

LINKING RISK COMMUNICATION AND BIOMEDICAL ETHICS: THE CASE OF PRE-
IMPLANTATION GENETIC DIAGNOSIS

by

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Abstract

The fundamental objective of this thesis as a collective work is to contribute to the interdisciplinary body of research that seeks to integrate the fields of bioethics and risk analysis. The goal was to move risk communication beyond procedural ethics to focus on substantive ethics or the values that guide such strategies. The research study discussed here includes three phases: (1) interviews with a heterogeneous collection of experts to determine the risks and benefits that pre-implantation genetic diagnosis (PGD) may pose to individuals, groups, and society; (2) mental model interviews with lay citizens to determine shared misconceptions and background knowledge of PGD; (3) and a series of risk communication experimental workshops with lay citizens informed by phase 1 and 2 findings.

Phase 1 employed a novel method of eliciting expert judgment by incorporating the views of conventional (e.g., physicians) and unconventional experts (e.g., lived experience of disability) relevant to PGD technology. The approach is based on the mental models method as described by Morgan and colleagues (2002). In total, 8 experts were interviewed individually to protect the diversity of expressed views. All were shown 3 charts based on an extensive literature review. This process allowed for qualitative feedback capable of incorporating a range of discrete skills sets and communication styles. The final products of the interview process were a revised series of charts (3 revised originals plus 2 additional charts) that illustrated technical, personal, and value-oriented messages communicated by those deeply engaged in PGD research.

The lay mental model interviews were conducted with 16 citizens. As anticipated, most were not familiar with PGD technology but were familiar with IVF, which must occur in conjunction with PGD. This finding is significant as IVF and PGD share many risks and benefits. Important misconceptions were also identified that were ultimately corrected during the workshops. For example, interview participants had a very difficult time anticipating the stakeholders of PGD and the full multi-scalar outcomes of this technology. Many also assumed that users of PGD technology were infertile. Understanding the multiple scalar nature of PGD is vital to understanding the full array of risks and benefits posed by this technology. It is also important for citizens to understand that users of PGD technology are submitting themselves to the risks of IVF although they are not infertile and could have their own biological children in most cases.

The deliberative workshops represented a holistic approach to risk communication. In total, 57 individuals were recruited to participate in 1 of 8 workshops. Randomly assigned participants in half of the workshops (Treatment B) viewed structured decision making (SDM) materials in the form of consequence matrices (informed by phase 1 expert results) while the others did not. Results showed that workshop participants were very successful in learning a wide range of value and technically-oriented risk messages. However, those who received SDM training were better able to make ethical decisions concerning risk communication strategies for PGD technology. This finding underscores the value of including SDM materials in communication strategies for ethically contentious issues.

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Dedication

This thesis is dedicated to my thoughtful committee members Tim McDaniels, Michael McDonald, and Susan Cox, my parents Marguerite Longstaff (nee Gibb) and John Longstaff who are both deeply committed educators, and my partner Joey Mikawoz who has always encouraged me to pursue my career with great passion. I also dedicate this work to my informal mentor Michael Burgess.

Co-authorship statement

Each manuscript included in this thesis was authored solely by Holly Longstaff including the identification and design of the research program, performing the research, data analyses, and manuscript preparation.

Chapter one: Linking risk communication and biomedical ethics: the case of pre-implantation genetic diagnosis

Introduction

In March 2009, the US based *Fertility Institutes* suspended their pre-implantation genetic diagnosis (PGD) eye and hair colour program due to media backlash and public outrage. In a statement appearing on their website the Institute explained that “*Though well intended, we remain sensitive to public perception and feel that any benefit the diagnostic studies may offer are far outweighed by the apparent negative societal impacts involved*” (The Fertility Institutes, 2009). Pre-implantation genetic diagnosis is the process of screening fertilized human embryos during in vitro fertilization (IVF). In Canada, the process is typically used to screen embryos for chromosomal abnormalities or specific genetic conditions or select embryos that are tissue matches for sick siblings. Using PGD for non medical purposes such as sex or hair colour selection is frequently viewed as controversial due to obvious eugenic inferences. However, the ethical issues associated with this new emerging reproductive technology are much more complicated and far reaching than they may initially appear. Pre-implantation genetic diagnosis is a *systemic hazard* comprising a wide range of obscure risks and benefits for individuals, groups, and society at large. Communicating information about this technology therefore poses special challenges for risk communicators.

