strength of particular advocacy groups or it can try to remove bias from the process.

Interviewer

Because it is just based on evidence?

Participant 43

It's not just based on evidence. Evidence is a big part of it but they do often have expert panels and I do think that there would be consideration of the impact on the public and patients and carers of commissioning or decommissioning particular services.

Interviewer

OK, the next example that we are going to come on to, I suppose it links back to Consultation A, and this is the downgrading of a local A&E department to an Urgent Care Centre and I would like you to just think there ideally, in an ideal world, what kind of involvement would the public have in that decision?

Participant 43

I think in an ideal world you would say from the start 'look, this is what we are facing in terms of our financing, this is the issue,' present them with evidence and be honest about what impact it will have on travel times, what the evidence for that is on quality of care, what the evidence of positive impacts of reorganising care are, what the options that are available are and make that clear to the public. I think if I was to do that I would get some kind of public group involved right from the start in terms of controlling that information process or facilitating that, facilitating the involvement of local people as well.

Interviewer

Do you think that, in these kinds of decisions, the public have the necessary information to have a view?

Participant 43

I think at the moment we struggle to give people a balanced view. Those things, for example closing a local A&E unit, they become very political because the local press might give a different picture to the NHS managers or the people who are trying make the changes and then there is no kind of middle ground, there is nowhere to get that kind of balanced information so it's quite difficult for people to get high quality information about the implications of any changes or the rationale for any changes.

Interviewer

In that respect there then, do you think that the media have got a big part to play in involving the public?

Participant 43

I think that the media do have a part to play. I mean the media is one way in which the public do get involved in decisions about health care or health care issues but the media also have an agenda to sell advertising space, sell their material. So the media isn't necessarily about giving people balanced information or giving people a complete breakdown of all the facts, sometimes it's about

the story rather than giving information in a balanced way. But they do play a really important role and I do think that obviously they have some responsibility to report in a balanced manner but that's not always the case, not just in health care but in other areas as well. Media groups have their own agendas as well.

Interviewer

You mentioned these kinds of decisions becoming political there, in the example that you gave earlier, Consultation A , have politicians had much of an input? Do you think that they should have much of an input?

Participant 43

They have had an input because politicians, where there are local hospitals that have been earmarked for downgrading, have obviously opposed the closures and there is a strong local feeling as well that they shouldn't be closed. People don't want to lose their local services so if you actually gave people the choice, I don't know, even if you gave them the full sort of balanced case, they would still want to have.....there's an attachment, there's a real strong attachment to having an A&E close by that's always been there because that's where you have attended and that's where family members have attended. It may be regardless of the quality of the service that you get there, there's just something about having it in the locality and I think that there is a fear amongst local politicians that if they support the closure, or argue that the downgrading may actually have benefits for the population, people won't buy that and they will get kicked out basically at the next election. Politicians have definitely put their weight against local closures and this has happened all over the country, so you can see why these tensions arise really because on some grounds changes need to be made. Maybe there is a lack of real clarity about why those changes need to be made and then, because there's that lack of clarity, people think that these things don't have to be done, or it's unnecessary or the status quo can remain. Then everyone wants to protect what's going on in their local area, it's like High Speed Rail or something like that, people might think it's a good idea, or even of people might think that there needs to be a change, they don't want it to affect their local community or their local area. They don't want to be the one who loses out, when there are winners and losers in a decision they don't want to be the loser.

Interviewer

The last example is, again, a slightly different example, it's a decision to replace consultant led outpatient Dermatology clinics with community based clinical nurse specialist clinics. Do you think that there is a role for the public in that kind of decision?

Participant 43

Yeah, I do, I mean these are the decisions that are often made because of financial pressures or they may be for equality of service or they may be to have a more local service; it may be driven with quality and patient experience in mind but quite often finance is behind it. I think that if you

don't get people on board with that decision, involve them with that decision, then you are going to lose out. Again, transparency, for me, is the key, you know, even saying 'this is how much money we need to save from this service,' or 'this is why we need to change this service,' but 'we really want you to get involved and this is how you can influence this and take the opportunity to negate a loss of quality in the service or even improve the service.' I think definitely be transparent about it.

<u>Interviewer</u>

You mentioned there that we want the public to get involved, I would just like you to go into a little bit more depth about the choice that the public have as to whether or not they do get involved in these decisions. Do you think that there is a choice? Do you think that they have a responsibility to be involved?

Participant 43

Do the public have a responsibility? No, I don't think that people do have a responsibility to be involved. I think that there are definitely some people who would just say you know 'let's leave it to the decision makers and people with the technical expertise to make the decision,' but there are others who want to engage and we should try to encourage people to engage wherever possible. I think these people actually do have a responsibility because they are often the first to say that services are not as good as they should be, so there is a need for them to have some kind of input rather than just be passive consumers but I do think that needs to be facilitated. Again that needs to be made transparent as well, the whole process of involving the public you need to be clear about what your aims are for that process and why you are doing it, and the goals, and the level of involvement that you would like to achieve.

Yeah, I think actually the public do have a responsibility and they are part of the health service, they are part of our health system but then you need some kind of expertise or some kind of skills in facilitating that involvement and stimulating that responsibility, especially for excluded groups and groups that are often not heard as much as the voices that you often hear in these kind of patient engagement exercises.

<u>Interviewer</u>

There's two little bits there really, do you think that it's an issue that there are some groups that are hard to reach?

Participant 43

It's a thing of terminology, 'hard to reach' or 'difficult for us to involve'? There is definitely an issue with certain groups that are excluded, for example rough sleepers or undocumented migrants, they are often difficult to engage with about health services and public services in general, and they are people that have the worst outcomes and probably the least good services. There is definitely a responsibility of people who deliver services, especially coming from a

public health point of view where we want to improve the health of the most deprived people in our communities. It is really difficult to do and there is not a huge body of evidence about how to do that well. We tend to avoid the things which are outside our comfort zone or which are difficult or new, so it can be difficult. I think that's going back to the way that we do public involvement at the moment; we try and find ways which are easy and that we can build into our day to day work. We are not looking at individual projects and outcomes for that, we are just saying that we have to involve the public so let's find a way of doing it.

Interviewer

Do you think that the way we try and involve the public now is almost a 'catch all' or we try and get as many people as possible but as long as we've got a few then that's OK?

Participant 43

Yes, that is fair to say. I wouldn't say 'catch all' I don't think that we even necessarily try to get as many as possible. On some things if you do some kind of public involvement, some kind of consultation, or some kind of focus group or something like that, it is actually considered...maybe not for large scale projects because you would need to do more. For small, local level projects, if you have some kind of involvement then that would be seen as good if you see what I mean. People wouldn't necessarily scrutinise how that involvement was, they would just see in your document or strategy or whatever that you've got some public comments or participation and they will say 'well that's good, they've engaged the public,' without thinking well, what has it actually achieved?

Interviewer

OK, now, what do you think the benefits of public involvement are?

Participant 43

I think that the benefit that I would like to achieve is having better quality services, more equitable services, and ones which give a better experience for users of services. There's also potential benefits for both the organisation and the staff involved in delivering health care and the members of the public who are involved in the engagement process in terms of raising their awareness of how to do things better and for people who are involved in public involvement in terms of developing their skills, developing their ability to advocate for themselves, care for themselves, so I think there's those kind of benefits as well as the benefits to services. Ultimately, yeah, it should be about improving services.

Interviewer

You mentioned there the benefits that public involvement can have for people who work within services, do you think that staff can have an influence over public involvement or should have an

influence over how much people get involved and the way they get involved and how the public influence services?

Participant 43

I think that's where it's got to come from really. Obviously you can have some top down approaches, you can have some guidelines and policies about how we should engage the public or patients but really, at the local level, it comes down to the determination of local staff and also local service users and it requires effort. So yeah I am sure that there examples locally of where it is done really well and I am sure that's because of the motivation and dedication of local staff and service users. I think that having that bottom up approach is where you are going to see the best approaches, I think that when it starts being done well is when you will get a kind of snowball effect in those local areas and that practice will spread across all public services. It may be a slow process but I think it will happen.

Interviewer

And what about any downsides that you can think of to public involvement?

Participant 43

I think there are costs involved. Obviously if you are spending large amounts of money, say if you've got a project that you want to deliver, for a relatively small amount of money and you are spending your money on activities trying to involve the public then....it has to be proportionate to what you are doing, or what your service is or what your change is. There's obviously downsides that you could be getting the wrong information. In a way it's like doing any kind of research isn't it, there's potential biases in the engagement that you are doing. Are they representative of your service users? Are those opinions that you are getting or are those decisions that are being made by your public, what you call public and patients, actually representative of your population that you want to serve? Are you biasing your services towards one particular group? So could it actually make your services less equitable. It is certainly a risk if it is not done well, that the voices that you hear or the people that take part are actually advocating or representing the people that have the best health outcomes and the best services.

Interviewer

Do you think that's a problem that we have with public involvement? Do you think that we get the same certain groups being overrepresented almost?

Participant 43

I think we get the same people who are enthusiastic and that is a danger but I often think that the people that you do get who are vocal do actually have a reasonable idea of what is going on and possibly a better idea than those who are providing the health services or delivering the service change. So, yeah, although it's a risk....and obviously you should try and broaden that engagement

as much as possible, make it as representative as possible. I still think that some involvement is better than none.

OK, and then just the last question for me really, in terms of decision making process, if we are talking about service change or disinvestment, are there any other groups that you think could or should be involved other than those making the decision and then public/ patients?

Participant 43

In the work that I do I would involvedother stakeholders who may impact. For example, you might be doing some work on…I'm doing some work on service B at the moment and helping to change services, so yes you want to include carers and service users and the people involved in commissioning services but you may also want to look a bit wider in terms of involving things like local businesses and other public or voluntary organisations that work with particular community groups. It depends on what you are doing really. You may also want to get the views of…sometimes it helps to get the views of people who have quite a lot of influence locally, even though they are not responsible for the decision, because whatever their views are, you may get some barriers to change depending on what they think. Do you see what I mean?

I guess, for example with the re-organisation of hospitals, it may be a good idea to involve local politicians from an early onset and have them in a group and again start that transparency of the process. If there is going to be such strong local opposition that you can't achieve the change that you want to do from a particular person with power then it is going to be very difficult and you have to be very sensitive to that. But that would be depending on what the change was and kind of analysing the stakeholders that were involved locally. You mentioned the media earlier, it may be a good idea, if it's a sort of significant change which is going to be controversial, to involve the media and to try and make the process transparent, to deliver facts in a press release about the changes and how people are going to be involved and do that from an early stage.

Interviewer

Actually, just one last question for me, you have talked quite supportively about public involvement, do you think it's more, or less, or equally important to involve the public when we are talking about disinvestment decisions as opposed to decisions on how to invest additional money?

Participant 43

I think it's equally important. I think it would be in proportion to the magnitude of the change what level of involvement you would want. Disinvestment is obviously more challenging but then I think you want to try and keep the people that you are serving on board as much as possible and then maybe there are things that they can tell you that you don't necessarily know. It may be that you are spending a lot of money on a service which you think is performing well or which you

think is a popular service and has good experience but actually it doesn't and that could be quite an easy win. You could say well 'this is a service which we ought to disinvest in because it's a service that's not valued by local people at all and that could actually make your life a lot easier.

Interviewer

OK, well that's great, that's all of my questions, is there anything else that you would like to add? Anything that we haven't covered that you think we perhaps should have done?

Participant 43

I just think that there are problems for practitioners. I am always keen to engage or involve the public as much as possible, so it's not that...I don't think there is a lot of good quality guidance or good quality case studies about how to do it well. I know that there are things like NICE guidance on community engagement but actually a lot of it is quite theoretical and it would be good to have some firm examples of how it has been done well in terms of the sort of moving up that ladder of engagement into co-production or delegating responsibility to patient groups. I think beyond that kind of consultation stage it is not embedded well into practice and maybe we've got to find a way of embedding it into practice or improving the implementation, as it were, of engagement strategies or community development strategies. I think that there is a real drive, especially from people around public health, to do it but you shy away from doing it because you don't feel confident and it's difficult but it doesn't need to be difficult I don't think. It feels like an under-developed field compared to things like Epidemiology...we feel more comfortable analysing data and that type of thing but this is difficult, so you shy away from doing it.

Interviewer

Certainly I think it's one of the things that is coming out so far is that it is quite under-developed and speaking to people from all different backgrounds from across the country I think that the range of experiences is huge to be honest. From people who have seen it done very well to others who are quite critical of the way that it's been done. There's a lot to go at certainly.

Participant 43

Yes, it's a real area for development, it's something that I am really interested in but I feel a bit inadequate about doing it. I don't feel as confident about is as in other areas of my practice. I think that you have to lose control. Something that you don't feel comfortable with, as a health professional, as a doctor, it's a question of losing a bit of control and seeing what happens sometimes it's not necessarily a bad thing. We think we know best but actually we need to challenge ourselves quite a lot.

Interviewer

I think that it's interesting to look at the things you have said there about how the public can possibly offer innovative ideas and solutions, I don't think that's really publicised, I don't think we make the most of the kind of resource that we've got there with the public to be honest.

Participant 43

No, definitely, it my view it's a kind of a tick box exercise is patient engagement and it's not really done to actually maximise how you are going to improve your services.

Interviewer

OK, that's the end of my questions now so I am just going to turn the recorder off, thank you.

Participant 43

Thanks

Appendix Four- Technical Appendix- Factor Analysis

Introduction

The process for carrying out Q Methodology research was introduced in the methods chapter but, as the method is still relatively little known in social research, one of its most fundamental aspects, factor analysis, will be covered in greater depth here. First the process of traditional factor analysis will be described, then the criticisms levelled at it by William Stephenson, the founder of Q Methodology, will be detailed before his solution (the forced ranking procedure outlined in the methods chapter) is justified. The detailed statistical steps taken in Q Methodological factor analysis will then be laid out before the appendix concludes with a glossary of key terms used in the Q-Methodology Literature. This technical appendix is written to compliment the brief introduction to the process of factor analysis presented in Chapter Six.

Traditional Factor Analysis

Factor analysis was first developed for use in Psychology by Charles Spearman in the early 1900's and was central to his research into intelligence (Schumacker, 1996). Factor analysis, as was put forward by Spearman, is a reductionist approach, aiming to simplify data and reduce complexity by uncovering latent factors that exist between a number of variables.

Traditional factor analysis begins with a data set consisting of a series of tests or measurements (variables) collected from a sample of participants. These participants

and variables are summarised in a table, such as the one below, which contains a small sample of data relating to patients at risk of diabetes;[4]

Participant	Age (years)	Height (cm)	Weight (Kg)	Blood Glucose Reading (mmol/L)	Alcohol Consumption (units/ week)	*cont....*
A	36	180	92	4.6	22	
B	58	176	95	5.9	30	
C	74	156	75	5.2	10	
D	24	190	105	4.8	36	
E	46	162	82	6.3	24	
cont....						

Table One- Example data set

Referred to by Stephenson as R-Methodology in reference to Pearson's R (Watts and Stenner, 2012, p.10), traditional factor analysis seeks to use 'tests or traits as variables and operate using a sample of persons' and would look for correlations across the columns in the table. It would, for instance, seek to establish if there was a correlation between age and weight. One of the first difficulties that an analyst would face in establishing correlation would be the range of different measures used to quantify the variables e.g. centimetres and kilograms. How is it possible to tell if someone is taller than they are heavy?

Traditional factor analysis would seek to overcome this by converting the data for each participant and each measure into a Z-score. This z-score uses standard deviation to give the participants' score a ranking relative to the mean of all other scores for that variable within the population (Birmingham *et al.*, 2009).

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[4] Please note this is fictional data devised by the author for the purpose of demonstration only

Z-Scores are calculated using the equation: $Z = (X - \mu) / \sigma$[5]. By using the relative score z-score, rather than the initial absolute value, it is possible to draw direct comparisons across the variables.

Having created the Z-scores, these are then correlated for each individual participant i.e. each of the variables is correlated with each other. This shows whether or not there is a statistical link between any of the variables at an individual participant level. These individual level correlations (i.e. the correlations between each of the variables for each participant) are then summed to give an aggregate correlation between each of the variables across the whole of the study population. Factor analysis calculations then use these aggregated correlations to highlight scores for different variables which vary (or covary)[6] proportionately and significantly across the population i.e. they demonstrate observed associations between the different variables. Tabachnick and Fiddell (2007) suggest that correlation coefficients of greater than (less than) + (-) 0.3 are indicative of the existence of a latent factor between variables.

Factor analysis seeks to reduce the data by looking for variance or covariance between two or more variables and using an underlying or 'latent' factor to explain this. In other words, where linkages are observed between variables, factor analysis seeks to uncover whether there is an underlying explanation (factor) for this link and whether or not the variables that have been tested are different manifestations of this latent factor. Latent

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[5] In this formula X is equal to the value or score for a particular individual for a particular variable/ measure/ test, μ is equal to the mean for the whole population for that variable/ measure/ test and σ is the standard deviation for that variable/ measure/ test

[6] Where two variables 'vary' proportionately, a higher score for one variable will mean a proportionately lower score in another variable (and vice versa). Where two variables 'covary' a higher score for one variable will mean a proportionately higher score in another.

factors have not, themselves, been tested within the variables in the data set and, because of their underlying nature, are often difficult to test or measure in an explicit way- this is not to say that they do not exist however, and the variance (or co-variance) observed between the variables demonstrates their impact.

Using the fictional diabetes risk factor data that was presented earlier, analysis of the correlation matrix may, for example, show that there is variance between age, alcohol intake and weight. Most statistical analysis would note that there was a correlation between the individual variables, for example that younger people drank comparatively more alcohol than the rest of the population, that they weighed comparatively more and that those who weighed more tended to drink more alcohol. In themselves these observations are interesting but they fail to recognise the link between all three of the variables and, furthermore, they fail to consider any explanation (or latent factor) as to why this link may exist. Factor analysis achieves both of these things. In this case factor analysis may highlight 'youthful risk-taking' as a factor- if younger participants felt that they could make up for any negative effects of their lifestyle later in life then this could explain why they were happy to drink more alcohol and why they were willing to carry more weight. Both alcohol consumption and weight could be alternative manifestations of this underlying 'youthful risk-taking' factor, but risk-taking was not measured as a variable and may be hard to test in isolation.

Stephenson's Criticisms

William Stephenson worked alongside Charles Spearman for a number of years and

was considered to be one of his most gifted PhD students. During this time Stephenson also worked with Cyril Burt who was widely credited with the continuing development of R-Methodology factor analysis following Spearman's retirement, and the two men gave Stephenson an unrivalled grounding in factor analysis. Because of the knowledge that Stephenson had built up, and his growing psychological research portfolio, he was in a better position than most to critically analyse factor analysis and he was critical of the traditional R-methodology approach, when applied in the 'individual differences' psychological tradition, for a number of reasons.