The fundamental objective in this introductory chapter is to explain the unique contributions of this thesis in terms of the topic that is addressed and the methods used to

analyze it. It begins by explaining why emerging systemic hazards like PGD deserve our attention in the field of risk communication.

Topic domain: systemic hazards

Issues falling under the rubric of *systemic hazards* in the life sciences have the ability to modify living things and therefore foster change at “breathtaking speed...on an unprecedented scale” (OECD, 2003). Analyses of such hazards must therefore stretch beyond conventional probability assessments and cause and effect predictions to involve examinations of “interdependencies and relationships between... risk clusters” (Renn & Klinke, 2004). Many hazards have systemic elements or effects. For example, alcohol consumed during pregnancy may result in a child with health impairments (family scale) who requires long term assistance from publicly funded health care and other social systems (societal scale). However, systemic hazards do not merely involve multiple scales or difficult tradeoffs between individuals and groups. There is the potential for them to have a fundamental effect and even permanently change (Joy, 2000) society’s most vital systems (e.g., health, environment) (OECD, 2003). Systemic health hazards such as biotechnology, nanotechnology, or global climate change are unlike other contained hazards in that they cross multiple domains (i.e., economic, regulatory, social, ethical, technological). They are also associated with both normative and interpretative ambiguity and thus often lead to uncertain outcomes for a broad range of stakeholders at multiple scales (Renn, 2006) (see section on PGD below for examples).

Norms are temporally bound and may become ambiguous if the application to which they apply evolves (e.g., applying conventional safety standards to substantially equivalent novel products), public attitudes towards that application change, or information about the application decreases or increases (e.g., new risks or benefits are discovered).¹ However, it is unclear how novel technologies such as PGD connect with existing social and ethical norms, if at all. Strong normative standards help experts determine socially desirable management options. Yet, with normatively ambiguous problems, experts may have difficulty predicting what is in the best interests of a diverse society (Tansey and Burgess, forthcoming) as the bounded rationality of experts cannot always detect norms embedded within the social rationality of laypeople (Perrow, 1984).² In some cases, a *single interest* that all individuals within a society share may not even exist³ while at other times, uncertainties may lead to explanatory complexities. Interpretative ambiguity occurs when it is unclear as to how the consequences of a potential hazard will be experienced by stakeholders at various scales (individuals, groups, society at large). Managing these types of topics as an extension of conventional hazards may foster ethical controversy and public outrage. Emerging health hazards therefore require interdisciplinary approaches to risk communication that blend intellectual contributions from both the bioethics and risk analysis communities. Risk analysis can address many issues surrounding these hazards including predicting probabilities and anticipating

¹ Potential hazards can become controversial when generally accepted norms are used to guide the management of novel applications or products through imperfect analogies and norm borrowing.

² For example, this type of mismatch led to a moratorium of the BC salmon aquaculture industry in 1995.

³ There may be times when it is morally appropriate to treat certain groups differently. For example, in Canada, special guidelines have been developed for conducting research with citizens of First Nation and Inuit descent. For more on this please see Section six of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans or TCPS (Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 1998) and the CIHR Guidelines for Health Research Involving Aboriginal People (CIHR, 2007). Chapter 9 of the Draft 2nd Edition of the TCPS is also dedicated to research involving Aboriginal peoples (Interagency Advisory Panel on Research Ethics, 2008).

interdependent relationships between risks and benefits. Risk research can also offer guidance on communicating difficult information about systemic hazards. Bioethics principles and approaches can be used to decipher normative and interpretative ambiguities and illuminate key values that may help to determine the best interests of a diverse society.