Stephenson's first and most vociferous criticism of R-Methodology, or by-variable, factor analysis was that the process of standardising scores for each individual participant had the effect of making the underlying factors that were uncovered less applicable to individuals. By creating the relative Z-scores, the measures used in the factor analysis are disassociated from the individuals that they relate to- instead of providing absolute data about that individual and their own lifestyle, personality traits and characteristics, the Z-score simply provides an idea of how that person compares relative to the rest of the population. Instead of being suitable for analysis of individual differences between people, Stephenson felt that the R-Methodology approach to factor analysis was limited to highlighting underlying explanations for general differences at a population level.

In order to overcome this criticism, factor analysts have suggested highlighting individual participants following the initial analysis and, where possible, subjecting them to further tests. These tests would attempt to provide a measure of how these

individuals differed specifically in relation to an emerging factor. In the earlier example, for instance, a verified test to measure risk seeking behaviour or risk aversion within the population may prove to be useful in demonstrating whether or not younger participants are willing to take more risks. This would help to ensure that the 'youthful risk-taking' was in evidence at an individual level as well as at a general, population level.

This testing of individuals following factor analysis is still common practice in individual differences psychology today, but it was not sufficient to dispel Stephenson's concerns. In highlighting the specific latent variable for testing, Stephenson felt that the individual, and their lifestyle, personality traits and characteristics, as a complete being, were being overlooked. Stephenson was more interested in seeking a way to define and understand each individual holistically and to consider the impact that the identified latent variable had in light of other personal characteristics. In order to find a way around the criticisms that he had of traditional R-Methodology factor analysis Stephenson sought to find a different way to handle the data and settled on Q-Methodology and an inverted approach to factor analysis.

Stephenson's Q Methodology

The inverted factor analysis that Stephenson proposed sought to analyse the individual participants (as whole entities) in the research rather than analysing each of the individual variables. Using table one to exemplify this, Stephenson sought to shift the focus of analysis away from being between the columns and on to being between the

rows. In so doing, he essentially made each of the individual participants in the research a variable in their own right and made the tests or traits being measured become the population or sample.

Arguably the most straightforward way to enable this inverted factor analysis would be to treat the columns in the matrix in the same way that the rows were treated in R-methodology- effectively turning the matrix on to its side. Whilst this is possible in theory it presents the same problem with data standardisation that exists within traditional R-methodology because of the range of different units that are used to quantify the different tests/ measures.

Having experimented with a number of approaches to data collection, Stephenson concluded that it was necessary for every attribute to be measured using an identical unit and that, as such, traditional R-Methodology would usually not yield the kind of data that was suitable for his factor analysis. What Stephenson proposed was to collect data using a heterogeneous set of stimuli relating to a personality trait (or their thoughts/ opinions on a subject e.g. the set of statements used in this study) and to ask participants to place them in rank order (e.g. to show the extent to which they agreed with them). This process became known as Q-sorting and is detailed further in Chapter Six.

Essentially what was proposed was for the stimuli to become the sample or population in the study and for the ranking given by each participant to be their measure for that variable (the participant). By plotting the standardised data produced into the rows of

the table it would not only allow direct comparisons between the way that a particular individual perceived and ranked each stimuli, but it would also allow for comparison between different individuals. The previous approach to data collection (as described earlier) would have relied on a standardization procedure to deliver this kind of data set and even then it would still have failed to adequately show the 'whole' view of an individual participant.

Q Methodology Factor Analysis Overview

Where the first stage in traditional R-Methodology factor analysis is to calculate the correlations between pairs of variables for each individual participant, the first stage in Q Methodology is to calculate the correlation between pairs of individuals (persons) and the rankings that they have assigned to each stimuli during the Q-sorting. The correlations for each stimuli are then aggregated to give an overall correlation showing how alike or different their overall views are from each other. This process is then repeated to give a comparison between the overall ranking (Q-sort) of each participant with each other participant.

As in traditional factor analysis, the data are then reduced. Instead of seeking correlation between variables (e.g. tests/ measures), however, the data are reduced by grouping highly correlated participants, whose rankings demonstrate significant (co)variance, into factors. As in traditional factor analysis, it is assumed that there is an underlying linkage (or latent factor) between the groups of participants and that, as each participant was asked to rank the same set of stimuli from their own first-person

perspective, the different groupings must represent different shared points of view on the topic in question or different shared personality types. The existence of these latent factors is explained by subjectivity, and the different views and understandings of the stimuli, within the participant sample.

As each of the 'tests' is the same and the Q-sorting procedure simply asks the participants to rank the stimuli according to their views, rather than collecting data through a range of specific tests which may require specific abilities to complete (e.g. intelligence tests used in traditional R-Methodology factor analysis), the effect of the instrument on the outcome of the analysis is minimised and the subjectivity studied is, therefore, considered to be operant (Brown, 1997). The steps taken in the factor extraction process in this study will now be explained in more detail.

Statistical Steps in Q- Methodology Factor Analysis- Factor Extraction

The first step in the process is a methodological decision relating to the underlying assumptions of the study and the approach to factor analysis that will be taken. One option is to follow the 'confirmatory factor analysis' approach, which seeks to use the factors identified through Q-Methodology to test an existing theory. The other approach, which was followed in this case because of the inductive-constructionist underpinnings of the research, is 'exploratory factor analysis'. This approach is inductive in nature and seeks to allow the data to speak for itself and for the factors to emerge without being tested against an existing framework.

The second step is to make a decision on which statistical approach to factor analysis to

follow- Principal Components Analysis (PCA) or Centroid Factor Analysis. The PCA approach identifies the 'mathematically best' factor solution (Watts and Stenner, 2012) by identifying the factors (components) which account for the maximum possible variance (Yong and Pearce, 2013). This data reduction technique seeks to reduce the data into as few components as possible; crucially the solution provided will ensure that all of the components or factors are uncorrelated with each other (Tipping and Bishop, 1999).

Centroid factor analysis is a more flexible approach to factor extraction, developed when calculations were done by hand and when factors were extracted from the data one by one (Watts and Stenner, 2012). As such it is more indeterminate than PCA and it allows the researcher to experiment with factor solutions (Ramlo, 2005), for instance allowing them to extract as many statistically significant factors as possible rather than extracting the fewest possible. Regardless of the differences between PCA and Centroid Factor Analysis, the literature suggests that they tend to deliver similar results (Brown, 1980).

There is much debate in the literature as to the merits of each of the approaches (Kline, 1994), and whether or not PCA (because of its focus on components) even constitutes factor analysis at all (Yong and Pearce, 2013). Although now rarely used outside of Q Methodology, centroid analysis remains popular with many contemporary Q Methodologists and is highly recommend by Watts and Stenner in their recent methodological text (2012).

The factor analysis detailed in this study was conducted following the Centroid approach. Further details of the rationale behind this decision and how it linked to the study's research design and epistemological underpinnings are provided in Chapter Six.

Before factors can be analysed they must be 'extracted'. The first stage of this extraction process is to correlate each of the Q-sorts completed by the participants with each other. The formula used to calculate the correlation between participants 1 and 2 would be as follows (Brown, 1980):

$$R_{1,2} = 1 - (\Sigma d^2 / 2Ns^2)^7$$

A correlation matrix is produced for each and every Q sort- this matrix represents 100% of the meaning and variability, i.e. the different understandings and perspectives of the participants, within the study. The totality of this meaning and variability is known as the study variance, this is made up of the common variance (that which is commonly held within, or by the group), the specific variance (that which is particular to specific individuals) and the error variance (that which occurs randomly or due to errors in data collection or the methods used). The aim of the factor analysis is to account for as much of the study variance as possible (Watts and Stenner, 2012).

Factor extraction is a complex statistical process[8] which begins with the summing of the rows of the correlation matrix (Σr) to show the extent to which each of the Q-sorts

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[7] R 1, 2 = correlation between participants 1 and 2, Σd^2 = the sum of the squared differences between the values that each of the participants ascribed to each of the stimuli, N= the number of stimuli, s^2 =the squared standard deviation of the range of possible values (i.e. +4 (strongly agree) to -4 (strongly disagree) in this study).

[8] Please note, the steps listed are the most fundamental steps in the process. A far more detailed description is provided by Brown (1980)

correlates with the rest of the group as a whole. The top row of the grid (i.e. the summed correlations of all Q-sorts with participant one's Q-sort) effectively then represents the factor to be extracted (Factor A). The square root of this summed correlation (Σr_1) is calculated before the sums of the correlations in each of other the rows are divided by this figure. The product of this calculation gives a factor loading for each of the Q sorts on to the first factor (Factor A).

Factor Loading for Q Sort N on to Factor A= $\Sigma rN / \sqrt{\Sigma r_1}$

Once the first factor has been extracted, the correlation matrix is recalculated to take account of the common variance or shared opinion between the individual participants which has been removed with the factor. In order to calculate the residual correlation (i.e. that which remains in the calculations) the loading of each of the Q sorts on to the first factor is multiplied by the loading of each of the other Q sorts on to that factor. The product of this calculation is then taken away from the initial correlation to give the residual correlation- this is then summarised in a revised correlation matrix.

Residual correlation between Q sorts 1 and 2 = $(F_1 \times F_2) \times R_{1,2}$

Having calculated the residual correlation, the process of factor extraction is then repeated using the revised figures and the updated summed correlations. Factors can continue to be extracted from the data indefinitely although each factor that is extracted will account for less and less of the variance; as a result of this the literature makes a case for extracting no more than seven factors in total (Brown, 1980; Watts and Stenner, 2012). In the case of this research, as the researcher was following an

inductive research tradition and was not seeking to test any existing theory, it was decided to extract as many statistically significant factors as possible. The process for establishing how many significant factors there were is described in section 6.2.7.

Factor Rotation

Having experimented with different factor solutions it became clear that three factors was the most that could be extracted whilst meeting the criteria that had been set, and so these three factors were extracted. At this stage the factors accounted for as much of the variance as possible (Russell, 2002) but did not necessarily closely reflect any of the individual Q-sorts i.e. the three factors represented the middle ground in between as many of the Q-sorts as possible. In order to ensure that the factor solution properly represented the data and gave a clear understanding of what the different perspectives displayed by the participants actually were it was, as is always the case with factor analysis (Yong and Pearce, 2013), necessary to rotate them.

Factor rotation begins with a multi-dimensional grid of all of the different Q-sorts/ participants (in this case the grid had three dimensions as there were three factors). Each of the factors makes up one dimension of the grid and is orthogonal (perpendicular) to the others (e.g. if there were only two factors the map would have two axis- X and Y). The loadings (or correlations) of each of the Q-sorts dictate their position on the grid- if a Q-sort loads strongly on to one factor (e.g. Q-sort B which loads strongly on to Factor One in the example below) then it will be positioned towards the end of that axis.

```
           Factor One
               1.0

                .B

-1.0 ──────────┼───────── 1.0  Factor Two


                      .A
              -1.0
```
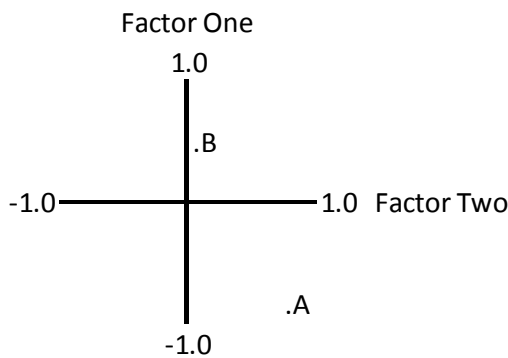
The process of rotation rotates the axis so as to increase the loading of each of the Q

sorts on to one factor or another. In the example above, a clockwise rotation of factor

two would increase the loading of Q-sort A on to that factor. If this rotation were

orthogonal (as the majority of Q Methodology rotations are, and as was the case in this

study) then factor one would also rotate clockwise which would have the effect of

reducing the loading of Q-sort B on to Factor Two and actually leading to a negative

correlation.

In this study a 'varimax' rotation was carried out. First developed by Kaiser (1958),

Varimax rotation uses the simple structure statistical principle to deliver the rotated

factor solution which takes account of the maximum possible level of variance (Brown

and Good, 2010). In addition to this, the statistical processes undertaken in varimax

rotation seek, as far as possible, to ensure that each variable (Q sort) loads strongly on

to just one factor and that each factor has a small number of strongly loading Q-sorts

(Abdi, 2003).

The decision to use a varimax rotation was taken as a result of the inductive,

exploratory nature of the research (Russell, 2002) and because the research was not

designed to test a particular theory. An alternative, more positivist approach, is hand-rotation whereby an existing theory is examined- one example of this could be to rotate the factors so that one individual Q-sort becomes one of the factors (i.e. it is set so that this Q-sort has a correlation of 1 with the factor). This approach could be used to provide a comparison between how other individuals in a population viewed a particular topic in comparison to one particular person of interest. The literature shows no particular preference for either of these approaches but it is clear that, where no theory is being investigated, varimax offers an objective and reliable solution (Watts and Stenner, 2012).

Factor Estimates and Arrays

After rotation, the final stage of factor extraction before interpretation is the production of factor estimates and arrays. These estimates are of the way in which an individual with a correlation of 1.0 with the factor would view the topic being studied (VanExel and DeGraaf, 2005), they are used to create an ideal rank order of the stimuli which can then be placed back into the original sorting grid to provide a factor array.

The first step in the production of the factor estimates is to calculate factor weights for each of the factors. In order to do this, all non-confounded exemplars of each factor (e.g. those participants who load strongly on to only one factor, calculated using the level of significance formula outlined earlier) are subject to the following calculations.

Initial factor weight for participant N= Factor loading / (1- Factor loading^2)

This calculation is repeated for each non-confounded participant. The largest weighting identified for that factor is then noted and a reciprocal of that factor weight is calculated.

Reciprocal of largest factor weight= 1/ Initial factor weight

This reciprocal then essentially becomes the benchmark against which the factor weightings of all of the other non-confounded Q-sorts are judged. The following calculations are used to establish the final factor weights of each of the other Q sorts and to calculate the influence that they will have over the factor estimates in comparison to the reciprocal.

Final factor weight for participant N= Initial factor weight for participant N x Reciprocal of largest factor weight

The final factor weight for the Q sort with the highest initial factor weight is counted as 1 and, owing to the nature of the calculations, the weights of each of the other factors is always less than 1. This ensures that the Q sort with the biggest correlation has the most influence over the factor estimate.

Having established the final factor weights for each of the non-confounded Q-sorts, the final stage in the creation of factor estimates is to map the positions that each of these exemplars assigned to each of the stimuli. Each of the positions on the Q-sorting grid is assigned a number- in this research the scale went from -4 (strongly disagree) through to 4 (strongly agree) so there were nine different positions (these are numbered 1 (-4) to

9 (4)). A weighted score is then calculated using the following formula:

Weighted score for each stimuli= final factor weighting for participant x ranking assigned by participant to that stimuli

The weighted score for each of the stimuli is then summed across all of the non-confounded Q-sorts. The total weighted scores can then be ranked, with the stimuli receiving the highest total weighted score ranked first and the one with the lowest score ranked last. This ranking effectively orders the stimuli in terms of the extent to which the factor would agree with them- those with the highest weighted score would be agreed with the most. Having produced this ranking, the stimuli can then be placed back into the original sorting grid in order of agreement to show what an ideal Q-sort would look like from the perspective of the factor. This process is repeated for each of the extracted factors and the ideal Q-sorts or factor arrays produced form the basis of the factor interpretation.

Conclusion

In this technical appendix, the author has introduced factor analysis, briefly explained what it is and detailed William Stephenson's criticisms of the traditional 'R-Methodology' approach (when applied to individual psychological differences). The author then laid out the individual steps in Stephenson's alternative 'inverted' factor analysis, known as Q-Methodology. Complex statistical processes from factor extraction through to rotation and factor estimates were outlined in order to compliment the brief introduction to these processes provided in Chapter Six. Whilst this technical

appendix should help to answer most readers' queries on Q Methodology factor analysis, the author would like to direct those who wish to find out more to Brown (1980), who provides much more detailed description, and Watts and Stenner (2012) whose text is similarly comprehensive but arguably more accessible

Glossary

Confounded- a participant that loads strongly (i.e. they are significantly correlated with) on to one or more of the factors

Exemplar- a participant (or a Q-sort) which loads strongly on to one factor and one factor only

Factor Analysis- the extraction and rotation of factors before factor weightings are calculated and factor arrays are produced

Factor Extraction- the process of removing factors (and their associated variance) from the data. These factors represent different perspectives, shared understanding and untestable linkages between participants in the research

Factor Interpretation- the use of factor arrays and qualitative data collected from exemplars to make sense of the different perspectives, to understand the shared points of view and to consider why they may exist and the impact that they may have in practice

Orthogonality- the rigid distinction between factors, the difference between factors,

often characterised by one factor being at 'right angles' to all others. If there is

orthogonality then when one factor is rotated, all other factors are also rotated equally

P-sample- the sample of human participants that take part in the research

Q-Sort- the action of arranging stimuli according to the condition of instruction (e.g. place these statements in order of your agreement with them). Once a participant has arranged the stimuli in order, this order becomes known as a Q-sort

Q-sorting grid- a forced distribution within which participants are asked to place the stimuli in order to show how much they agree or disagree with them. An example of the sorting grid used in this research is included in Chapter Six.

Q-sample- the sample of stimuli used to gauge the opinions of participants. In this research the stimuli was a set of statements, and the Q-sample size was 42

Rotation- process which takes places following factor extraction, its aim is to increase the loadings of individual Q-sorts on to one factor or another and to ensure that factors more closely reflect the views expressed by participants

Rotation (Varimax) - computer-based, statistical form of rotation aimed at maximising variance

Rotation (hand) - form of rotation carried out manually and aimed at testing particular existing theories

Stimuli- The items to be ranked by participants in the Q study. Previous studies have

used smells, pictures or colours as stimuli but now it is most common to use statements about a particular topic

Variance- In Q-Methodology, the range of different meanings, views and understandings that a group of individuals might ascribe to the topic being studied. There are three types of variance: common variance (that which is commonly held within, or by the group), specific variance (that which is particular to specific individuals) and error variance (that which occurs randomly or due to errors in data collection or the methods used).

Z-score- a standardised score used to enable comparison between tests/ measures/ variables collected using different units e.g. kg and cm. The z-score uses standard deviation to give an indication of how one participant compares to others in the population in a particular study. The Z-score allows for comparison and correlation across variables, for instance allowing for correlation between height and weight to be calculated despite the different units in which the data was collected.

References

Please note that references for this appendix are incorporated into the reference section for the overall thesis

Appendix Five - Online Instructions Given to Q-Methodology Participants

Introduction

Welcome to POETQ and thank you for agreeing to take part in this study exploring public involvement in health care disinvestment decision making.

Disinvestment in health care is the removal of funding from certain services or treatments. This may result in services closing or some treatments no longer being available on the NHS. Disinvestment is sometimes referred to as 'cuts'. 'Decision makers' are those people who currently take decisions about disinvestment and which services are and are not funded by the NHS. Depending on the organisation and the type of decision, these 'decision makers' could be doctors, managers, or more commonly, a combination of both groups.