Pre-implantation genetic diagnosis: an example of a systemic hazard

If the term *systemic hazard* is defined too broadly it quickly becomes meaningless encompassing virtually any hazard with cross scale or multi-system components. Systemic hazards pose special challenges to the field of risk communication and lead to unique outcomes. More specifically, they cross multiple domains and scales and often lead to both normative and interpretive ambiguities for a wide range of stakeholders. The nature of systemic hazards is explored in the passage from Ortwin, 2006 shown below.

Systemic risks are at the crossroads between natural events (partially altered and amplified by human action such as the emission of greenhouse gases), economic, social and technological developments and policy-driven actions, both at the domestic and the international level. These new interrelated and interdependent risk fields also require a new form of handling risk, in which data from different risk sources are either geographically or functionally integrated into one analytical perspective. Handling systemic risks requires a holistic approach to hazard identification, risk assessment, concern assessment, tolerability/acceptability judgements and risk management.

Pre-implantation genetic diagnosis, the focus of this thesis, fits into this definition well. This controversial reproductive procedure has three main applications that include screening embryos (1) for specific genetic conditions; (2) to detect irregularities in the structure or number of chromosomes; and (3) to determine the sex of an embryo (Health Canada, 2005). Pre-implantation genetic diagnosis was selected as the topic for this study

because it is a single technology that exhibits all the elements of a systemic hazard. It is therefore an appropriate starting point for analyses of systemic hazards as it is much less complicated than other examples such as global climate change that involve inputs from multiple industries, technologies, and behaviours.

As discussed, systemic hazards are special in that they cross multiple domains and scales and exhibit normative and interpretive ambiguities for a wide range of stakeholders including whole societies (Renn, 2006). I will argue that pre-implantation genetic diagnosis can be described as normatively ambiguous because as a novel procedure, it does not directly appeal to any existing moral or social norms. We cannot assume that norms for PGD are identical to those of abortion or IVF even though these procedures share some ethical and social concerns such as rights of the unborn and reproductive rights of citizens. Table 1.1 illustrates how the consequences of PGD cross multiple domains and thus may involve interpretive ambiguities for stakeholders at various scales. For example, screening human embryos could allow families to produce biologically healthy children. However, viewing fertilized human embryos with disabilities as *undesirable* may normalize or reinforce discriminatory behaviours towards people with disabilities. However, potential outcomes such as medicalizing the pregnancy process or reinforce discriminatory behaviours are best described as unintended consequences of PGD as opposed to intended consequences such as reducing genetic conditions in biological children (DeLeire 1999 and Freeman, 2007). Such consequences are not desired by proponents of PGD but may nonetheless occur with increased acceptance and use of this reproductive technology. As famously argued by Hazlitt (1946), it is important to look “...for all the consequences of a policy instead of merely resting one's gaze on

those immediately visible.” Thinking through both intended and unintended consequences of systemic hazards helps broaden one’s assessment of potential risks and may serve to anticipate and even avoid undesirable outcomes. In addition, screening out groups of people (e.g., those with Down Syndrome) could change the genetic and cultural fabric of society. Genetic materials are special in that they locate individuals within a web of complex relationships⁴ that include their ancestors, others within their genetic and cultural “group(s)”, and future generations. In other words, when PGD alters the genetic landscape of our society, it is altering forever what is passed on to future generations from our genetic history.