There are five main stages to the survey and it usually takes around 30 minutes to complete. There are instructions throughout each stage but if you get stuck at any point then click the help button in the top right hand corner and guidance here should assist you.

The five stages of the study are as follows:

• Collection of demographic data: This will help the research team to understand more about the people who have completed the study and to see how representative of Birmingham, as a whole, our group of participants is

• Selection of statements: In this section you will be asked if you broadly agree/disagree with or are neutral about a series of statements relating to public involvement in health care disinvestment decision making

• Refine statements: In this section you will be asked which of the statements you agree or disagree with most. This helps to build a picture of what your personal point of view is

• Checking the grid: In this section you will be shown a grid which demonstrates the order in which you placed the statements and represents your perspective. This section is particularly important because it allows you to see how you have rated each of the statements in comparison to each of the other statements. In addition to this, it gives you one last chance to change the order that you have placed the statements in

• Finding out why: in this section you will given the opportunity to give your reasons for ordering the statements in the way that you did

After you have sorted the statements, your grid will then be combined with the grids of all of the other participants to establish if there are any recurring patterns and to see if they are any shared points of view.

If you need to leave the survey or take a break at any point then simply make sure that you have completed that section of the survey and pressed the 'next' button in the bottom right hand corner.

When you go back to the survey you will then be able to pick up from the last section that you completed

If you would like to view a 1 minute youtube video demonstrating the sorting procedure, or learn more about the tool we are using click here
http://poetqblog.blogspot.com

Your participation in this study is greatly appreciated and any information that you give will be treated in the strictest confidence.

Appendix Six- Coding Structure

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
8	CCG and GP Involvement Advocating for Patients	Decision Making Process	Reasons not to involve the public	Arguments Against Involvement	Question One	GPs and CCGs can advocate on behalf of their patients	No
62	Interest Groups	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Interest groups can have an undue influence over decision making processes	Yes
63	Involving the right people	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Difficult to ensure that the right 'local' people are involved in decision making	Yes
64	Lack of Objectivity	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	The public struggle to see beyond the impact on themselves	Yes
65	Lack of Public Knowledge	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	The public lack the clinical knowledge and knowledge of health systems to contribute	Yes
66	Mixed Messages to the Public	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	The public don't receive clear information, there are always mixed messages and it can be difficult for them to make a choice	Yes
70	Public Can Know Too Much	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Sometimes the public can know too much about how decisions are taken	No
71	Public Disagreements and Discrimination	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Within the 'public' there have been examples of disagreements- they are not a heterogeneous group	Yes
72	Public Expectations	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One and Two	Public involvement can raise expectations unreasonably	Yes
73	Self Interest	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	The public are self-interested	Yes
74	Undesired Outcomes	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Involving the public may produce some unexpected or unwanted outcomes e.g. it may produce illogical outcomes, it may make services less equitable if involvement is not representative	Yes
75	Wrong involvement is worse than none at all	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	If public involvement goes wrong it can be worse than not involving the public at all	Yes
93	Uninformed, Ignorant Public	Public Capability	Public Capability and Desire to be involved	Arguments Against Involvement	Question One	The public are not capable of understanding decisions that need to be made	Yes
95	Public Engagement is Not easy	Public Engagement is Not easy	Reasons not to involve the public	Arguments Against Involvement	Question One	It can be difficult to involve the public	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
99	Hard to Reach Groups	Representation	Reasons not to involve the public	Arguments Against Involvement	Question One	Difficult to secure a representative sample	Yes
101	Usual Faces	Representation	Reasons not to involve the public	Arguments Against Involvement	Question One	The same people keep coming out when we involve the public- not representative	Yes
113	Vested Interests	Vested Interests	Reasons not to involve the public	Arguments Against Involvement	Question One	Opening decisions up to the public allows those with single or vested interests to take part	Yes
120	Involvement Not Necessary	What is public involvement	Reasons not to involve the public	Arguments Against Involvement	Question One	Decisions can be taken in other ways e.g. cost effectiveness- no need for public involvement	Yes
44	Public are ill-informed- NICE	Decision Making Process	Reasons not to involve the public	Arguments Against Involvement	Question One and Question Four	The public are not well informed enough to contribute effectively to decision making	Yes
68	Pace of Decisions, Time Constraints	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Public involvement can slow decision making down- disinvestment needs to be done fast	Yes
69	Potential Erosion of Trust	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	If decisions go against the public then trust can be eroded	Yes
33	Public Involvement not necessary- Individual Service	Decision Making Process	Reasons not to involve the public	Arguments Against Involvement	Question One	There may be no need to involve the public- it's possible that patient involvement might offer better results for instance	Yes
35	Bias towards certain services- NICE	Decision Making Process	Reasons not to involve the public	Arguments Against Involvement	Question One	The public may introduce a bias towards certain services e.g. acute services and away from others	No
78	Disinvestment not necessary	Disinvestment not necessary	Public Capability and Desire to be involved	Arguments Against Involvement	Question One	The public don't always believe that disinvestment is necessary	Yes
59	Can't Make a Difference	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	Involving the public won't change the outcome of decisions that are taken	Yes
60	Costs and Resource Implications	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One and Question Four	Involving the public can be expensive and resource intensive	Yes
61	Fashionable Services	Disadvantages	Reasons not to involve the public	Arguments Against Involvement	Question One	The public prioritise 'fashionable' services	Yes
37	Existing Process is sufficient- NICE	Decision Making Process	current practice/ experience	Experience, Understanding and Expectations	Question Two and Three	The current process for deciding on specific treatments for individual groups i.e. NICE is sufficient and incorporates enough public involvement	Yes
43	Patients not public- NICE	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	Patients should be involved in decision making around individual services/ access for individual groups	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
46	Public not patients- NICE	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	The public, rather than patients, should be involved in decision making around individual services/ access for individual groups	No
47	Public should be informed or consulted- NICE	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	The public should be informed of decisions/ consulted on decisions relating to individual services and access for individual groups	Yes
56	Public Involvement in Process	Decision Making Process	Current Practice/ Experience	Experience, Understanding and Expectations	Does not fit with research questions	Examples of decision making which didn't involve the public but could have benefitted from public participation	Yes
76	Experience of Disinvestment	Disinvestment	Current Practice/ Experience	Experience, Understanding and Expectations	Does not fit with research questions	This code relates to experience of disinvestment and how decisions are currently taken	Yes
90	Patient, Public Feedback into Investment Decisions	Patient, Public Feedback into Investment Decisions	Current Practice/ Experience	Experience, Understanding and Expectations	Does not fit with research questions	Public and patients are involved in making investment decisions	Yes
110	LINK or Healthwatch or other Existing Structure	Statutory Responsibilities	Role of organisations in involvement and decision making	Experience, Understanding and Expectations	Question Two and Three	There are existing organisations set up to involve and gauge public opinion	Yes
114	Carers not Public	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	participants discuss involving carers in discussions rather than the public	Yes
115	Consultation is Involvement	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	Participants understand 'consultation' and 'involvement' to be the same thing	Yes
116	Definition of Public Involvement	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	Participants' definitions of what public involvement is	Yes
118	Genuine Public Involvement	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	Examples of real and 'genuine' public involvement	Yes
121	Not good at involvement	What is public involvement	Current Practice/ Experience	Experience, Understanding and Expectations	Question Two	The NHS is generally not good at involving the public	Yes
122	Patient and Public Involvement Converge	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	Patients are members of the public- they are all part of one group	Yes
123	Patients Not Public	What is public involvement	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Does not fit with research questions	Patient involvement is the same as public involvement	Yes
124	Public Involvement Experience	What is public involvement	Current Practice/ Experience	Experience, Understanding and Expectations	Does not fit with research questions	Examples of participants' experiences of public involvement	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
125	Tokenistic or flawed involvement	What is public involvement	Current Practice/ Experience	Experience, Understanding and Expectations	Question Two	Examples of tokenistic involvement from the experience of the participants	Yes
7	Co Production, Volunteering, Personal Budgets	Co Production, Volunteering, Personal Budgets	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	Involving the public in delivering care and designing their own care is involvement	Yes
10	How Decisions are Taken	Decision Making Process	current practice/ experience	Experience, Understanding and Expectations	Does not fit with research questions	Examples of how disinvestment decisions have been taken in the participants' experience	Yes
11	Consultation- ED	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	Involving the public in disinvestment decisions relating to health system level decisions e.g. ED downgrade should incorporate some form of consultation (or has incorporated consultation in the experience of the participants).	Yes
12	Justification of decisions- ED	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two	Involving the public in health system level disinvestment decision making gives organisations the chance to justify decisions that they have already taken	Yes
24	Difference between theory and practical experience	Decision Making Process	current practice/ experience	Experience, Understanding and Expectations	Question Two	Involving the public is easy in theory - practical experience suggests it is more difficult	Yes
32	Patients not Public- Individual Service	Decision Making Process	Definition of/ understanding of 'public' involvement	Experience, Understanding and Expectations	Question Two and Question Four	Participants refer to the patient involvement, rather than public involvement at an individual service level	Yes
1	Communitarian	Advantages	Motivation for involvement	Motivations for involvement	Question One	Public involvement can help to build a community	Yes
2	Educative	Advantages	Motivation for involvement	Motivations for involvement	Question One	Public involvement can help to educate the public as to the decisions that have to be taken and how they have been taken	Yes
3	Identifies Unexpected Outcomes	Advantages	Motivation for involvement	Motivations for involvement	Question One	Public involvement can ensure that any unintended consequences of decisions are taken into account	Yes
4	Innovative ideas	Advantages	Motivation for involvement	Motivations for involvement	Question One	Public involvement can identify and highlight new ideas that hadn't previously been considered	Yes
5	Instrumental	Advantages	Motivation for involvement	Motivations for involvement	Question One	Public involvement enables the 'right' decisions to be taken and helps ensures that they are accepted	Yes
6	Other Advantages	Advantages	Motivation for involvement	Motivations for involvement	Question One	A range of other advantages e.g. involvement ensures that services deliver what the public want, ensuring services are valued, breaking down clinical silos	Yes
67	No disadvantages	Disadvantages	Motivation for involvement	Motivations for involvement	Question One	There are no reasons not to involve the public	No

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/Description	Sufficient Evidence?
92	Informed Intelligent Capable Participants	Involvement the right thing to do	Public Capability and Desire to be involved	Motivations for involvement	Question One	The public are capable of contributing to decisions	Yes
119	Involvement Gives Credibility	What is public involvement	Motivation for involvement	Motivations for involvement	Question One	Public involvement gives decisions and decision makers credibility	Yes
27	Educational Value of Involvement- Individual Service	Decision Making Process	Motivation for involvement	Motivations for involvement	Question One	Involving the public in decisions around individual services can help to educate them about the ways that the services are delivered and the pressures that they are under	Yes
28	Involvement Gets the Public on-side and gives confidence	Decision Making Process	Motivation for involvement	Motivations for involvement	Question One	Involvement can increase public confidence in decision making organisations	Yes
80	Engagement Provides Reassurance	Engagement Provides Reassurance	Motivation for involvement	Motivations for involvement	Question One	By engaging the public you can help to reassure them and allay any fears about service provision	No
82	Importance of public discussion	Importance of public discussion	Motivation for involvement	Motivations for involvement	Question One	It is important that the public have a say	Yes
85	Involvement the right thing to do	Involvement the right thing to do	Motivation for involvement	Motivations for involvement	Question One	Regardless of outcome/rationale, we should always involve the public	Yes
9	Factors other than public opinion	Decision Making Process	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Other issues should be considered alongside public involvement e.g. quality of care	Yes
15	Impact on other services- ED	Decision Making Process	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Disinvestment decisions at a system level have a direct impact on related services	Yes
53	Multiple Stakeholders	Decision Making Process	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	There are numerous stakeholders within the disinvestment decision making process- the public are just one of them	Yes
54	Opposing views	Decision Making Process	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	There are a range of views (even within the 'public')- they should all be allowed to have a say	Yes
91	Politics	Politics	Influence Over Public	Multiple Voices in Debate	Question Two	Politics and Politicians have an influence over the views of the public	Yes
105	Role of Industry and Academia	Role of Industry and Academia	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Industry and academia have a part to play in disinvestment decision making	Yes
106	Role of Staff in Decision Making	Role of Staff	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Staff have an important role to play in decision making	Yes
111	Third Sector or Charities	Third Sector or Charities	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Charities and third-sector organisations have a role to play in decision making	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
29	Links to other services- Individual Service	Decision Making Process	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Disinvestment decision relating to one service could impact upon other related services, this should be reflected in the decision making process	Yes
86	Local Authority	Local Authority	Multiple stakeholders- public just one group	Multiple Voices in Debate	Question Two	Local authorities also have a role to play in decision making	Yes
87	Media	Media	Influence Over Public	Multiple Voices in Debate	Question Two	Media can influence public opinion	Yes
45	Public need evidence- NICE	Decision Making Process	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	The public rely on strong evidence if they are to contribute to micro level decision making	Yes
16	Information- ED	Decision Making Process	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Regardless of the extent of involvement, organisations have a responsibility to ensure that the public have sufficient information to contribute effectively in decisions around health-system level disinvestment	Yes
20	Still must seek involvement even if public are apathetic- ED	Decision Making Process	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Even if the public are apathetical about becoming involved in decision making, organisations still have a responsibility to make every effort to involve them	Yes
38	Honesty about reasons for disinvestment- NICE	Decision Making Process	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Decision makers should be honest about the reasons and rationale behind disinvestment	No
48	Public unaware of resource constraints- NICE	Decision Making Process	Public Capability and Desire to be involved	Roles and Responsibilities	Question One	Organisations have a responsibility to educate and inform the public of resource constraints	Yes
94	Public Delegate Responsibility to Professionals	Public Delegate Responsibility to Professionals	Public Capability and Desire to be involved	Roles and Responsibilities	Question Two	Public are happy for 'agents' to act on their behalf	No
96	Public Involvement Not Encouraged	Public Involvement Not Encouraged	Role of organisations in involvement and decision making	Roles and Responsibilities	Question One	Organisations discouraged public and patient involvement	No
97	Public Must Make Difficult Choices	Public Must Make Difficult Choices	Public Capability and Desire to be involved	Roles and Responsibilities	Question Two	The public must make tough choices- they need to understand what is required	No
100	Payment, Incentivisation, Making it easy to be involved	Representation	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two and Three	Organisations should encourage involvement by paying participants	Yes
102	Citizen Responsibility for involvement	Responsibility for Involvement	Public Capability and Desire to be involved	Roles and Responsibilities	Question Two and Three	Citizens are responsible for ensuring that they contribute	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
103	Citizen Responsibility for involvement- Public Apathy	Responsibility for Involvement	Public Capability and Desire to be involved	Roles and Responsibilities	Question One, Two and Three	Citizens are apathetical about becoming involved	Yes
104	Organisational Responsibility for involvement	Responsibility for Involvement	Role of organisations in involvement and decision making	Roles and Responsibilities	Question One, Two and Three	Organisations are responsible for involvement	Yes
107	Role of staff in public involvement	Role of Staff	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Staff have a role to play in encouraging the public to get involved	Yes
109	Statutory Responsibilities and Existing Bodies	Statutory Responsibilities	Role of organisations in involvement and decision making	Roles and Responsibilities	Question one, Two and Three	Organisations have statutory responsibilities to involve the public	Yes
112	Transparency and Honesty	Transparency and Honesty	Role of organisations in involvement and decision making	Roles and Responsibilities	Question One	Organisations must be honest about funding and services- they can do that through involvement	Yes
81	Importance of Process and Rationale	Importance of Process and Rationale	Role of organisations in involvement and decision making	Roles and Responsibilities	Does not fit with research questions	Regardless of the outcome, the process of actually making decisions is the most important thing	No
83	Professional Information	Information	Role of staff in involvement and decision making	Roles and Responsibilities	Question Two	Professionals have a responsibility to provide the necessary information to public and decision makers	Yes
84	Public Information	Information	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Public must be provided with the necessary information to make decisions	Yes
88	Need to Show Outcomes of Involvement	Need to Show Outcomes of Involvement	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Public must be aware of how they have influenced a decision and what the outcomes were	No
89	Patient Safety and Quality	Patient Safety and Quality	Role of organisations in involvement and decision making	Roles and Responsibilities	Question Two	Need to be clear about what the impacts of proposals could be on patient safety and quality	Yes
52	Mediating or External Bodies	Decision Making Process	Multiple stakeholders- public just one group	Roles and Responsibilities	Question Two	Other parties should be involved to provide evidence (e.g. cost effectiveness) and to ensure that the process is fair. Decisions can't be made on public opinion alone	Yes
22	Why Public involvement in ED is important	Decision Making Process	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	Certain decisions at the health system level e.g. ED downgrades and maternity closures are viewed differently by the public	Yes
25	Different Approach to Involvement for Individual Service	Decision Making Process	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	Decisions at the Individual service level require a different approach to involvement	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
34	Reasons for service change dictate level of involvement- Individual Service	Decision Making Process	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Two	The level of public involvement in individual service level decision making should be influenced by the reasons and rationale behind the decision- if the decision is about quality rather than cost then they should be involved	Yes
39	Micro level is different- NICE	Decision Making Process	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	Decisions relating to individual patients/ patient groups/ services at the macro level are different from decisions at the macro or meso level, approaches to public involvement should reflect this	Yes
40	Micro Level is not different- NICE	Decision Making Process	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	Decisions relating to individual patients/ patient groups/ services at the macro level are the same as decisions at the macro or meso level, approaches to public involvement do not need to change depending on the level of decision	No
77	Importance of Public Participation in Disinvestment	Disinvestment	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	The public should be, and want to be, involved when services are going to be taken away and this will have direct and indirect impacts on them	Yes
79	Emotive Decisions	Emotive Decisions	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	The public become attached to local services- disinvestment can make the loss more tangible, particularly if they have a link to an A&E department or maternity department for instance	Yes
98	Public Protest	Public Protest	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	High profile' examples of disinvestment have resulted in public protests	Yes
108	Scale of Decision	Scale of Decision	Scale of decision/ nature of decision	Scale and Nature of Decision	Question Four	The scale of the decision affects the extent to which the public should be involved	Yes
13	Early involvement- ED	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Three	The public should be involved early in disinvestment decisions at a health-system level	Yes
14	Existing Structures- ED	Decision Making Process	current practice/ experience	Stage/ Breadth/ Extent of Involvement	Question Two and Three	There are existing organisations and structures in place that are set up to involve the public and to gauge public opinion around health system decisions such as ED closure	No
17	Clean slate- ED	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	Health system issues or problems should be explained in full to the public and they should be given the chance to come up with their own solutions	Yes
18	Options on the Table- ED	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	Decision makers should go to the public with ready-made options and give them the opportunity to discuss them and raise concerns	Yes
19	Patient Not Public- ED	Decision Making Process	Definition of/ understanding of 'public'	Stage/ Breadth/ Extent of Involvement	Does not fit with research	This code relates to discussion of patient involvement in health system-wide disinvestment	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
			involvement		questions	decisions	
21	Token Involvement-ED	Decision Making Process	Definition of/ understanding of 'public' involvement	Stage/ Breadth/ Extent of Involvement	Question Two	Some approaches to involvement fail to give real decision-making power to the public and may be viewed as tokenistic	No
23	Consultation is involvement-Individual Service	Decision Making Process	Definition of/ understanding of 'public' involvement	Stage/ Breadth/ Extent of Involvement	Question Two, Three and Four	Consultation' is seen by participants as being public involvement	No
26	Early Involvement-Individual Service	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Three	The public should be involved early in the decision making process for decisions around individual services	No
30	Options on the table-Individual Service	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	In terms of decisions about individual services, the public should have the full range of options and the outcomes/ consequences of these options available to them when they are involved in decision making	Yes
31	Clean slate-Individual Service	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	When involving the public in decisions about individual services, the issues should be explained to them and they should be given the opportunity to come up with the solutions	No
36	Early and full Involvement-NICE	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Three	The public should be involved early in the decision making process for decisions around individual patient groups, they should also be given the opportunity to be fully involved in decision making	Yes
41	Options on the table-NICE	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	Decision makers should go to the public with ready-made options and give them the opportunity to discuss them and raise concerns	Yes
42	Clean slate-NICE	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Question Four	Decisions at the individual or patient group level should be explained in full to the public and they should be given the chance to come up with their own solutions	No
49	Wide involvement-NICE	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two	The public should be involved as widely as possible in decision making	Yes
50	Wide involvement not practical- NICE	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two	Whilst wide involvement may be desirable it is not necessarily practical	Yes
51	Majority Support	Decision Making Process	Influence Over Public	Stage/ Breadth/ Extent of Involvement	Question One	If the majority support one idea this can influence the public more broadly	No
55	Options on the table or clean slate	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Two and Four	The public should have an opportunity to participate in decision making but opinion is divided as to whether they should be given a set of pre-defined options to choose from or to be allowed to	Yes

Code Number	Level One Coding	Level Two Coding	Level Three (thematic) Coding	Level Four- Revised Thematic Coding	Link to Research Question?	Explanation/ Description	Sufficient Evidence?
						make their own minds up	
57	Rational Involvement Processes	Decision Making Process	Public Capability and Desire to be involved	Stage/ Breadth/ Extent of Involvement	Question Two and Three	There are too many engagement processes- we must find a way to rationally involve the public otherwise they will lose interest- organisations have a responsibility to do this	No
58	Review of Decisions Taken	Decision Making Process	Stage/ Breadth/ Extent of Involvement	Stage/ Breadth/ Extent of Involvement	Question Three	It should be possible to review decisions after they have been taken in light of the impacts on users/ service provision etc.	No
117	Early Involvement	What is public involvement	Definition of/ understanding of 'public' involvement	Stage/ Breadth/ Extent of Involvement	Question Three	The public should be involved in decision making as early as possible	Yes

Appendix Seven- Literature Review Table

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
Abelson, Julia (2003)	Health Policy 2003; 66 (1): 95-106 (October 2003)	Empirical	Does deliberation in health care decision making make a difference to public opinion?	The population for this study was members of the public from Ontario, Canada	The paper is written from a perspective that involvement is a good thing- benefits/ drawbacks are not considered The paper focuses more on the kinds of decision which would benefit from deliberative involvement methods rather than which would benefit from involvement more generally. The paper concludes that deliberation has more of an impact on 'concrete' or tangible issues (e.g. health concerns) than on less tangible concerns e.g. determinants of health.
Anderson, W Florin, D (2000)	BMJ. 320(7249):1553-4, 2000 Jun 10.	Theoretical	How successful have the UK government been in involving the public in decisions about NHS spending?	Not applicable- this is a theoretical paper criticising existing government approaches to public involvement	The public should be involved but the approach taken should not be tokenistic. The consultation process described in the paper is accused of risking 'consultation fatigue' amongst the public and undermining other local efforts. The paper highlights two motivations for public involvement: "the need to ensure the democratic basis of publicly owned health services and the view that user involvement leads to services with better outcomes"- democratic and instrumental benefits The paper discusses public involvement at a national level but is critical of the approach taken. The paper implies that more success has been had at a local level- maybe public involvement should be encouraged at the meso rather than the macro level.
Arvidsson, E André M, Borgquist L, Lindström K, Carlsson P (2009)	Scand J Prim Health Care. 2009;27(2):123-8	Empirical	How do patients/ members of the public in Sweden view priority setting?	GP patients using four health centres in Southern Sweden	The public don't necessarily need to be involved in decision making- decision making authorities/ bodies should have legitimacy but this does not necessarily require actual public involvement. The participants did not, on the whole, accept that rationing decisions needed to be made and were happy for health professionals to make these types of decisions: 72% were considered to be 'not priority oriented'. The participants did, however, demonstrate a lack of trusts in politicians to take decisions on their behalf. This paper questions the public's ability to actually make priority setting decisions and to understand the nature of the problem.
Ayres, PJ (1996)	Social Science and Medicine 1996; 42 (7): 1021-1025 (April 1996)	Empirical	What are the views of GPs on rationing and priority setting?	GPs working within one district health authority in the UK	The article suggests that there may be a role for the public but it is very clear that GPs and professionals should maintain control. Involving the public would make them 'feel better' if they had been part of the debate. Having a public debate ensures that everyone gets treated fairly and there would be no postcode lottery. But, the paper suggests that all of these advantages can come from simply informing the public not necessarily giving them decision making responsibility. In terms of extent of involvement, the public could (possibly) be involved as part of a committee although that committee should have a significant level of clinical and professional input- it is hard to tell how much impact the members of the public would be able to have. Any public involvement would be as part of a committee deciding on which services are and are not available- rationing at the meso level.
Baker, R Wildman, J Mason, H Donaldson, C (2014)	Health Economics 2014: 23 (3) p283-297	Empirical	What are society's shared views on health priority setting?	The population for this study is members of the UK public	The paper is written from a perspective which shows support for involvement from the outset. The important thing to remember is that there is a plurality of views within the public and the full range should be taken into account. The paper discusses the involvement of the public on national panels e.g. The NICE citizens' council and suggests that efforts should be made to ensure that all views are represented. This implies individual members of the public having a genuine say on decision making. However, the broader work on which this research is based is actually concerned with the incorporation of societal values into economic evaluation- this implies that the public should be involved to the extent that their values play into decision making and that decisions are taken on an economic basis.
Bowie, C Richardson, A Sykes, W (1995)	BMJ VOLUME 311 28 OCTOBER 1995	Empirical	Can focus groups be used to consult the public on priority setting decisions? How will the	Two groups of participants took part; one was a representative sample of the public and the other was a sample of GPs	The paper is supportive of public involvement, however, only 24% of the medical sample suggested that they would have faith in the results of the involvement exercise. 10% of the sample suggested that they did not have confidence whereas 66% remained sceptical of the process and remained to be convinced. Involving the public can ensure that services which reflect their values are purchased on their behalf. Local level decision makers are also mandated by the government to involve the public. Public involvement is best suited to value based judgements rather than ones which can be

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
			focus groups work and what do doctors think?	and hospital consultants	resolved through economic and technical analysis.
Bowling et al. (1993)	Soc Sci Med. 1993 Oct; 37(7):851-7.	Empirical	What services do members of the public prioritise? Do public views differ from those of professionals?	The population for this study was GP patients from City and East London practices, UK	Points for and against involvement are raised in the paper. The public have a different opinion to that of professionals, and professionals don't always represent the wants and desires of their patients and the public. Also, as the results show that 'the public' and 'professionals' are not homogenous groups it suggests that they should all be involved to give fair representation. No- what happens if public and professionals don't agree? Who is right? In this case involvement may protract the process. In terms of stage and extent of involvement the paper seems to suggest that health authorities should have an idea what professional opinion is before the public are involved and should know what to do if the public aren't in agreement with professionals. This calls into question how much of an influence the public can have and suggests that, at best, they would either be involved late or simply ratify professional decisions. The paper is not specific about the level of priority setting at which the public should be involved but the prioritisation process that the paper details takes place at the service (meso) level.
Bowling, A (1996)	British Medical Journal, London, vol 312, 1996, p 670-674	Empirical	Which health services do the public prioritise the most?	The population for this study was members of the public from across the UK	This paper is supportive of public involvement, although the majority of participants feel that doctors should make the final rationing decision. Only 17% of people felt that the public should take rationing decisions but 88% of people felt that public opinion surveys should be used in the planning of health services Health authorities are democratically unaccountable bodies so involving the public can help to give their decisions some legitimacy. Involving the public, and working with clinicians, can also help to foster public trust. 88% of participants felt that public opinion surveys should be used in the planning of health services....but only 17% felt that the public should have the most important say in setting priorities. This implies that the public want to be involved but only at a minimal level, maybe as one of a number of stakeholders or maybe by incorporating public values into decision making.
Bradley, N Sweeney, K Waterfield, M (1999)	British Journal of General Practice, London, vol 49, no 447, Oct 1999, p 801-805	Empirical	To what extent do the public agree with the priorities included in the 'health of the nation' strategy?	The population for this study was GP patients from Plymouth and Exeter, UK	The paper suggests that the public can come up with ideas that contribute to health strategy and offer alternatives to the experts, but it also suggests that the public tend to agree with expert opinion. In addition, the paper shows that the public are capable of making wish lists but there is no evidence that they understand opportunity cost or that they are capable of making tough choices. The paper implies that the public could/ should be involved to validate expert opinion or that they should have been involved as part of a wide ranging consultation to start off with. The level of priority setting is unclear but in the paper the public are essentially asked to make a wish list and to contribute to a strategy, this implies high level (macro) involvement. However, the nature of the research asks the participants to set priorities within service areas, this implies involvement at the meso level.
Bruni RA Laupacis A Levinson W Martin DK (2007)	BMC Health Services Research. 7:186, 2007.	Empirical	How are the public involved in setting priorities for investment to tackle long waiting times in Ontario?	The population for this study was decision makers working on the Ontario Wait Time Strategy	Involvement helps you to gain buy-in and public support, only the public/ patients know about their lived experience with illness and the health system, the public have a democratic right to be involved because the health system is public and lastly, because resources are limited the public should be involved to decide how limited resources should be spent to ensure that they are informed about the limits to what can be afforded. However, the public are biased/ self-interested, the public are not interested or motivated enough to be involved, involvement takes too much time and the public are not sufficiently informed/ intelligent to take part. Despite the drawbacks, the paper still suggests that the public should be involved and highlights ways that the risks can be mitigated. The research does note that public involvement is a continuum and that, at the moment, they are at the lowest level by simply informing the public through the website. In the case of the OWTS, the participants suggested that the public could be involved in identifying priorities, setting benchmarks, decision making within panels and selecting targeted service areas. In addition, the paper also suggests a role for the public in deciding whether health should be prioritised over other areas of public spending. This implies that the public should be involved in meso/macro level decision making.
Bruni, RA Laupacis, A Martin, DK.	CANADIAN MEDICAL ASSOCIATION JOURNAL Volume:	Theoretical	Should the public be involved in priority setting decision making?	Not applicable-this is a theoretical piece	Public involvement gives a process legitimacy and fairness, it is democratic, it encourages the public to support decisions (instrumental) and it ensures that decisions are taken with public values in mind. However, the public are not objective, and are not well enough informed, the public do not identify themselves as being appropriate to take part in decision making, those involved in decision making can't be representative and public involvement will lead to a protracted process. Despite identifying these arguments, however, the authors take each one in turn and

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
(2008)	179 Issue: 1 Pages: 15-18		What are the advantages and disadvantages?		suggest that it is not as much of a barrier as may otherwise have been thought.
Campbell, A V (1995)	Bioethics. 9(3-4):252-8, 1995 Jul.	Empirical	If citizens were given the opportunity to influence decisions on the allocation of health resources in New Zealand, what criteria would they opt to use?	The population was citizens in New Zealand	The public are capable of being involved and making far-sighted decisions- however- decision makers should be careful that involvement is not seen as 'softening up' the public. Involving the public can help to deliver a democratic decision making process to make difficult choices. The paper is written in a context where the 'Core Services Committee' take decisions on what services should be provided. This implies that the public should be one of a number of groups who feed into this decision making process- similarly to Nice decision making. The public should be involved in decisions at the meso level. If asked to make decisions at the macro level then the public will ignore the need for rationing and will look to move funding from other departments/ raise the level of finance available.
Chafe, R Neville, D Rathwell, T Deber, R (2008)	Health care Management Forum. 21(4):6-21, 2008.	Empirical	Which key questions must be addressed by decision makers when deciding on, structuring, evaluating and disseminating the results of public engagement exercises, specifically relating to resource allocation?	Two groups of citizens and two of senior health decision makers from Canada	The public should be involved because resource allocation decisions are bound to have winners and losers. Where no legislative guidance is available guidance must come from other sources e.g., stakeholders and society. Involving the public can also increase the transparency and legitimacy of the decision making process, making the health system more responsive to the needs of the public, building and strengthening the organisation's relationship and gauging the public's response to a proposal (i.e. when decision making is still in progress) or building support for a final decision. However, when involving the public there can be significant costs to the organisation and the participants; if the participation goes poorly then the organisation is putting its reputation with the public at risk. There should be some dialogue between citizens and decision makers, and the public must have some influence over the final decision. Public involvement should either greatly influence the decision making process or be the deciding factor in the outcome. Where possible the public should be allowed early and real influence over how the process is structured- The public can't be involved in all decisions so organisations must be selective about which topics are most viable and which questions are most appropriate for involvement. The framework suggests that two broad decision types are particularly well suited to involvement: "Broad service categories"- "Meso-level decisions concerning the allocation of funding across service areas" AND "Socio-demographic circumstances"-"Micro-level decisions about whether a patient's characteristics should influence his or her level of care"
Charles C DeMaio S (1993)	Journal of Health Politics, Policy & Law. 18(4):881-904, 1993.	Theoretical	How can different levels of decision, roles of the public and levels of participation in health care decision making be conceptualised in a single framework?	Not applicable- this paper presents a theoretical framework	The paper highlights a range of advantages/ drivers for and disadvantages/ barriers to of public involvement. Advantages/ drivers: a loss of faith in the legitimacy and superiority of health care professionals to take decisions aligned with increasing awareness of consumer rights, redefinition in the role of government in allocating resources locally, the desire to hold health care providers more accountable, to ensure that decisions reflect community preferences, a push to increase the efficiency of decision making and ensure that local needs are reflected Disadvantages: if one of the purposes of involvement is to deliver improvements in health status then it is unlikely to do this- the public are not well enough informed and this is best left to experts, the public are not well organised enough and their interests are too diffuse to actively press for a decision making role , the public lack the technical knowledge, information and resources to participate effectively. The extent of public involvement depends on the nature of the decision being taken- it could range from being 'informed/ consulted' about a decision through to actually being in control and taking that decision. The paper suggests that the public could be involved in decisions ranging from micro level decisions about 'treatments' affecting individuals to macro level decisions affecting broad populations i.e. Decisions at a national level
Clarke, S Weale, A (2012)	J Health Organ Manag. 2012;26(3):293-316	Theoretical	How can the social values that are used in priority setting decision making be	Not applicable- this is a theoretical paper	Involving the public gives the process legitimacy and the public will have a greater understanding of how decisions have been made- this could ensure that they are more likely to accept decisions. Through public involvement we can gain a clear understanding of social values around process and content. Also the public are affected by decision making and health is a 'vital interest' so the public should be involved. The public/ patients can also contribute to technical arguments and ensure the quality of decisions that are taken. The public offer a wider, more inclusive view than patients'

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
			justified?		Public involvement can make the decision making process cumbersome. Public involvement initiatives can struggle to ensure a representative view- it may be necessary to make special arrangements for some demographic groups. Public involvement could be a way of professionals or elected representatives shirking their responsibilities._ In terms of extent of involvement, the public are mentioned as one of a number of stakeholders and the article discusses social values and the way that priority setting decisions can embody these. This implies early involvement at the value setting stage with others tasked with making the final decision.
Coast, J (2001)	Health Economics. 10(2):159-74, 2001 Mar.	Empirical	What is the nature of the relationship between citizens and agents in the priority setting decision making process?	Two groups were interviewed- one group of UK citizens, one of 'agents' working in decision making clinical or managerial positions	The majority of the public participants were happy to let agents take decisions on their behalf. Some wanted direct involvement but, even then, they sought to reduce the level of individual responsibility. The public want to be involved because decisions are being taken around their services but they recognise the value of societal agents in their knowledge and objectivity. Both groups questioned whether the public have the knowledge and objectivity to play a part in rationing. Citizens are very keen to avoid the 'disutility' of denying care to one group or another- even when they feel that they should be directly involved, citizens seek to minimise their responsibility e.g. by sharing decision making through a large group or using a computer algorithm. The implication from this article is that, if the public do have a desire to be involved in decision making, then they wish to be involved as one member of a larger group in order to remove some of the responsibility for denying care and the disutility associated with this. The influence of the public is further diluted by equivocation and the need for public views to be interpreted so many times by so many different groups before decisions are actually taken- decisions taken at the end e.g. by GPs, Trusts etc. rarely actually reflect societal views or even the approximation of societal views put forward by health authorities. The paper implies that public involvement is probably best suited to macro level decision making and/or to giving general views and values rather than taking specific decisions with visible consequences.
Cookson, R Dolan, P (1999)	Health Policy, Amsterdam, vol 49, no 1/2, Oct 1999, p 63-74	Empirical	Which ethical principles do the public support when rationing decisions are being taken?	Members of the public registered with GP practices in York, UK	The paper suggests that the public are capable of being involved in rationing (disinvestment) decision making. Only 8% of respondents refused to make a decision between the patients in the study on the basis that it was unethical. The paper is interested in establishing the general principles that the public use to ration services. This interest in principles suggest early public involvement in decision making. The examples used in the paper are of individual patients- this suggests that the public are capable of involvement in rationing decisions at the micro level. .
Coulter, A (2003)	Health Expect. 2003 Mar; 6(1):1-2.	Theoretical	How can technical decisions on allocation (e.g. those made using economic approaches) be made more legitimate?	Not applicable- this is a theoretical paper	The public should be involved in decision making; the citizen's council model could be a good way of doing this....but, there should also be a wider public debate on priorities. Public involvement should be sought because technical, cost effectiveness analysis alone cannot necessarily reflect the values of citizens; technical expertise should be supplemented by lay opinion. The public should be involved widely and early in order to influence the values that are used in priority setting decision making. The NICE Citizen's Council used as an example in the paper discusses decisions at all levels e.g. wide scale decisions on the availability of drugs across treatment areas to a large number of patients, right through to decisions on high cost drugs which affected only a handful of individuals
Danis, M Kotwani, N Garrett, J Rivera, I Davies-Cole, J et al. (2010)	Journal of Health Care for the Poor & Underserved. 21(4):1318-39, 2010 Nov.	Empirical	What are the spending priorities of low-middle income residents for tackling the social determinants of health?	The population for this study was residents of Washington, D.C., aged 18-65, with a personal income at or below 200% of the federal poverty threshold, or a household income at or below 200% of the federal poverty threshold for 2006.	The paper starts from a position which suggests the public should be involved. Participants found the process educational and informative and it gave them a sense of the kind of services that are available and the difficult trade-offs that must be made. Involving the public can ensure that services are shaped around the needs and desires of those who use them. It is possible that the decision making process detailed in the paper could allow the public to have a final say, or to be the sole decision makers, however, what seems more likely is that their views and values would play into a larger overall decision making process. In this paper discussions are at a macro level e.g. Making decision between whether to increase spending on education or on health insurance.