Table 1.1 Consequences that cross domains for stakeholders of PGD at multiple scales

Consequences	Sample domains and examples of potential consequences (both positive and negative) by scale					
	Health	Regulatory	Ethical	Technological	Economic	Social
<u>Family scale</u>	Healthy biological child is born	Access to PGD is granted	Pressure for “high risk” families to undergo PGD	Successfully screening out conditions for families	High cost of PGD is prohibitive for some families	Families suffer stigma associated with PGD usage
<u>Group scale</u>	Reducing the number of children with genetic condition X who are born	Conditions to be screened are selected (groups of citizens that will be screened out)	Pressure for all women to eventually participate in screening programs	Less assistive technology innovations directed towards citizens with screenable conditions	Wealthy groups of citizens have fewer biological children with particular genetic conditions	Groups of citizens with screenable conditions are stigmatized as their numbers decrease overall
<u>Societal scale</u>	Healthier citizenry overall (in terms of genetic conditions)	Locating responsibility for people with disabilities (family or society)	Building an unjust society when discrimination towards people with disabilities is normalized through frequently used screening programs	Knowledge gleaned from experiences at the family scale is employed to produce more efficient, safer technologies that lead to widespread use	Economic burden of people with certain genetic disabilities is reduced, allowing these health care funds to be allotted to other programs	Canadian citizens become less tolerant of people with genetic disabilities as they become increasingly rare

⁴ I would like to acknowledge Michael McDonald for introducing me to this concept.

Each of the sample consequences shown in Table 1.1 involves physical, ethical, and a range of other domains that must be considered by citizens (especially those who will bear the consequences). For example, regulations (some of which are currently in flux in Canada⁵) will ultimately determine who has access to PGD and who should be responsible for the costs of this procedure (e.g., families, society). There are consequences to individuals who undergo or have PGD performed on them (e.g., unknown long-term health outcomes for children born following PGD and women who undergo PGD), individuals who DO NOT undergo PGD (e.g., pressure to submit to PGD technology if it becomes a standardized medical procedure), groups (e.g., increased intolerance towards people with disabilities and further medicalizing the pregnancy experience for all women) and society (e.g., decreased overall diversity and economic effects within the health care system).

Novel risk communication strategies for addressing systemic hazards

“Next-generation technologies” like PGD⁶ draw on heterogeneous expertise from medical and regulatory experts as well as unconventional experts that include educated stakeholders and activists (e.g., those living with a disability or caring for someone with a disability, those speaking on behalf of people with disabilities). Risk communication strategies for such hazards are therefore particularly difficult to craft as they must

⁵ Before 2004, there were no regulations, standards, or professional guidelines for the use of PGD in Canada. An agency called Assisted Human Reproduction Canada that reports to the Minister of Health now regulates this technology in Canada. However, the regulatory framework is currently under development and the Province of Québec has brought a constitutional challenge in regards to certain provisions under the Assisted Human Reproduction Act (Supreme Court of Canada, 2009)

⁶ Other next-generation technologies include nanotechnology and genetically modified organisms (OECD, 2003), and synthetic biology (Andrianantoandro et al., 2006).

communicate a range of technically -oriented (defined here as focusing primarily on technical understandings, the design of alternatives and consequences of PGD including the regulatory landscape) and value –oriented (defined here as focusing primarily on preferences and the emotional or experiential dimensions of PGD such as the lived experience of disability) information to the target audience in order to foster informed decision making and deliberation.⁷ Leading experts from the field of ethics and risk analysis have all articulated the need for novel strategies and approaches capable of dealing with this new class of hazards (see Renn, 2003 & 2006; Slovic, 2007; & Sherwin, 2008). Such methods call for holistic strategies that draw on input from a variety of sectors, expert groups, and civil society (Renn & Klinke, 2004 and McDonald, 2000).

Democratising science policy (McCormick, 2007) through collaborative risk decision making involving experts and lay citizens is now a key objective for many social scientists, risk researchers, and practitioners (Longstaff & Burgess, forthcoming; Webler & Renn, 1995; Renn, 2004; Lidskog, 2008; and Walmsley, 2009). Involving diverse input into risk analysis processes means that one must also be prepared to allow multiple understandings of hazards to inform risk communication strategies in line with Irwin's *Citizen Science* concept where science is at least in part “developed and enacted” by citizens (Fisher, 1991 and Irwin, 1995). Such strategies will necessarily include both value-oriented and technically-oriented risk messages. However, lay citizens must be *communicatively competent* to produce meaningful input for policy or risk management decisions concerning hazards, which requires adequate information among other things

⁷ Many would argue that all values are infused with experiential or technical understanding and all technical understanding has some value-based influences. However, it is useful and important in this case to distinguish among aspects of decision making that rest on emotional and technical understanding as both types of information should inform ethical risk communication strategies for PGD.