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Dixon, J Welch, HG (1991)	Lancet. 337(8746):891-4, 1991 Apr 13.	Theoretical	What can the NHS learn from the Oregon experiment?	Not applicable- this is a theoretical paper considering how lessons from the Oregon experiment could be applied to the NHS	The public should be involved in priority setting and decision making should be made explicit, but decision makers should bear in mind some of the difficulties faced in Oregon. Explicit rationing ensures that that decisions are taken in a systematic way, and it takes decision making pressure of individual physicians Simply having an explicit process will foster public and professional debate on priorities. Implicit methods may result in disparities across geographical areas- this would be avoided with explicit approaches Involving the public can ensures that decisions reflect their preferences but it is difficult to ensure a representative sample which is not biased by personal interests The free market can't be trusted to show what the public truly value/desire therefore they must be involved in decision making However, implicit rationing is more 'politically expedient' and flexible than explicit rationing i.e. decisions/ principles can be changed more easily depending on the situation. In terms of extent, public values should play into the economic/ clinical analysis. This implies early involvement. Broad public values should be used to influence decision making- this suggests very high level priority setting.
Dolan, P Olsen, J A Menzel, P Richardson, J (2003)	Health Economics 12: 545-551, 2003	Theoretical	From what different perspectives can the public view resource allocation decisions?	Not applicable- this is a theoretical paper	The paper is clearly supportive of public involvement but one limitation that it highlights is the self-interest of participants- it suggests that Rawls veil of ignorance could be a way around that. The paper isn't clear about the extent of involvement although the economic preference elicitation techniques used suggest that public opinion could be used as one criteria in a decision making process. Public preferences could be used, for instance, as part of the QALY calculation on top of quality and length of life. The only mention of levels relates to decisions between two individual patients or groups of patients and the paper suggests that the public are uneasy making these decisions. The way round it is to ask the public to 'offer advice to decision makers' rather than telling them that they are actually making the decision.
Dolan, Paul Cookson, Richard Ferguson, Brian (1999)	British Medical Journal, London, vol 318, no 7188, Apr 3 1999, p 916-920	Empirical	Does deliberation (and time) make a difference to the views of the public on how (and by whom) priority setting decisions should be made?	Population was patients from two urban practices based in North Yorkshire, UK	The public should be involved, and using deliberative methods can have an impact on their views. The benefits of public involvement aren't made clear; it is just implied that the public should be involved. After the deliberation exercise, 63% of people felt that the public should have more involvement. This was against 90% of people who felt that doctors and nurses should have more involvement, 20% who felt that NHS managers and pressure groups should and 12% who felt that politicians should. These results imply that the public should be involved as one of a number of stakeholders and that they should be involved to a greater extent than managers, pressure groups and politicians. The research asks the public to prioritise between patients and groups of patients. However, following the rationing exercises in the first week, the public's view of their own importance in decision making fell and their view of NHS Managers rose i.e. their responses to the survey were different in week two to week one. This suggests that, after deliberation, the public were less keen to be involved in micro level decision making.
Donaldson, C Baker, R Mason, H Pennington, M Bell, S et al. (2010)	Online report. Available at http://research.ncl.ac.uk/eurovaq/EuroVaQ_Final_Publishable_Report_and_Appendices.pdf	Empirical	What are the shared viewpoints of the European public and decision makers on values for priority setting?	The population for this study was members of the public from 10 countries: UK, Denmark, Palestine, France, Hungary, Norway, Poland, Spain, Sweden, the Netherlands	This paper is written from a perspective which is supportive of public involvement. The paper suggests that if the range of views within the public are taken into account within the decision making process then it can add legitimacy to the process. However, the paper's findings that actually a lot of the public's views on priority setting are shared with decision makers calls into question two of the main drivers for public involvement i.e. that decision makers do not represent the public's best interests and that the public offer a unique perspective The extent of public involvement is not discussed although the paper is part of a wider research project aiming to incorporate societal values into QALYs so it can be suggested that the paper is promoting public involvement in terms of sharing values.
Doyal L (1995)	Quality in Health Care. 4(4):273-83, 1995 Dec.	Theoretical	How can the moral quality of health care rationing be improved?	Not applicable- this is a theoretical paper	The paper suggests that not allowing the public to participate would be 'morally repugnant' but it then goes on to suggest that the role of the public should be limited to consultation and that decision can be taken without their consent. Public involvement may be seen as 'fashionable' but it cannot overcome the moral dilemmas associated with utilitarian distribution and the majority making a decision which affects the minority. Efforts to involve the public are unreliable and inconsistent- different approaches/ questionnaires etc. can give a different answer to the same question. The public should be involved to the extent of providing information to aid the needs assessment and the evaluation of the different treatment options.

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Doyal L (1998)	Quality in Health Care. 7(2):98-102, 1998 Jun.	Theoretical	How can we make morally fair decisions on health care rationing?	Not applicable- this is a theoretical paper	Yes, the public should be involved in decision making but the role should be limited. This is because the public can't be trusted to make fair decisions and the majority may opt to ration (or disinvest in) services which affect the minority. Also, those who are already ill may be impeded from actually taking part in the first place- this could make their position worse. If the public are to be involved then they should be involved alongside experts. The public should not have the final say on decisions.
Edgar A (1998)	Health Care Analysis. 6(3):193-8, 1998 Sep.	Theoretical	How is 'health' conceptualised by the public in different health care system structures?	Not applicable	The paper suggests that the involvement of the public could influence the way that resources are allocated and also increase support for the health service overall. The paper is not clear about the extent of involvement although it seems to be implied that the public have a right to decide for themselves how services are allocated (e.g. by the state or the market). There is no mention of the role of politicians, health service decision makers etc. The paper implies that the public should be involved almost at a level above 'macro'. The paper discusses involvement in decisions about the fundamental structure of health services and their philosophical underpinnings.
Edgar, W (1998)	Paper for 2nd International Conference on Priorities in Health care, London, 1998	Theoretical	How are the public involved in rationing decisions in New Zealand?	Not applicable	The paper suggests that the public are able to prioritise. Public involvement ensures transparency of decision making, it relieves the moral and ethical responsibility of decision making on health professionals, it makes decisions more acceptable and ensures that needs are fairly assessed and balanced. Involving the public gives the process legitimacy, ensuring that legal requirements are met, making it more likely that decisions will be taken up. Involving the public can ensure that outcomes from the decision making process e.g. guidance are 'user' friendly. The public have different views, when it comes to rationing, to health professionals- professionals can't be relied upon to speak up for the public. However, the public may view involvement as being pointless if decisions do not go their way. Also, 'full' democratic public involvement and decision making is impossible because there are too many views. The public are fickle and their views change regularly, and the range of involvement that is underway and the number of health reforms may have left the public uninterested or disillusioned. Lastly, involvement is expensive, time consuming and resource intensive. The paper is clear that the public are just on stakeholder and their input should be more than just a general view on priorities or principles, they should be asked about specific services or treatments and their feedback should form part of an in-depth evaluation. The paper suggests that the public should be involved at all levels of rationing. The extent of involvement should change dependent on the level.
Fleck LM (1992)	University of Pennsylvania Law Review. 140(5):1597-636, 1992 May.	Theoretical	How can health care rationing decisions be made in a democratic way?	Not applicable- this is a theoretical paper discusses possible approaches that could be taken to involving the public in rationing decisions	The public should be involved as they are current users of services as well as potential futures users. Rationing decisions should be made explicitly- involving the public ensures accountability and ensures that the values that have been used to guide decision making are acceptable to all. The paper implies that the public should decide for themselves the extent of their involvement and how decisions are taken. There is a suggestion that the public should be involved in making actual decisions on funding between services. The public should be involved in rationing decisions between different treatments for particular conditions- this suggests meso level involvement. Where necessary, the public could even be involved in deciding how other decisions are taken e.g. should cost effectiveness analysis be used?
Fleck LM (1994)	Journal of Medicine & Philosophy. 19(4):367-88, 1994 Aug.	Theoretical	What lessons can we learn from the Oregon experiment and how can we use these to forward the rationing debate in the US?	Not applicable	Involving the public (or at least having explicit priority setting processes which are carried out in public) can ensure that rationing is carried out systematically and applies equally to all- this can ensure that is just. Involving the public will make rationing decisions 'self-imposed'. When rationing is carried out explicitly it can help physicians to maintain their moral integrity as both patient advocates and rationers of society's resources. The paper implies that the public should be involved to the extent that they set values which are then used in assessments of which treatments to fund and which to disinvest in. Having said this, the paper is critical of Oregon because legislators were able to 'tinker' with the list of services that were provided and ignore public values to an extent- this potentially suggests that the public should have the opportunity to make decisions without the need for legislators to mediate. Similarly, as the paper is written as an assessment of the lessons to be learnt from Oregon then this would imply that the public should be involved in decisions at the meso level.
Friedman, A (2008)	Bioethics. Vol.22 (2), Feb 2008, pp. 101-112.	Theoretical	What are the criticisms of Accountability for Reasonablen	Not applicable- this theoretical paper is a critique of the existing Accountability	The paper suggests that there should be increased levels of public involvement throughout the decision making process. Without an increased role for public participation 'it is unclear how the process can hope to confer legitimacy on the decisions that it produces, or why it would be fair or reasonable to expect people not to object and fight back with any means necessary' (Page 111). The public should be involved in order to not only help to set the weights for priority setting

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			ess?	for reasonableness framework	criteria but also to contribute towards the actual values underlying the process e.g. What is justice/ fairness? This could partially be done through public deliberation.
Gallego, G (2007)	Health Expect. 2007 Sep;10(3):224-35	Empirical	What are the views of the general public on access to high cost medication in public hospitals?	Individuals members of the public from Sydney, Australia	It is unclear whether the findings suggest that the public should participate. The background suggests that the public should be involved but 50% of respondents actually did not want to take part in the priority setting exercise. The National Medicines Policy (NMP) mandates that the public should be involved Involving the public (rather than patients) can ensure that a wider range of views is taken into account and there is less chance of bias through self-interest. Also, the public may have different views from decision makers and politicians and, as they bear the cost of providing the health services, they should be involved However, half of the participants did not wish to set priorities for high cost medicine expenditure- the paper suggests that this may be to do with the fact that the Australian public are not used to public discussion on spending cuts. Also, the results of the priority setting exercise seem to show the public not setting priorities and dividing their funding equally- this implies an inability to prioritise Overall the research implies that the public should be involved at an early stage to help set the criteria upon which decisions are taken. This research backs up the work by Litva et al. and Wiseman in suggesting that the public want to be involved in priority setting/ rationing up to the point of devising criteria but they don't feel comfortable in deciding between treatments/ patients.
Gallego, G Taylor, SJ Brien, JE (2011)	Australian Health Review. 35(2):191-6, 2011 May.	Empirical	What are the views of decision makers on public involvement in priority setting for decisions around high cost medications taken at the hospital level?	The population for this study was decision makers from across South East Sydney Area Health Services including executive directors of hospitals, area health service managers, directors of hospital pharmacy departments and professors of medicine	Arguments for public involvement: involvement can deliver an accountable, open process with a well-informed citizenry. The public have shown that they want to be involved in priority setting decision making and they bring different values and knowledge to decision making. However, there is not enough time to consult with the public adequately, there is a lack of infrastructure and knowledge within the community, there is a lack of managerial skills and resources to support involvement. It is also difficult to know what the best way to go about involving the public actually is. The public can lack objectivity and view decisions based purely on their own opinions/ needs etc. It is difficult to define exactly who the 'public' are. The public lack the knowledge of the health system and the knowledge of priority setting to be able to participate effectively Public views can be too easily swayed by the media. The public can have great difficulty in accepting limits to health care The findings suggest that the public should be kept informed but they don't suggest that the public should necessarily be involved in decision making as such. The paper suggests that 'consultative and collaborative approaches' to decision making should be considered- this implies that, at least the public should be informed and, at best they should be involved as one of a range of stakeholders alongside decision makers. In terms of level of priority setting, the public should be involved in macro level (government) decisions. Their involvement at the meso/ micro level and in highly technical decisions should be limited
Garland MJ Hasnain R (1990)	Hastings Center Report. 20(5):16-8, 1990 Sep-Oct.	Theoretical	What do Oregon citizens value in terms of health prioritisation and is the 'Oregon Health Decisions' approach to involvement an appropriate way to elicit these values?	Not applicable- the paper is a critique of an existing public involvement model (the incorporation of 'Oregon Health Decisions' views into 'Health Services Commission' recommendations).	The public should be involved in resource allocation decisions. In order to gather technical information, decision makers turn to experts e.g. Clinicians, health economists etc. The only way to gain expert opinion on what the public think is to ask the people themselves. In terms of the extent of involvement, the paper suggests that we could gather public values to help to inform the priority setting process. Final decisions would seemingly still be taken by experts. The paper seems to describe involvement in macro level decision making and quite high-level aims and values. At this stage there seems to be little to suggest that they should be involved in any decisions regarding specific services/ patients
Gold, M (2005)	Health Affairs 2005; 24 (1) 234-239 (January/February 2005)	Theoretical	How have the public been involved at local level in priority setting decisions in the English	Not applicable- this paper is a comment/ think piece	We should look to involve the public because it can have the effect of informing and educating them as well as providing values and ideas upon which to base decisions, and making them responsive to public views. Involving the public can ensure that decisions are considered on a population basis as well as an individual one (i.e. involving patients in decisions about their own care). The approach reported in the paper implies that public views were just one input amongst many, and that decision makers could opt to accept the recommendations of the public report or not. The paper suggests that the public are far more comfortable making prioritisation decisions

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			NHS and can the US learn anything from this approach?		and deciding on new investments- they struggle when asked what service they would stop doing if the new drug in the example were to be funded. The public are also unwilling to make decisions which may have a detrimental effect on one group of patients or another. This implies that they are more comfortable being involved in macro/meso level priority setting than they are in micro level.
Goold S,D (1996)	Journal of Health Politics, Policy & Law. 21(1):69-98, 1996.	Theoretical	How can pluralism of views be incorporated into decision making on health allocation?	Not applicable- this is a theoretical paper suggesting a way in which existing structures and theory could be combined to deliver an effective approach to public involvement	The public should be involved in rationing decision making so as to gain their 'consent'. Involving the public ensures representation, accountability and the capacity for free, equal and reasoned deliberation within the process. Community involvement allows individual views and differences to come to the fore in the decision making process. The public should be represented on local boards alongside other stakeholders including staff and patient group representatives. Local level boards could make 'concrete' decisions about specific funding issues at the meso level and could set guidelines as to how decisions are taken at the micro level rather than actually taking the decisions themselves. Macro level decision making seems to be best left to existing democratic structures with elected representatives taking decisions although the public would obviously be involved as electors.
Goold SD Biddle AK Klipp G Hall CN Danis M (2005)	Journal of Health Politics, Policy & Law. 30(4):563-601, 2005 Aug.	Empirical	Is the 'CHAT' tool a helpful approach in assessing the public's health spending priorities?	Members of the public from North Carolina	The public should be involved and using a deliberative approach like CHAT can educate them and make them understand the nature of the decisions being taken. Involving the public can make rationing decisions self-imposed and provide consent to the rationing that is taking place. Also, the 'citizen involvement in rationing' model can promote an 'activated and motivated citizenry'- this also suggests some societal advantages of involvement. The nature of CHAT implies that the public could make actual spending decisions at the system wide level. The paper suggests that there are two ways in which the public can be used to set priorities the first is the 'consumer sovereignty' approach whereby customers are free to choose the services that they want to use and these are then prioritised i.e. market forces. The second is the 'citizen involvement in rationing model' whereby community opinions are sought and active decisions are taken on the basis of their thoughts.
Goold, S,D Baum, N,M (2008)	BRITISH MEDICAL JOURNAL Volume: 337 Issue: 7675 Article Number: a2047	Theoretical	Where are we in the rationing debate? How is public participation being incorporated into decision making processes?	Not applicable- this is a theoretical paper	Yes, on balance the public should be involved in decision making. Public participation can ensure the legitimacy of the decision making process. The value laden nature of the decisions being taken means that the public must be involved. However, public participation can cloud judgements and can mean that a process finds the wrong answers or avoids difficult prioritisation decisions. It is difficult to ensure representativeness, and the extent to which the public can actually have an influence over decisions that are taken is questionable. In some cases the public actually expect doctors to take on the role of rationer. Studies have shown that the public may be unwilling to ration, and that they may not be capable of taking such difficult decisions. This suggests that the public should be involved, but that doctors should potentially have the final say. The article suggests that it is particularly important to involve the public in more value based decisions- these can't be taken on cost effectiveness analysis alone.
Green, Colin Gerard, Karen (2009)	Health Economics 2009; 18 (8): 951-976 (August 2009)	Empirical	Which health service attributes do the public value most?	Members of the public living in Southampton UK	Public values should play a role in priority setting and disinvestment decision making- public involvement is a policy objective in the UK. The reasons for this are not made clear. In terms of extent of involvement, the public should be involved in setting values and helping to define parameters within which decisions are taken. As this is an economic paper, it probably leans towards technical analysis as the best way to make disinvestment decisions. In this case decisions would be made by experts or decision makers with the only involvement from the public being some influence over values and weightings of attributes. This research was carried out with Health Technology Assessment in mind- this implies that the public should be involved in decisions at the treatment/ service level.
Henshall, Chris Schuller, Tara (2012)	International Journal of Technology Assessment in Health Care 2012; 28 (3): 203-210 (July 2012)	Empirical	Who are the stakeholders in the use of HTA for disinvestment? What are the barriers and how can we overcome them?	Participants at an international HTA forum: leaders and senior managers of for-profit and not-for-profit health organisations with strategic interests in HTA as well as	The public should be involved in decision making The public are more likely to readily accept decisions and understand the need to set limits in order to improve quality and cut spending if the process is open and transparent and they are actively involved from the start. The public may even become an ally in the decision making and implementation process if they are sufficiently involved. The public should be involved alongside patients, clinicians and other stakeholders. HTA gives recommendations to decision makers who can choose to accept these or not- The paper suggests involvement at key points throughout the process including at 'identification', 'prioritization', 'reassessment', 'decision making' and 'implementation' phases.

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				'invited experts'.	
Hofmann B (2013)	Medicine, Health Care & Philosophy. 16(3):349-56, 2013 Aug.	Theoretical	What are the trends in priority setting practice in Scandinavia?	Not applicable- this is a theoretical/ opinion piece written by a Norwegian Bioethicist on the basis of his knowledge and experience	The public should be involved in decision making; involving them can give them an influence, increase public education and make them more accepting of the need to prioritise. But it might be difficult to reach consensus in a large group of powerful stakeholders. Even when decisions have been taken they can still be bypassed on a practical or clinical level. Also, different approaches to public involvement can deliver different results. The public should be involved as one of a number of stakeholders with their thoughts and views being fed into a decision making committee. The public should not be involved at all levels of prioritisation- they do not have the time or the energy. This paper discusses priority setting at the health authority (meso) level and appears to prioritise involvement at that level over others.
Jacobson B Bowling A (1993)	British Medical Bulletin. 51(4):869-75, 1995 Oct.	Empirical	What are the practical and ethical issues related to involving the public in rationing decision making?	Patients of GP practices in City and East London, UK as well as members of local community groups	The paper starts off from a view that the public should be involved but it actually gives a number of arguments against; Difficulty in involving a representative sample of participants- the example that the paper uses is one of a postal survey which received just an 11% response rate. The public lack the necessary information to participate effectively Society and modern values push members of the community towards individualism but involvement in rationing requires a more community focused view- this may be difficult for the public to achieve. Public involvement raises expectations too high It is also difficult to formulate questions that are easy for the public to understand and answer. The example used in the paper is at a meso level, although the paper does suggest that much previous public focus has been on rationing at a micro level. The paper also suggests that the public hold strong opinions on macro-level rationing e.g. between different government departments, but that efforts to involve the public often focus on the meso level.
Kitzhaber, J (1993)	BMJ. 1993 Aug 7;307(6900): 373-7	Theoretical	How were health priorities set in Oregon?	Not applicable- this is a descriptive account of the priority setting process in Oregon	The paper is not clear on exactly why the public should be involved; the implication from this is that the public should be involved because the discussion is around public services and how taxes should be spent- this implies a democratic motivation The paper suggests that the public should be involved in setting values and early priorities but that the final say on decision making should remain with a decision making body. The implication from this paper is that the public should be involved in decisions setting broad priorities e.g. spending on health over education and then looking at priorities at a service level and deciding between specific service categories. This implies public involvement at a macro and meso level.
Landwehr, C (2013)	Contemporary Political Theory (2013) 12, 296–317	Theoretical	How should health priority setting decision be made?	Not applicable- this is a theoretical paper discusses ethical positions and theories of justice that is applicable to health care rationing decision making	The public should at least be involved in making decisions on what the process for rationing decision making should be- procedural justice is more important than distributive justice in priority setting decisions. Involving the public in actually deciding the process by which decisions are taken will ensure procedural justice- in turn this will enable the public to decide the approach to distributive justice that is taken and will help to ensure just outcomes. This implies very early involvement.
Lees, A Scott, N Scott, S, N MacDonald, S Campbell, C (2002)	Health Expect. 2002 Mar;5(1):47-54	Empirical	To what extent does the Priority Scoring Index used to set priorities in Argyll reflect public opinion? And who should be involved in making decisions on health	The population for this study was members of the public, GPs and hospital consultants based in Scotland	Involving the public can help decision makers to share responsibility. However, the public think that the funding problems in the NHS can be solved by raising more money and they are not happy to shift spending from one department to another. This questions the extent to which the public grasp the need for priority setting/ disinvestment. The public should be one of a group of stakeholders involved in making decisions- doctors should have the most influence within the decision making process. The paper suggests that the public don't want to have the responsibility of making actual decisions. The paper states that findings from the research regarding the priorities of the public will be passed on to a decision making body and will be adopted if local stakeholders agree- this implies that, in reality, the influence of the public may actually be quite limited. The public should set criteria for decisions to be made at a meso level- they are unwilling to take decisions themselves at an individual level because they do not want to 'play god'.

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			spending?		
Leichter, HM (1992)	University of Pennsylvania Law Review. 140(5):1939-63, 1992 May.	Theoretical	How can we ensure that the health care rationing process is accountable?	Not applicable-this is a theoretical paper	The paper is supportive of participatory democracy but it actually highlights a number of arguments that have been made against the public being involved in decision making. The public are not well informed enough and do not have enough understanding, time or skills to hold politicians to account. Public involvement is unnecessary because 'the elite' are already well aware of what public values are and actually the values of the community are more in evidence in decision makers (who are better educated) than they are in the citizens. The paper espouses participatory democracy which would see society 'own' decisions that are taken and implies that citizens should be free and able to take the final decision.
Lenaghan J (1999)	Health Policy. 49(1-2):45-61, 1999 Oct.	Empirical	Why involve the public in rationing decisions? Who are the public? How can the public be involved? Are citizens juries an appropriate method for eliciting public values?	The population for this study was UK citizens	The public should be involved because they have a democratic right to be involved, they may offer new insights, and involving them will increase their trust in those taking the decisions and in the service itself. The paper suggests that the public should be involved in setting the values with which decisions are taken. In practice this is likely to mean very early involvement, almost before it has been established that disinvestment needs to take place. This paper suggests that citizens' juries are best suited to setting the values with which decisions are taken, rather than making actual decisions on priorities. Citizens' juries are particularly well suited to setting values at a national level because they are expensive to run; this implies that the public should be involved at a macro level.
Lenaghan, J New, B Mitchell, E (1996)	BMJ. 312(7046):1591-3, 1996 Jun 22.	Empirical	What are the public's views on how health priorities should be set? Are Citizen's Juries an effective way to elicit these views?	Members of the public from Cambridge, UK	Public involvement should be encouraged because it can allow decisions to be challenged and ensures that decision makers are accountable for their decisions. In addition, it ensures a more transparent process with more clarity over who is making decisions. The public should be involved in setting general values e.g. Distributive justice and should help to decide on the process- this implies early involvement, although the paper also suggests that making decisions based on a number of pre-existing options could be a good way to use citizens' juries. The public should be involved as one of a number of stakeholders and the health authority can decide for themselves whether they follow public recommendations (although they should justify any decision not to follow the public). The public should be involved in high level decisions, setting the values for priority setting but not necessarily making decisions between individual services or patients.
Litva, A Coast, J Donovan, J Eyles, J Shepherd, M et al. (2002)	Social Science & Medicine. 54(12):1825-37, 2002 Jun.	Empirical	Do the public have a desire to be involved in priority setting at different levels?	The population for this study was citizens of two localities (one 'middle class', one 'working class') within a health authority region in the UK.	This paper suggests that the public should be involved in priority setting decision making, but only in decisions at a level at which they feel comfortable. Instrumentalist benefits; the public can defend their own goals and promote them. This may ensure that they are more firmly behind the final decision that is taken Communitarian; by involving the public decision makers can ensure that the services that are provided represent the needs of the community. Involvement may also help to build that community. Educative; it can help to educate the public about how and why decisions are being taken. Involvement can be an end in itself and can teach participants about the democratic process Expressive: involvement allows the public to express their own political identity and belonging The public are happy to be involved at the 'system' and 'programme' level but not in decisions at the 'individual' level. At the system and programme levels the public wished to be 'consulted' and to provide constructive and creative solutions to problems but they did not wish to have the final decision making say- they felt that health professionals were paid to carry out that role. At the individual patient level, the public were not keen to be involved in decision making and they were happy to set values and criteria early and then to leave decision making up to professionals.
Lomas, J (1997)	Journal of Health Services & Research Policy. 2(2):103-11, 1997 Apr.	Empirical	From what different perspectives can the public view resource allocation decisions?	Not applicable-this is a theoretical, descriptive paper	The paper suggests that the public should be involved but that it is vital for decision makers to give careful consideration to the type of decision that they are taking and what role it would be most important for the public to take e.g. taxpayer, collective community decision maker or patient. Involving the public can share decision makers' 'pain' In their role of (potential) 'patient', the public can view decisions under the veil of ignorance and have more of a grasp on the consequences of the decisions that they take. However, in the role of current patient, the public lack objectivity and focus too much on the services that they use. In many cases the public (as taxpayers) are reluctant to be involved in rationing decisions

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					and, at times when funding is reducing i.e. when disinvestment is required, it may be more beneficial not to seek public involvement as they may seek increased funding/ funding transfers rather than understanding or accepting the need to prioritise. Citizens are unsure whether they have the requisite skills and abilities to contribute to decision making. Public and professional values differ- the public value high cost, high technology treatments more- they 'orient to the the dramatic rather than the effective'. Efforts to involve the public have shown significant difficulty in ensuring that a representative sample of citizens participate. The public could be involved (in their role as patients and under the 'veil of ignorance') in setting limitations relating to socio-demographics e.g. age, lifestyle. They should not, however, have a say on clinical rules. There is little desire to change the democratic process whereby politicians act on behalf of the electorate e.g. taxpayers are involved using the ballot box. Where they do have a desire to be involved, the public wish to add their values into the mix. They do not want to take the final decisions. The public should be consulted as one stakeholder amongst a number of interested parties. The public, in their role as collective community decision makers, are best suited to making decisions at the broad service category level (meso level). In their role as patients they are suited to setting socio-demographic criteria which could be used to make decisions between individuals (micro level) and in their role as taxpayers they are best suited to high level decision making (macro level).
Martin, Douglas Abelson, Julia Singer, Peter (2002)	Journal of Health Services Research and Policy 2002; 7 (4): 222-229 (October 2002)	Empirical	How do participants in priority setting committees think that these committees should be set up? What roles should be included in an ideal process?	The population for this study was members of priority setting committees in Ontario, Canada	Involving the public increases the legitimacy of the decision making process and ensures it is just. The public should be involved as part of the decision making committee right from the start of the process. The role of the public should be clearly defined and they should have real influence- the paper is critical of much of the rest of the literature which seems to promote consultation. The paper is not clear about which specific types or levels of priority setting decisions the public should be involved in although there is an implication that all decisions should aim for what A4R would view as a fair process i.e. the public should be involved in all priority setting decisions.
Mason, H Baker, R Donaldson, C (2011)	Journal of Health Services Research and Policy (2011), 16 (2), pp.81-89	Empirical	What features of health care interventions, including the type of health gain, are important to members of the public and why?	The population for this study was members of the public from North East England.	This paper is written from a perspective which supports public involvement in decision making- the paper is concerned with what the public value in terms of health gain, rather than whether or not they should be involved. The paper is concerned with the incorporation of public values into QALY calculations. This implies early involvement but also suggests that public views could be incorporated into decision making alongside other evidence and considerations- this is not, however, clarified in the paper. There is also no clear message on types of decision but the incorporation of public values into QALYs implies involvement in macro or meso level decisions, but not micro level decisions.
May, J (2008)	International Journal of Market Research 2008 vol.50 no.2 p319-338	Empirical	Can market research methods be applied to a problem of public involvement in health priority setting?	The population for this study was existing members of the citizens panel of Barnet PCT, UK and representatives of local patient groups	The public should be involved; involvement can help to avoid the twin evils of the 'postcode lottery' and decisions being taken by 'faceless bureaucrats'. The paper also highlights the legal obligation that decision makers/ commissioners have to involve the public. This paper is more interested in how to involve the public, than whether or not to involve them. There is an implication in the paper that the public could and should be included in the final decision making process, and that they should be presented with options by health professionals. The public seek 'accountable consultation' where their views are heard and where decisions taken are fully explained to them. They want to know that they can make a difference and see a link between their views and the outcome but they do accept that decisions may not always go in their favour. The author suggests that the public should be involved early in the decision making process and that a potential way forward could be for the public to take decisions on whether or not services are 'meritorious' before further work is carried out (presumably by experts) to establish how cost effective they are. The research implies that the public should be involved in decisions at the service level (i.e. They should be able to make decisions on funding between individual services).

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McIver S (1995)	British Medical Bulletin. 51(4):900-13, 1995 Oct.	Theoretical	How can public information relating to priority setting and rationing be improved?	Not applicable- this is a theoretical paper	The public should be involved; as patients/ service users they can ensure that the services that are provided are what is needed and can suggest new and innovative ways to provide services. Increased public involvement can enable the public, as taxpayers, to ensure equity in the provision of services and ensure fairness in rationing at a local level. In terms of extent of involvement, the paper suggests that the public should be properly involved in consultation and information provision should be improved to enable this. This implies that the public should be informed of decisions/ should have some opportunity to feedback but should not have decision making power. The paper discusses rationing decisions although it suggests that the kind of decisions that the public typically become involved in are issues such as hospital closures- this implies that the public have more desire to be involved in decisions linked to disinvestment and that they are more suited to macro level decision making.
McKie, J Shrimpton, B Hurworth, R Bell, C Richardson, J (2008)	Health Care Analysis, vol 16, no 2, Jun 2008, p 114-126	Empirical	Who should be involved in priority setting at different levels?	The population for this study was members of the general public and health professionals in Victoria, Australia.	Involving the public in an open discussion can allow for options to be considered that have never been suggested before, it can allow all participants to consider their own views in light of the other participants and can ensure that decisions are reached that are in everyone's interests. The public should be involved alongside a number of other stakeholders- clinicians, politicians, ethicists, health administrators etc. The paper suggests that the public should be involved in devising a set of rules by which decisions are made, rather than being involved in each and every decision- this implies early involvement in decision making. In this paper, the level of decision making is not considered to be as important as the group of people who are involved in the process. In this sense it could be suggested that the public should be involved in any kind of health prioritisation decision. In reality, the difference between the findings of McKie et al. and other findings (e.g. Litva) may not be so great because the respondents in this paper suggest that they should be involved in decision making as one group amongst a number of others so it is unlikely that they would make a final decision.
Meetoo, D (2012)	British Journal of Nursing. 22(7):372-6, 2013 Apr 11-24.	Theoretical	Should the public be involved in priority setting decision making? From a nursing perspective, what are the advantages and disadvantages?	Not applicable- this is a theoretical piece	Public Engagement (PE) creates an informed citizenry, generates new ideas, increases the probability of implementation, increases public trust and confidence in the system, fosters global communication and the generation of global viewpoints. The public are the funders and users of the health system and are, therefore, a key stakeholder, and is legitimate and right for them to be involved. Greater PE also corresponds with the principles of democracy and can ensure that 'higher quality' decisions are made. Barriers/ arguments against (note that these are discounted in the paper) - the public are not objective or knowledgeable enough, it is impossible to gather a representative sample of the public, members of the public don't consider themselves to have an important role to play, failure to act on advice from the public can result in anger and cynicism, involving the public will lead to a protracted decision making process. The paper suggests a number of ways in which the public could be involved in priority setting decision making: - As representatives on priority setting committees - As representatives on executive committees and boards -As members of citizens' councils to provide ongoing advice on specific matters - As participants in surveys, citizens juries, community meetings and focus groups to provide feedback on all aspects of priority setting
Menon, D Martin, D Stafinski, T (2007)	Health Policy 2007; 84 (2/3): 220-233 (December 2007)	Empirical	What steps are taken in the health care priority setting process in Alberta, Canada?	The population was board members of regional health authorities in Alberta, Canada and also members of three expert priority setting committees.	The public should be involved in priority setting in order for the process to be considered fair under A4R. Providing an opportunity for the public to feedback can make decisions easier to implement- this is an instrumental motivation for involvement. At the minimum there should be an opportunity for the public to provide electronic feedback after a decision has been reached- this is very late involvement. In terms of levels of priority setting and types of decision, there is no 'one size fits all' approach. Different organisations should consider their own approaches to involvement depending on the types of decision.
Mitton, C Patten, S Donaldson, C Waldner, H (2005)	Healthc Q. 2005; 8(3):49-55.	Empirical	What is the current experience of priority setting amongst senior administrators and clinicians in Calgary?	Senior level managers and clinicians involved in the priority setting process in the Calgary Health Region	The paper generally implies that the public should be involved (and that respondents want them to be involved) but that decision makers need to find an appropriate way in which to do this. Public engagement can deliver 'buy-in' for the choices being made. The public should be involved as the service is publicly funded. However, the public are not always well informed enough to understand the need for limits and rationing. Also, politics and the media highlighted public attention on to technology-intensive procedures and less expensive, potentially more effective options were ignored. The public lacks the expertise to make decisions on 'treatments'. The public should be involved as one of a number of stakeholders (e.g. Ministry of health, medical staff etc. should also be involved); they should be involved in setting criteria and values in the region rather than in actually making treatment decisions. The paper is written about public involvement at the macro level of priority setting but also

456

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
					shows some support for involvement at the meso level.
Mitton, Craig Smith, Neale Peacock, Stuart (2011)	Evidence and Policy 2011; 7 (3): 327-343 (August 2011)	Empirical	How can public input be integrated into priority setting decision making alongside other information/ knowledge?	Not applicable-this is based on a scoping review of the literature	Public involvement in priority setting is 'both desirable and valuable'. The public should want to be involved and they feel that their views should be heard. Involving the public can have an instrumental benefit in terms of the quality of decisions that are taken. The public may offer new information about their preferences, about the local context or about community capacities that can help to inform decisions. Also, public involvement can have an intrinsic value in itself- it can help to create a more active citizenship and develop the capacities of individuals within society. In terms of extent of involvement, depending on the decision making process, decision makers may wish to call on different scientific or expert evidence to integrate with the public values. The paper suggests that it is rare for the public to be called upon to make a final decision and reiterates other findings that, at most, they are usually just one of a number of stakeholders.
Mitton, Craig Smith, Neale Peacock, Stuart Evoy, Brian Abelson, Julia (2009)	Health Policy. 91(3):219-28, 2009 Aug.	Empirical	What is the state of knowledge/ literature on public involvement in health care priority setting?	Not really applicable- 'participants' were essentially papers sourced from eight academic databases	It is implied that public involvement is to be encouraged but it is not stated explicitly. The review suggests that the literature does not provide a clear consensus on the extent to which the public should be involved, neither does it provide guidance on the most effective means of involvement, although it does note that public views are very rarely the only information taken into account when making decisions. The scoping review suggests that the vast majority of public involvement takes place at the macro level. It is suggested that this is because there is a lack of willingness for the public to become involved in decisions which may affect individual services or individuals.
Mooney G (1998)	Social Science & Medicine. 47(9):1171-80, 1998 Nov.	Theoretical	Can priority setting be viewed from a community perspective e.g. can the community set priorities for the benefit of the community, rather than individuals setting priorities for their own benefit?	Not applicable-this is a theoretical paper	Yes, the community should determine what constitute 'claims' on resources and what the relative strengths of these 'claims' are. Involving the public may bring a different view and apply different values. Also participation as part of a community may be beneficial in its own right for citizens; it could help to build the community. Taking decisions on a communitarian basis would ensure that 'agents' e.g. decision makers acted on behalf of the community sticking to the rules that are set. The paper suggests that the 'community' (public) should set the principles under which decisions are made and influence the process but not take decisions themselves. Participants set the rules by which decisions are made and then only intervene if decision makers break these rules. This paper implies very high level public involvement- involvement at a level actually above macro level.
Mooney, G (2005)	Soc Sci Med. 2005 Jan;60(2):247-55	Theoretical	How can communitarian claims be incorporated into the priority setting decision making process?	Not applicable-this is a theoretical paper	Public involvement can give more credibility to decisions taken through economic analysis Involvement in decision making can have utility in itself. Individuals value being part of a society and contributing to that society and its goals. Involving the community in decision making can ensure that all interests and individual circumstances within that community are taken into account. Citizens have the long term interests of the organisation and health service at heart (they use it and pay for it). Individual decision makers lack 'credible commitment' because they only think about their own service or area. Decision makers should maintain the final say over resource allocation but they should make decisions with community values in mind. The paper calls for incorporation of public values into the PBMA process; this implies that they should be involved mainly at the macro/meso levels.
Mossialos, E King, D (1999)	Health Policy, Amsterdam, vol 49, no 1/2, Oct 1999, p 75-135	Empirical	What are the views and attitudes of the public regarding health care rationing?	European households (households were continually selected at random until at least 1000 surveys were returned) in Germany (East	The public should be involved; they are capable of overlooking self-interest and can put the community first. Public involvement can help to ensure acceptance of difficult decisions. Rationing by physicians alone is inconsistent (different individuals prioritise in different ways). There are statutory obligations to involve the public. Involvement increases transparency and accountability and helps to educate the public about issues involved in decision making. However, the media can unduly impact upon the views of the public- as can politicians. The public can, at times, be self-interested. The public are, in some countries, less familiar with the need for rationing and don't necessarily agree that it is required. The public lack the necessary knowledge and information to participate. Public views are context dependent, and they depend on their own experiences and situations. It is difficult to ensure