(Dryzek, 1990). Although it is generally agreed that citizens must be informed during such processes (Sunstein, 2002, Dryzek, 1990, National Academy of Sciences, 2008), specific conditions that would help determine the sufficient amount and type of information are rarely outlined as they will inevitably vary somewhat by hazard. It is also a subject on which lay citizens (who would eventually receive the information) are capable of producing important insights and was therefore one of the deliberative questions posed to participants of this study. The experiment described in this thesis demonstrates one method of crafting a deliberative risk communication strategy that informs participants while incorporating relevant values and norms. It is based on similar efforts conducted by Arvai et al, Renn, and others. For example, Arvai *et al* sought to enhance decision making through deliberative risk communication experiments that include components of Keeney's Value Focused Thinking approach (Arvai, Gregory, and McDaniels, 2001). Renn introduced the *concern assessment* to incorporate value based expertise directly into his risk governance framework (Renn, 2006). This novel assessment would complement (not replace) the more conventional technical risk assessment process.

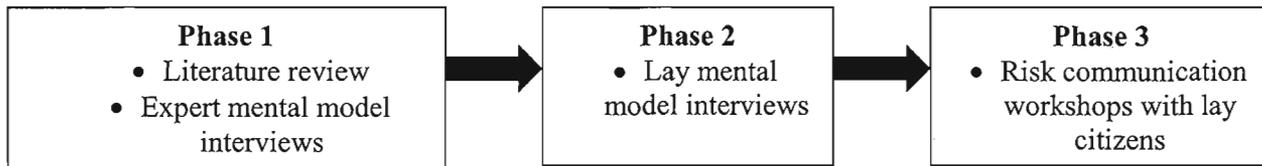
Overall study design

The purpose of this section is to provide a brief descriptive overview of the entire study described in this thesis. Subsequent chapters provide a more detailed analysis of each individual phase.

Phase 1: literature review and expert mental model interviews

This thesis project is divided into three phases shown below in Figure 1.1. The first phase involved (A) a literature review and (B) mental model interviews with experts to confirm and supplement these findings. The review included position statements and information produced by the National Society of Genetic Counsellors and the American Board of Genetic Counseling, academic papers written within the last five years and included on PubMed, and policy documents regarding PGD. The purpose of the literature review was to clarify the risks and benefits of PGD across domains at multiple scales (family, group, society). These findings were then transformed into a series of 4 charts that recorded major themes and possible outcomes (2 additional charts were added in accordance with advice from experts).

Figure 1.1 Conceptual framework for study



Expert mental model participants were initially identified from contributions in position statements, academic papers included on PubMed, and policy documents regarding PGD. Additional experts were also added to this group based on recommendations by two or more participants in a snowball sampling method. All who participated in this study are widely acknowledged as experts in this narrow field. The study topic draws on a diverse range of experts that include some lay stakeholders who have specialized knowledge of PGD (e.g., parents of children with disabilities). Risks and benefits at the family scale

drew primarily on experts in reproductive medicine, genetics & genetic counselling, and the experience of living with or caring for someone with a disability. Major topics associated with the group and societal scales called for experts in the ethical, legal, economic, and social dimensions of PGD and disability rights advocacy.

The expert interview phase of the study was broken into three steps. First, the expert was contacted via email to request their participation in this project. During this first email exchange, the expert was provided with a brief overview of the entire project and their potential role in this phase of the study. If the expert agreed to participate, they were then sent a more detailed explanation of their responsibilities, the charts produced through the literature review, and a consent form. Each individual was given at least a week to review the charts, make comments, and prepare for the interview, which would take place in person, over the phone, or via email depending on their preference and location. In total, eight experts were interviewed with a fairly even gender split. Interviews lasted about one hour on average.

Phase 2: lay mental model interviews

The second phase includes mental model interviews with lay citizens. The objectives of these interviews were to determine shared misconceptions and background knowledge of PGD. All lay participants were recruited through poster advertisements and were randomly assigned to be either interviewed or participate in one of two workshop treatment groups (phase 3). During the interviews, participants were asked open ended

questions that helped them to explore their own mental model of this novel technology. Participants were also asked about more specific risks, benefits, and stakeholders for PGD technology to determine awareness of or ability to anticipate information included in the finalized expert charts from phase 1. In total, sixteen individuals participated in this process, which lasted between 45-60 minutes on average. Findings were then used to complement phase 1 results and inform phase 3 workshop materials.

Phase 3: experimental deliberative workshop with lay participants

Findings from phase 1 and 2 were combined to inform materials used during a series of experimental deliberative risk communication workshops with lay citizens (phase three). The materials emphasized either value-oriented or technically-oriented information relevant to PGD. In total, fifty-seven individuals were recruited through poster advertisements to participate in one of eight 2.5- hour workshops. Those involved in the workshops (and lay mental model interviews) do not to represent any specific group or population. The purpose of the workshop experiment was to test learning outcomes and differences between treatments (structured and unstructured decision making) during a risk communication experiment.

This study includes a within–subject,⁸ before and after comparison design that analyzes how all participants learn about the ethically contentious and novel risks and benefits associated with PGD. The experiment in this study employs a between-subject⁷ design

⁸ Within –subject is a term used to describe studies in which repeated measurements are taken from the same participants while between –subject is a term used to describe the process of asking 2 groups of participants the same questions but with a different treatment.

described as follows. Randomly assigned participants in half of the workshops (Treatment B) viewed structured decision making (SDM) materials in the form of consequence matrices while the others did not. Treatment A participants received no information regarding the objectives and alternatives for PGD in terms of consequence tables, and were therefore considered the control group. The matrices were derived from expert interview findings. The deliberative workshops were not experimenting with the success of various risk communication methods (e.g., video, FAQ's, etc) to communicate particular risk messages about PGD. Instead, participants were presented with a great deal of information about PGD in a range of formats and openly asked to evaluate them. By making this process transparent (as opposed to part of the experiment by showing participants informationally equivalent communications), participants were able to offer advice such as switching the content of one approach with another, or ruling out one method but not its contents. The objective of the workshop experiment was to examine the influence that a series of consequence matrixes had (if any) on participants' decisions about risk communication strategies for PGD.

The two areas of analysis that are of primary interest to this study are the (1) within-subject before and after comparison and (2) between subject two treatment or SDM experiment. I analyzed all study data using the individual unit of analysis as opposed to comparing groups for several reasons. First, the before and after and treatment group sizes that comprised this study were slightly small for statistical tests typically used to analyze differences between groups (e.g., T-Test, Matched Pairs T-Test, Analysis of Variance (ANOVA)) (Levin and Fox, 2004). Secondly, two groups (in the case of the before and after comparison) is an insufficient number to confirm significant variations

between results. In other words, with only two groups, one cannot determine if differences are random in nature. Examining differences between groups therefore requires one to examine differences between multiple groups. However, financial constraints on this student project made recruiting participants for multiple groups impossible and examining differences at the individual unit of analysis the more practical alternative. Finally, testing group differences between SDM treatments (the between subject experiment) would require group scale analysis such as content analysis of qualitative discussions or group oriented tasks and questions. Individual workbook tasks were used in this study because it is a method of eliciting responses that can be managed easily by a single researcher without the need for expensive transcriptions and extensive qualitative coding of group conversations. Statistical significance at the individual unit for both the within subject and between subject analyses was therefore determined using the McNemar test for the significance of changes at a 95% confidence interval (Sirkin, 1995). This formula measures the number of individuals who respond differently after being exposed to new information or a new condition (Daniel, 1990).