457

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
				and West), France, Italy, the Netherlands, Britain and Sweden	representation from across the community. The public should be involved as one stakeholder in a group of stakeholders (the most important view coming from doctors). This implies that public values should be played into a wider decision making process. Questions relating to macro and meso level decisions suggest that the public should be involved. There is a question relating to an individual patient and who should decide whether or not she receives treatment (question 5) but this was not included in the analysis due to statistical difficulties.
Mullen, P (1999)	Health Expect. 1999 Dec; 2(4):222-234.	Theoretical	What approaches are available for eliciting the values of the public in health care priority setting?	Not applicable- this is a theoretical piece looking at methods that could be used for public involvement	Public involvement is viewed by some as being axiomatic- this paper takes the view that it is desirable and focuses its attention on the most appropriate methods to involve the public. There isn't a 'one size fits all' approach to involvement. Decision makers must consider what they want to achieve- do they want a single or multi attribute (stage) approach, do they want constrained or unconstrained choices, do they want participants to be able to display the intensity of their choices, do they want to be able to aggregate their findings to wider society, and is it important for the process to be transparent (according to Mullen, it is not always desirable for processes to be transparent). Decision makers should make their own decision on process depending on what they want to get out of it- this implies that they could use different processes/ extents of involvement for different levels of priority setting
Murphy, N, J (2005)	Health Expectations 2005; 8 (2): 172-181 (June 2005)	Theoretical	Can citizen deliberation help to illicit values for priority setting? How can it be improved?	Not applicable- theoretical paper applying Taylor's theory to four existing studies	Involving the public can help to guide policy makers to prioritise health expenditure in a way which 'responds to health inequalities associated with social contexts' i.e. Citizens know what causes health inequalities and they can help to direct funds. The paper suggests that by involving members of the public, priorities can be set in such a way as to empower citizens to experience 'self-mastery' and take more responsibility for their own health. In terms of disadvantages, the paper suggests that the public can struggle to overlook self-interest and that they are bound to make decisions with their own subjective experiences in mind. It suggests, however, that this can be overcome through effective deliberation (i.e. following Taylor's theory)
Nelson, JL (1994)	Journal of Medicine & Philosophy. 19(4):333-42, 1994 Aug.	Theoretical	Should 'grassroots' decision making be an integral part of the rationing decision making process?	Not applicable- this is a theoretical paper considering a number of perspectives on 'grassroots' involvement in decision making	Involving the public can help to remove bias towards powerful groups in society, make individuals less 'self-interested' and more likely to act for the good of the community as a whole. Involving the public/ publicising the process can ensure 'fair co-operation' and mutual advantage amongst interested parties, it can protect the autonomy of those parties, foster stable social arrangements, promote truth and honesty, facilitate critical assessment of social arrangements and protect due process (Fleck, 1990). The public face dilemmas every day and are capable of dealing with rationing. However, the public aren't capable of taking tough decisions where one life is seen to be given more value than another. Involving the public might debunk some 'social myths' such as the myth that society is egalitarian- this could challenge the spirit of community. Public involvement could make us less scrupulous about the value of life and more willing to trade it off in ways that were 'insufficiently examined and justified'. The public may view trade-offs in an over simplified way. The public should not be left with the responsibility to take final decisions. Public involvement should be considered as one part of a wider theory of just rationing, with careful thought given to the types of decision that the public should be involved in and why we are seeking their input.
Norheim OF (1999)	BMJ. 319(7222):1426-9, 1999 Nov 27.	Theoretical	Health care rationing- are additional criteria needed for assessing evidence based clinical practice guidelines?	Not applicable- this is a theoretical paper	The paper highlights two motivations for public involvement....' it enhances public accountability and that it secures a wider representation of interests so that conflicts between different values or preferences can be explored and considered.' The paper seems to suggest a fairly low-key role for the public and that they could be involved to quite a small extent- they could be represented indirectly in the decision making process by, for instance, staff who know their views. Alternatively, they could be included as part of a wider consultation amongst multiple stakeholders. The paper suggests that public involvement at all levels of decision making is not practical, although it does not state which levels it should be carried out at. The paper is written in the context of a rationing decision affecting one individual patient but it perhaps suggests that involvement at a higher level might be more practical (although this is unclear)
Obermann, K Buck, DJ (2001)	The European Journal of Health Economics, Vol. 2, No. 3, 2001	Theoretical	Can the issue of rationing health care be clarified by dividing rationing processes into two	Not applicable- this is a theoretical paper	Involvement allows for public scrutiny of decisions, it forces decisions that are taken by authorities and individual physicians to be audited, it prevents secrecy and is in line with developments to ensure democratic patient involvement and reduced paternalism in medicine However, systematic knowledge of rationing could undermine shared social values and confidence in the medical profession. It may also challenge the public's notion of equity across society, of security at times of illness and the idea that they will always receive the highest possible standard of care. It has been argued that too much knowledge of rationing

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			group-systematic e.g. decision taken in a standardised way, such as cost effectiveness analysis and non-systematic e.g. decisions taken by clinicians on a case by case basis?		processes may be detrimental to the public and that there may actually be benefit or a 'utility of ignorance' in not having full knowledge
Obermann, K Tolley, K (1997)	Obermann, K. and Tolley, K. (1997), The State of Health Care Priority Setting and Public Participation, Centre for Health Economics Discussion Paper 154, University of York	Empirical	How are priorities currently set in English health authorities?	The population for this study was the chairs of all health authorities in England, Wales and Scotland	Results from the survey suggest that the public should be involved in priority setting; involvement can increase accountability and ensure that services are better suited and more appropriate to local needs. In terms of extent of involvement the paper suggests that there should be increased input from a wide range of sources, including the public. Other sources include non-fundholding GPs, patients and Health Economists. The paper discusses the different services that the public are currently involved in decisions on and suggests that the public are less likely to be involved in more technical services e.g. intensive care or clinical, scientific and diagnostic services. They are more likely to be involved in services like maternity or mental health
Owen-Smith, A Coast, J Donovan, J (2010)	Journal of Health Services & Research Policy. 15(1):14-20, 2010 Jan.	Empirical	Is explicit rationing desirable to patients and health professionals?	The population for this study was health professionals working in teaching hospitals in a city in England and patients of services that had been 'rationed'.	Patients want to know about rationing, and the alternative to involvement (implicit rationing) is disempowering and paternalistic. If rationing is explicit, at least patients know that potential treatments may be available and they can appeal the decision or seek treatment elsewhere. Explicit rationing would give patients the opportunity to challenge decisions However, rationing care explicitly may be distressing for the patients and for clinicians- it is sometimes in the patient's best interests not to be explicit The paper implies that the patient should be made aware of decisions that have been taken but not necessarily involved in the decision making process. In many cases, this research seems to show that guidelines were set out of the control of clinicians and that 'explicit' rationing would only really entail letting patients know that services were being denied and letting them know what the appeals process could be. In terms of level of priority setting, this paper relates to micro-level decision making. The decisions in question relate to rationing of services to the participants themselves- the fact that they wish to be informed/ involved in rationing decisions involving them could imply that they would also be willing to be involved in rationing decisions involving other people and other patient groups although this is a difficult leap to make.
Redden, CJ (1999)	Journal of Health Politics, Policy & Law. 24(6):1363-89, 1999 Dec.	Theoretical	What are the different approaches that could be taken to involving the public in rationing decision making?	Not applicable- this is a theoretical paper discusses a range of approaches that have been/ could be taken to involve the public in priority setting and rationing decision making.	The public should be involved because they are losing trust and faith in governments to make tough decisions. Also, health care is now being seen more and more as a right, and the public feel like they must contribute to decision making in order to maintain it. Public involvement can increase transparency and openness. The paper suggests that, in Canada, the public are often involved to the extent of either electing members of health decision making boards or nominating themselves to become part of these boards alongside other stakeholders. Once elected these boards have the opportunity to take far reaching decisions and can have an influence right from setting values through to final decisions. In the US example (Oregon), the public were involved firstly as part of a committee to decide on the general principles of medicaid provision and secondly as part of a prioritising exercise to decide exactly which treatments should be provided. Similarly, the range of levels of priority setting in which the public could/ should be involved depends on the decision making context- different geographical areas have taken different approaches. However, caution should be given to public involvement in actual prioritisation of services because this may throw up unexpected results and anomalies-

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					may be they should set the principles/ values but should not have the final decision.
Richardson A (1997)	Journal of Management in Medicine. 11(4):222-32, 1997.	Empirical	What are the public's values regarding health care rationing? Are the public capable of contributing to the debate?	Population was local citizens from Somerset, UK	The public are willing and capable of discussions of highly complex and contentious issues and can understand the limitations within which the NHS is working and weigh their views accordingly. The paper suggests that the public should be involved in discussions under active consideration by the health authority- this implies that the public become involved later rather than earlier. In terms of extent of involvement, the public should not be the sole arbiter but they can make a real contribution to the debate. The paper encourages public involvement in 'value based judgements' although it is not clear at what level these judgements/ priority setting decisions should be taking place.
Richardson, A Charny M, Hanmer-Lloyd S (1992)	BMJ. 1992 Mar 14; 304(6828):680-2.	Empirical	What are the views of the general public on health priority setting?	The population for this study was members of the public from Bath, UK	The paper highlights a range of arguments. Arguments against involvement- the public are not informed enough and they may have different priorities from the professionals. Also, the paper suggests that the public may not actually want to become involved in disinvestment decision making (58% of respondents agree that decision should be left to doctors and experts). On the positive side, the public do want to have more of an influence over decisions (65% agree that they should have more of a say) and they are capable of making trade-offs. Level of priority setting isn't discussed in the paper although the examples used in the question are at the meso and macro level.
Richardson, R Waddington, C (1996)	International Journal of Health Planning & Management. 11(4):307-15, 1996 Oct-Dec.	Theoretical	What issues should be considered when deciding whether or not to involve the public in rationing?	Not applicable- this is a theoretical paper	This paper suggests that decision makers should show some caution before involving the public. The public can be swayed in the making of emotive decisions by the media and interest groups. The public may be unable to look beyond the individual patient and consider wider public values
Roberts, Tracy Bryan, Stirling Heginbotham, Chris (1999)	Health Expectations 1999; 2 (4): 235-244 (December 1999)	Empirical	Is the QALY Maximisation model a good predictor of public responses to health priority setting choices?	The sample was selected by MORI, a polling company, and was demographically consistent with the population of a health authority in the South East of England	The public should be involved because decisions are being taken on a societal level- society should have some input. Also, the empirical work shows that the public have a different view from that which is typically taken by economists, so involving them would add something to decision making. Public views should be played into economic analysis, they should not replace it. Essentially, this could mean that public views could, and possibly should, contribute to economic analysis at whichever level it takes place. This could include micro, meso and macro level decision making.
Robinson S Glasby J Allen K (2013)	Health & Social Care in the Community. 21(6):614-22, 2013 Nov.	Empirical	What can be learned from decision makers' experiences of decommissioning older people's services?	12 Directors of Adult Social Services in England who had been highlighted nationally as having extensive experience of home closures	Yes, the public should be involved in decision making and should contribute alongside other stakeholders. Public involvement can give the decision making process transparency and legitimacy. The public should be involved early on in the process alongside other stakeholders. This paper specifically discusses disinvestment decisions around the closing of care homes. It implies that the public should be involved at the meso level.
Rosen, P (2006)	Health Policy. 79(1):107-16, 2006 Nov.	Empirical	Does providing the public with information on health priority setting and allowing them to	The population for this study was members of the public in the Skane region of Sweden	The public themselves (84% in this survey) felt that they should be involved in decision making. Public involvement gives the decisions that are taken legitimacy. Public involvement ensures that funds are spent on what the public/ patients actually want and it can ensure that spending is more efficient. Having an open and transparent decision making process ensures justice. The paper does implies that the public feel that they should be involved in setting overall values or priorities for expenditure more widely but that they do not wish to be involved in the actual decision making.

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
			participate in meetings with decision makers have an effect on the views, values and expectations?		
Russell J Greenhalgh T Burnett A Montgomery J (2011)	BMJ. 342:d3279, 2011.	Theoretical	How much public involvement is there on IFR (individual funding request) panels?	Not applicable- this is a short commentary piece	The paper is broadly in favour of public involvement on IFR panels. Involving the public can improve both the quality and legitimacy of decisions. Lay members can bring common sense and life experience to the decision making table. The paper discusses affording lay members of panels 'observer' status, although it suggests that this is not sufficient and that current efforts to involve the public could actually be considered 'tokenistic'. The paper suggests that there should be wider scale public debate about the financial situation facing health services and the tough decisions that need to be taken. This paper suggests that there has been a lack of public appetite for involvement in panels because of the adverse effect that their decision could potentially have on the individual patients. Despite this, the implication of the paper is that there should be increased involvement at the micro level.
Sabik, LM Lie, RK (2008)	International Journal for Equity in Health 2008, 7:4	Theoretical	What can be learned from priority setting experiences in a selection of countries? Which has the most successful process?	Not applicable	Priority setting experiences in the UK, Israel, New Zealand and Oregon have demonstrated success and public acceptance having been led by experts and only minimally involved the public It remains 'unresolved' how extensive public involvement in priority setting decision making should be...full public discussion and open, transparent deliberative processes have yet to be achieved. Public acceptance of decisions can be gained through discussion of the outcomes of a process with the opportunity to appeal the decision. This suggests that simply informing the public could be enough.
Shickle, D (1997)	Bioethics. 11(3-4):277-90, 1997 Jul-Oct.	Empirical	What are the key themes to come out of efforts to involve the public in health prioritisation?	Not applicable- this paper used combined existing studies	In favour of public involvement: public guidance can greatly assist in the process of purchasing health care- this implies that 'better' decisions are taken because of public involvement. The public have different views to clinicians and managers, therefore it cannot necessarily be said that public views/ interests are represented by professionals. However, different studies have shown different public preferences- lack of consistency. The public don't necessarily feel that they should be involved in decision making or may not want to be involved. The paper suggest that the public should "assist (in) the process of purchasing health care." This implies that public values should be used to guide decision making. The level of decision making is not discussed in depth but the studies from which the themes emanated are based predominantly at the meso level.
Stewart, E (2013)	J Health Serv Res Policy April 2013 vol. 18 no. 2 124-126	Theoretical	What is the point of citizen participation in health care? What are we trying to achieve but involving the public?	Not applicable- this is a theoretical paper	The paper suggests that we should not automatically assume that public participation is a good thing. Policy makers and decision makers should be clear about specifically why they wish to involve the public - is their motivation consumerist, democratic or 'new social movement'. Involving the public for the sake of it, without a clear motivation or rationale in mind and without a clear approach could result in a flawed process which doesn't achieve the intended outcomes.
Street, J Hennessy S Watt A Hiller, J Elshaug, A (2011)	Int J Technol Assess Health Care. 2011 Oct;27(4):376-83	Empirical	Can analysis of web content give an understanding of the way that disinvestment is framed by the media and what community perspectives	The population was effectively web content provided by the media and members of the public	Expressed community views tend to be polarised. Web analysis did provide a good range of public views and discourses around disinvestment but in order to understand more widely held views it may be necessary to seek public input rather than waiting for them to post. The public should be involved in disinvestment decision making, particularly in decisions which provoke emotional responses e.g. valued or entrenched services. By monitoring reaction to decisions/ media articles, this paper seems to suggest that the public could be involved at a late stage- certainly after initial ideas have been formulated. In terms of 'type' of decision, it is particularly important to gauge the socio-political environment when taking decisions on highly valued or entrenched services.

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
			are?		
Tenbensel T (2002)	Health Policy. 62(2):173-94, 2002 Nov.	Theoretical	What is the role of 'mediating' bodies in incorporating public views into priority setting decisions?	Not applicable- this is a theoretical paper	Yes, the public should be involved but only if there are sufficient systems in place to ensure that their input is interpreted effectively. There is an instrumental benefit in involving the public-priority setting is easier for policy makers to achieve if the public are involved in the process. Also, priority setting inevitably involves value judgements which can't be worked through with technical analysis alone. The paper seems to suggest that the public should be involved early but that the amount of influence they can have is actually decided by others- if a mediating body is necessary then the public must input to them early in the process, the mediating body can then decide how much influence public opinion has.
Theodorou, M Samara, K Pavlakis, A Middleton, N Polyzos, N et al. (2010)	HELLENIC JOURNAL OF CARDIOLOGY Volume: 51 Issue: 3	Empirical	What are the views of members of the public and doctors in Greece on roles in priority setting?	The population for this study was employees of organisations in the Attica Perfecture region of Greece	The public feel that they should be involved in decision making....but they feel that other groups e.g. doctors and patients that should have a more important say than them. Involving the public would allow for 'real health needs and expectations' to be taken into account. The paper also suggests that the public should be involved because decision makers and priority setters are unsure of what public preferences are. In terms of extent of involvement, whilst the public felt that they should be involved in decision making at all three levels, they did rank themselves 5th out of 7 groups to be involved in prevention programmes and 6th out of 7 in both medical procedures and population groups. This implies that they feel that there are other groups whose input is far more important in all of these decisions (this is doctors or patients in all cases). The doctors also agree that there are more important groups than the public that should be involved in decision making (doctors ranked the public 5/7 for prevention programmes, 6/7 for medical procedures and 5/7 for population group programmes). The results imply that the public should be involved as one stakeholder amongst a large group. In terms of level and type of decision, the public felt that they should be involved in all three types of decision that they were questioned on but the proportions in favour varied: prevention programmes- 82.7% support for public involvement Medical procedures- 70% support Programmes for different population groups- 83% support
Ubel, PA (1999)	Kennedy Institute of Ethics Journal. 9(3):263-84, 1999 Sep.	Theoretical	Are current approaches to measuring community values appropriate for health priority setting?	Not applicable- this is a theoretical paper	The public should be involved in priority setting because service providers must ensure that the services that are on offer are what their patients want to use and are in line with their values. However, different approaches to measuring the values of the community have yielded different results. It could be implied from the paper that, because of the differing results yielded from different approaches, there is an argument against public involvement i.e. that the public lack consistency in their views. The paper is not clear about extent or timing of involvement, although it discusses measuring community values which implies early involvement in high level decision making. This also implies that public values should be used to inform the process but that the public should not be involved in actual decision making.
Walker RL Siegel AW (2002)	Health Economics. 11(3):265-73, 2002 Apr.	Theoretical	Should Societal Value Preferences (SVPs) be incorporated into Cost Effectiveness Analysis (CEA)?	Not applicable- this is a theoretical paper	No, societal values should not be incorporated into economic analysis at this time (i.e. until a more effective way to incorporate them or a more convincing argument has been put forward). There is a lack of clarity in the relationship between societal values and moral principles. For instance, at what stage would societal values become too morally objectionable to be incorporated into economic analysis? E.g. what is society suggested rationing care for over 75s? This could be considered to be morally objectionable If moral values can overrule SVPs then why do we need to measure SVPs at all? Can't we just incorporate moral values straight away? As processes for gathering societal values aren't currently democratic i.e. they don't include everyone, just a small sample, they can't be procedurally just.
Watson, Verity Carnon, Andrew Ryan, Mandy (2012)	Journal of Public Health 2012; 34 (2): 253-260 (June 2012)	Empirical	What attributes for health services do the public prioritise using discrete choice experiments?	The population for this study was members of the public from Dumfries and Galloway, Scotland	Individuals have a right to participate in the decision making process; the public bring different knowledge to the process and providers should be accountable to their communities. Failing to involve the public can lead to decisions which lack transparency and accountability. The public seek 'accountable consultation', whereby they are involved in the decision but are not actually responsible for making it: "the public are comfortable being involved at the organization level but want doctors to make decisions at the patient level. We sought public involvement at the organization level, to ensure the priority setting process reflected the values of the Dumfries and Galloway population, but the responsibility for the decision remained with the organization (as is required by legislation)." (Page 258)

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
Watt, Amber M Hiller, Janet E Braunack-Mayer, Annette J Moss, John R Buchan, Heather et al. (2012)	Implementation Science. 7:101, 2012.	Empirical	How can wide stakeholder engagement be incorporated into the disinvestment decision making process?	Two Australian case study examples are described. Different stakeholders are involved in each. In ART the groups were consumers, clinicians and the community. In B12 they were just clinicians and the community.	Yes, the public should be involved as one of a number of stakeholders. Involving the public can help to balance out the vested interest of single issue consumer and special interest groups, it can also help to add diverse knowledge and experience to the decision making process. The public should be involved in an advisory capacity along with other stakeholders. The public should be provided with systematic review evidence on the effectiveness of a treatment and its cost efficiency and, along with the other stakeholders, they should be given the opportunity to express their thoughts on whether public funding should be provided or not. These thoughts should then be shared with policy makers (alongside the systematic review evidence) and they can make the final decision.
Williams et al. (2013)	Leadership in Health Services, Vol. 27 Is: 1, pp.5 - 19	Empirical	To what extent is the combined World Café/ 21st Century Town Meeting approach effective in involving the public in priority setting?	UK Citizens including those who use services e.g. mental health users and deaf patients, and individuals who participate solely as taxpayers.	Public involvement through deliberative methods can have an educative impact and enable the public to understand how and why decisions must be made. But, we must show the impact of involvement if it is to be as effective as possible. This approach used in the paper involves the public at an early stage to help to define the overall principles for priority setting. This suggests using public involvement to define values rather than to actually make decisions. The approach described asks participants to decide on overall priority setting principles e.g. prevention or treatment- this implies involvement at the macro level, or possibly even at a higher level than that.
Wilmot, Stephen Allan, Clare Ratcliffe, Julie (2004)	Journal of Health Services Research and Policy 2004; 9 (1): 7-13 (January 2004)	Empirical	Are the public capable of taking part in rationing/ health priority setting in a fair and rational way?	The population for this study was members of local community groups in Derby, UK	The paper starts from a position which is in favour of public involvement in disinvestment/ priority setting decision making; they have a democratic right to be involved. The paper seems to imply that the public could/ should be involved late on in the process and could be asked to make a final decision. In the exercise detailed in the paper the participants were asked to choose between four patients; this suggests that the public are capable of being involved in such difficult micro level decisions and that they can take a rational and objective view.
Wiseman V Mooney G Berry G Tang KC (2003)	Social Science & Medicine. 56(5):1001-12, 2003 Mar.	Empirical	Do the public feel that they should be involved in priority setting at different levels? Which other groups do they feel should be involved?	Not applicable- this is a short commentary piece	The public should be involved but only as one group amongst a number of different stakeholders. Public involvement can be valuable in its own right i.e. It can help build communities and increase education/ awareness etc. The public have a democratic right to contribute to decision making, it can help to increase available resources (in developing countries) and can offer cost effective solutions. Involvement may offer innovative solutions and may make providers think carefully about the way they provide services. Involvement can ensure that services are culturally sensitive and greater public scrutiny can ensure improvements in the quality of services provided. The public should be involved at all levels of decision making although they are more comfortable being involved at the level where priorities are set between population groups and between health care programs and feel that clinicians and managers should have the most important say in decisions around medical procedures and treatments
Wiseman, V (2005)	Applied Health Economics and Health Policy. Vol.4 (2), 2005, pp. 129-137.	Empirical	Should the public be involved in priority setting decision making? What are the views of the public themselves and health	Members of the public attending GP surgeries and health care professionals with responsibility for allocating funds. All of the population lived/ worked	Both health professionals and the public themselves feel that they should be involved in decision making. Involving the public can broaden the value base upon which priority setting decisions are taken. The public (and patients) are in the best position to place a value on different treatments and interventions. Involving the public shares the burden and responsibility of decision making and helps to ensure a fair process which can instil trust in decision makers and help to build long term relationships. Involving the public allows for a more transparent process and the outcomes are more readily accepted by the public. Involving the public gives the process legitimacy and transparency.

Author	Source	Article Type	Question addressed	Research Population	Main Findings Relevant to Research Q's
			professionals?	in Sydney, Australia	The public can and should be involved in health priority setting at all levels although the research does show that, amongst the public, there is less support for public involvement at the medical procedure level than at the population group or health programme levels.
Zwart, H (1993)	Health Care Analysis. 1(1):53-6, 1993 Jun.	Theoretical	How can we overcome the tension between liberalism and communitarianism in health care rationing?	Not applicable- this is a theoretical piece	The public should be involved in decision making as individuals within a society. Each individual should take responsibility for making realistic decisions relating to their own aspirations and their own life course. The medical profession should act in accordance with these wishes. It is not the community's position to set limits on what could and should be expected of each individual and to set an age limit as to when interventions should be withdrawn- this should be deliberated over by individuals.

Appendix Eight- Study Participant Information

Participant No.	Professional Background	Type of Organisation	Disinvestment Experience?	Factor Exemplar?	Interviewed in Phase Two of Study?
1	Management/ N.E.D	Other e.g. National body	Yes	No- Confounded	
2	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Advocates of Involvement	
3	Clinician- AHP	Commissioning Organisation	Yes	No- Confounded	
4	Management/ N.E.D	Commissioning Organisation	Yes	No- Confounded	Yes
5	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Cautious Supporters	
6	Clinician- AHP	Provider Organisation	Yes	No- Confounded	Yes
7	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Cautious Supporters	
8	Clinician- Medical	Provider Organisation	Yes	Yes- Advocates of Involvement	
9	Clinician- Nursing	Other e.g. National body	No	Yes- Advocates of Involvement	Yes
10	Clinician- Medical	Commissioning Organisation	Yes	Yes- Advocates of Involvement	
11	Clinician- Medical	Provider Organisation	Yes	Yes- Advocates of Involvement	Yes
12	Clinician- Medical	Commissioning Organisation	Yes	Yes- Cautious Supporters	Yes
13	Clinician- Medical	Provider Organisation	Yes	No- Confounded	Yes
14	Management/ N.E.D	Provider Organisation	No	Yes- Cautious Supporters	
15	Clinician- Medical	Provider Organisation	Yes	Yes- Advocates of Involvement	
16	Management/ N.E.D	Commissioning Organisation	Yes	No- Confounded	Yes
17	Clinician- Nursing	Provider Organisation	Yes	Yes- Advocates of Involvement	Yes
18	Clinician- AHP	Provider Organisation	Yes	Yes- Advocates of Involvement	

19	Management/ N.E.D	Provider Organisation	Yes	Yes- Advocates of Involvement	
20	Clinician- AHP	Provider Organisation	No	Yes- Advocates of Involvement	
21	Clinician- Medical	Provider Organisation	No	No- Confounded	
22	Management/ N.E.D	Commissioning Organisation	No	No- Confounded	Yes
23	Clinician- Medical	Provider Organisation	No	Yes- Advocates of Involvement	Yes
24	Clinician- AHP	Provider Organisation	Yes	Yes- Cautious Supporters	Yes
25	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Cautious Supporters	
26	Clinician- Nursing	Commissioning Organisation	Yes	Yes- Advocates of Involvement	
27	Clinician- AHP	Provider Organisation	No	Yes- Advocates of Involvement	Yes
28	Clinician- AHP	Provider Organisation	No	No- Confounded	
29	Clinician- Nursing	Provider Organisation	No	No- Confounded	
30	Management/ N.E.D	Commissioning Organisation	Yes	No- Confounded	Yes
31	Management/ N.E.D	Other e.g. National body	Yes	No- Confounded	Yes
32	Clinician- Medical	Provider Organisation	No	Yes- Advocates of Involvement	
33	Clinician- AHP	Provider Organisation	No	No- Confounded	
34	Clinician- Medical	Provider Organisation	Yes	Yes- Advocates of Involvement	
35	Clinician- Nursing	Commissioning Organisation	Yes	No- Confounded	
36	Management/ N.E.D	Other e.g. National body	Yes	No- Confounded	
37	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Cautious Supporters	
38	Management/ N.E.D	Commissioning Organisation	Yes	No- Confounded	Yes

39	Management/ N.E.D	Commissioning Organisation	Yes	No- Confounded	Yes
40	Management/ N.E.D	Provider Organisation	Yes	Yes- Cautious Supporters	
41	Management/ N.E.D	Commissioning Organisation	No	No- Confounded	
42	Clinician- Nursing	Provider Organisation	Yes	No- Confounded	
43	Clinician- Medical	Other e.g. National body	No	Yes- Advocates of Involvement	Yes
44	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Advocates of Involvement	
45	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Advocates of Involvement	
46	Clinician- Nursing	Provider Organisation	Yes	No- Confounded	
47	Clinician- AHP	Provider Organisation	Yes	Yes- Freedom of Choice	
48	Clinician- Medical	Provider Organisation	No	Yes- Advocates of Involvement	
49	Clinician- Medical	Provider Organisation	Yes	No- Confounded	Yes
50	Clinician- Medical	Provider Organisation	Yes	Yes- Cautious Supporters	
51	Clinician- Nursing	Provider Organisation	Yes	Yes- Cautious Supporters	
52	Clinician- Medical	Commissioning Organisation	Yes	No- Confounded	
53	Clinician- Medical	Provider Organisation	No	Yes- Cautious Supporters	
54	Management/ N.E.D	Commissioning Organisation	Yes	Yes- Advocates of Involvement	Yes
55	Clinician- AHP	Provider Organisation	Yes	Yes- Freedom of Choice	Yes

Appendix Nine - Literature Review Data Extraction Form

Title of Paper	
Name of Author(s)	
Source of Paper and year	
What are the main arguments in the literature item?	
Is the paper specific to one country or are the findings/conclusions relevant internationally?	
What are the key concepts/theories introduced by the author?	
What are the key questions answered by the literature item?	
Does the literature item support public involvement in disinvestment decision making?	
If public involvement is supported, why? If not, why not?	
If the public should be involved, then to what extent?	
If the public should be involved, then at what stage in the process?	
Are there any particular types of decision which require greater public involvement?	
Are there any underlying assumptions influencing the author's views on public involvement?	
Are the conclusions supported by empirical evidence?	
If so, who were the participants in the research and what was the method of data collection?	

Appendix Ten- Literature Review Thematic Analysis

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Healthcare is different	Health is different from other commodities	Community Interest	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Health is a conditional good	Health is different from other commodities	Community Interest	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Health is a vital interest	Health is different from other commodities	Community Interest	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Public involvement is the right thing to do- it ensures fair allocation across society	The 'right' thing to do	Community Interest	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Legal duty to consult the public	The 'right' thing to do	Community Interest	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Public want to participate	Public Desire	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Intrinsic value of involvement	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Involvement can help to builds communities	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Involvement encourages less self-interest	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Communitarianism- viewing health from the community perspective	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Involvement encourages Community Responsibility	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Involvement encourages Active Citizenry	Wider Benefits of Involvement	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Public involvement debunks social myths	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
The public will prioritise their own needs over the common good of the community	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Involvement disproportionately affects minorities	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
			whole
Public can know too much	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
'utility of ignorance' - better not to know	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Involvement causes moral dilemma for participants	Unforeseen Societal Consequences	Societal Benefits/ Consequences	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Burden of responsibility	Benefits of shared responsibility	Risk and Reward of Shared Responsibility	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Decision Makers need public support	Benefits of shared responsibility	Risk and Reward of Shared Responsibility	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Decision Makers Competing demands	Benefits of shared responsibility	Risk and Reward of Shared Responsibility	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Organisation Reputation Risk	Risk of sharing responsibility	Risk and Reward of Shared Responsibility	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Tokenistic Involvement- reputational risk	Risk of sharing responsibility	Risk and Reward of Shared Responsibility	Health disinvestment decisions affect the whole community; public involvement in these decisions can offer a number of benefits to the community as a whole
Raised Public Expectations	Importance of Approach	The right approach is vital	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Organisational Motivations for Involvement	Importance of Approach	The right approach is vital	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Flawed Involvement	Importance of Approach	The right approach is vital	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Inconsistency in Public Involvement	No 'one size fits all'	The right approach is vital	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Unique Organisations	No 'one size fits all'	The right approach is vital	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Deliberative Involvement Favoured	Deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Large Scale Questionnaires and Surveys	Non-deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Prevalence of Discrete Choice Experiments	Non-deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Oregon Ranking	Non-deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Citizens Juries	Deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Deliberative Approaches	Deliberative Involvement	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Priority Setting Boards-Drawbacks	Non-deliberative involvement- Priority Setting Boards	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Priority Seting Boards-Responsibilities	Non-deliberative involvement- Priority Setting Boards	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Priority Setting Boards-Advantages	Non-deliberative involvement- Priority Setting Boards	Range of Options	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Outcomes of Involvement	Publicity Condition	Poor Implementation of Involvement	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Informing as Involvement	Publicity Condition	Poor Implementation of Involvement	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all
Legitimacy of Involvement Processes	Publicity Condition	Poor Implementation of Involvement	There is no 'one size fits all' approach to public involvement in priority setting, but poorly implemented public engagement is worse than none at all

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Positive Public Views on Involvement	Public Should Make Decisions	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Positive Professional Views on Involvement	Public Should Make Decisions	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Public Preference for Doctors	Others Should Make Decisions	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Extent of Public Influence	Understanding of Level of Responsibility	Understanding of Role	The public should be involved in disinvestment decision making because they want to be involved
Rationing or priority setting	Understanding of Priority Setting	Understanding of Role	The public should be involved in disinvestment decision making because they want to be involved
Levels of Priority Setting	Understanding of Priority Setting	Understanding of Role	The public should be involved in disinvestment decision making because they want to be involved
Micro Level Decisions	Understanding of Priority Setting	Understanding of Role	The public should be involved in disinvestment decision making because they want to be involved
Lack of Public Willingness to be Involved	Others Should Make Decisions	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Public Lack Skills to Participate	Public Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making because they want to be involved
Public View Depends on System	System Factors	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Rate of Change	System Factors	Public do/ do not want to be involved	The public should be involved in disinvestment decision making because they want to be involved
Public Understand the Need to Disinvest	Public Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making because they want to be involved
Public do Not Understand Need to Disinvest	Public Do Not Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making because they want to be involved
Public Not Priority Oriented	Public Do Not Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
			because they want to be involved
Organisational Paternalism	Public Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making because they want to be involved
Public Understand Opportunity Cost	Public Have Ability to Contribute	Propensity to Prioritise	The public should be involved in disinvestment decision making because they want to be involved
Public Have Different Views	Decision Makers Acting for Public	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Decision Makers Do Not Speak Up for Public	Decision Makers Acting for Public	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Range of Views on Priorities Amongst Public	Risk of Involving Public	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Range of Views on Priorities Amongst Professionals	Value of Public Views	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Link between public and decision maker views	Decision Makers Acting for Public	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Public support for utilitarianism	Risk of Involving Public	Wide Range of Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Technical Means of Gathering Public Views are Insufficient	Risk of Involving Public	Risk of Involving Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Balance between social values and moral principles	Risk of Involving Public	Risk of Involving Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Cultural Sensitivity	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Life Experiences	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Experience of Service Use	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Innovation offered by public	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Potential or current service users	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Involvement increases efficiency	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
			represented
Decision Makers as Agents	Decision Makers Acting for Public	Decision Makers Acting for Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Professional knowledge and experience	Decision Makers Acting for Public	Decision Makers Acting for Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Education of decision makers	Decision Makers Acting for Public	Decision Makers Acting for Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Decision Makers act responsibly	Decision Makers Acting for Public	Decision Makers Acting for Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Involvement allows decision makers to avoid responsibility	Risk of Involving Public	Risk of Involving Public	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Public Have Lost Faith in Decision Makers	Value of Public Views	Value of Public Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Public Views Clouded by Media	Risk of Involving Public	Influences over Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented

Level One- Descriptive Coding	Level Two Coding- Thematic Coding	Level Three- Revised Thematic Coding	Level Four- Propositions
Public Views Influenced by Politicians	Risk of Involving Public	Influences over Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Public Favour 'fashionable' services	Risk of Involving Public	Influences over Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented
Public Views are Changeable	Risk of Involving Public	Influences over Views	The public have a different view from health professionals and decision makers- they should be involved because otherwise their views would not be adequately represented