Organization of thesis papers and discrete objectives

The first paper in this thesis outlines the conceptual framework for the project. I argue that risk and bioethics experts each have valuable contributions to make in the area of systemic health hazards and that lessons from the field of bioethics can fortify risk communication efforts for these difficult problems. Furthermore, lessons from the field of bioethics could potentially shed light on many significant aspects of risk communication for systemic hazards including how to: identify the moral values that guide our efforts;

build an ethical communication strategy; choose experts that will ultimately inform that strategy as well as the target audience; and evaluate findings.

The second paper focuses specifically on phase one of the thesis project. Characterizing expert judgment is an integral component of all risk communication strategies. This paper attempts to convince the reader that we must broaden our understanding of expertise for systemic hazards like PGD to include non-conventional experts (e.g., those speaking on behalf of or living with disabilities) in order to encourage holistic or “all things considered” ethical judgments (McDonald, 2000). However, broadening the scope of expertise should not involve lowering the bar for inclusion or appealing to extreme outliers. It is important that one maintain good reasons and evidence for including each expert point of view, and balance such perspectives in a fair and justified manner. All experts who were included in this study were identified through a thorough literature review and confirmed by other PGD experts in a snowball sampling method. In addition, including new types of experts presents the need for new methods of gathering and compiling expert judgments that can make sense of value-oriented and technically-oriented risk information. The approach presented in this paper experiments with the Mental Models Method (Morgan et al, 2002) but is also inspired by bioethics concepts and principles.

The third paper discusses learning outcomes for phase two (mental model interviews with lay citizens) and three (risk communication experiment with lay citizens) of this study. It demonstrates that the mental models approach can effectively communicate the risks and benefits of novel and unfamiliar hazards. Despite their lack of previous awareness of

PGD, participants were in fact successful in acquiring a range of technically –oriented information about this emerging reproductive technology. However, they were concerned about the value-oriented risk and benefit messages contained in certain risk communication methods (e.g., news media articles and videos). Although they agreed that the lived experience of disability and other aspects of these messages were important to convey, they also believed that such messages were biased and intended to manipulate instead of informing viewers' decisions.

The final paper discusses the results of study phase three or the experimental risk communication workshops. These findings demonstrated that lay participants, especially those who review even minimal SDM materials, (in this case a series of consequence matrixes that summarize the kinds of information required for responsible decision making (Hammond et al, 1999 and Clemen & Reilly, 2000) derived from expert interview findings) are able to make well informed, inclusive, and therefore meaningful decisions about a complicated novel technology. Workshop findings also fared well against the National Academy of Sciences, 2008 criteria that judged the quality of the workshops and associated outputs. It was concluded that incorporating SDM materials in risk communication efforts is in fact worth the extra time they consume and effort from participants as these materials helped participants to make better, more holistic, and ultimately more ethical decisions.

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Chapter two: Integrating bioethics concepts with risk communication theory and applications⁹

Introduction: the value of ethical analysis

Ethics matters to risk communication. Unethical work masquerading as risk communication (e.g., to foster damage control, whitewash controversy or fulfill legislative obligations without real intent (Renn, 2004)) has the potential to erode public trust in the field of risk analysis (Morgan and Lave, 1990) and leave communication strategies incapable of achieving important objectives such as strategic or collaborative decision making with lay citizens (Null, 2002). Effective risk communication strategies therefore require strong ethical foundations to ensure that they are both ethically constructed and serving the public good.

Although appeals for collaboration between the fields of applied ethics and risk communication have been made over time, limited progress has occurred to date.¹⁰ Some of these appeals point to the need for additional research on the ethical implications of particular communication methods (see the McComas, 2006 review of risk communication research from 1996-2005). Others call for more general advice regarding systemic hazards¹¹ (Johnson, 1999; Sherwin, 2008). Whatever the purpose, encouraging risk analysts to engage with ethics literature should not be understood to imply that past or current risk communication work is necessarily unethical. It should instead be viewed

⁹ A version of this chapter has been submitted for publication. Longstaff, Holly. Blending bioethics concepts with risk communication theory and applications.

¹⁰ A few notable researchers who work in this interdisciplinary area include the following: Sherwin, 2001, 2008; Burgess, 2003, 2004 & 2005; Keeney, 1984, 1992, 1994; Renn, 2004, 2006; Morgan and Lave, 1990; Johnson, 1999; and Sellnow et al. 2008.

¹¹ For more on systemic hazards please see the introductory chapter of this thesis.

as a way of enhancing and improving what risk analysts do and how they do it. For example, risk communicators working within the health domain can benefit from engaging with bioethics literature, or the critical examination of advances in the field of health technology and medicine. Those working in the area of bioethics represent a wide range of disciplinary backgrounds including philosophy, applied ethics, medicine, religion, social sciences, and law. These practitioners and academics spend their careers working on topics of great relevance to the field of risk analysis (e.g., protection of human research subjects, the ethical implications and governance of novel technologies) providing research findings and recommendations that should not be ignored.

Many who are unfamiliar with the field of bioethics falsely believe that this area of research is inherently and endlessly subjective or thinly disguised political or religious rhetoric about right and wrong actions. In summary, moral judgements are “best described as integrative, holistic, or *all things considered* judgements requiring the intelligent integration of different types of knowledge and expertise” (McDonald, 2000 and Hurka 1993) and those who engage in bioethics research conduct systematic analyses of value-laden areas in a scientific manner (Danielson, 2007). Bioethicists also acknowledge sets of consensus values¹² commonly shared by risk researchers (see section on the state of substantive ethics). Ethical analysis can be helpful in “determining responsibility, fair distribution of outcomes, and fair procedures”, among other things (Sherwin, 2008). I will argue that the field of ethics can provide informative insights on a wide range of issues in risk communication including how to: identify the moral values that guide our efforts; build an ethical communication strategy; choose experts that will

¹² In for example the 1979 Belmont Report and Beauchamp and Childress, 2001.

ultimately inform that strategy as well as the target audience; and evaluate findings. The fundamental objective of this paper is to demonstrate how bioethics concepts can help fortify risk communication strategies. In particular, it will show how explicitly considering substantive ethics generally and public ethics more specifically will help risk communicators cope with novel systemic hazards within the health domain. Conclusions are provided in the final section.

Guidance from substantive ethics

From how to why: moving beyond procedural ethics

Much attention in the field of risk communication has been focused on *procedural ethics* or ethically constructed strategies for pursuing assumed (but often not explicitly considered) ends. For example, a great deal of effort had been directed to developing strategic frameworks¹³ for risk communication, such as those created by Government bodies in Canada, the United States, Turkey, the UK and others. Such frameworks naturally lead to greater examination of and (ideally) consensus on ethical procedures for risk communication. The processing of technically-oriented risk information has also been a prolific area of study for risk communicators. Studies consistently show that most individuals have difficulty understanding the “dose makes the poison” concept in exposure assessment (especially in regards to carcinogens (McCallum et al, 1990), and

¹³ Selected examples include: The Public Health Agency and Canada’s (PHAC) framework for strategic risk communications; The Interagency Working Group on Import Safety’s strategic framework for import safety; The Government of Turkey’s strategic communication framework and plan for the prevention and control of avian and pandemic influenza; The Department for Environment, Food and Rural Affairs’ strategic framework for the control of bovine tuberculosis.

dose response assessments (especially the relationship between high doses in animals and extrapolations to human health risks) (Fisher, 1991). Small probabilities (at or below one in a hundred lifetime risk) are also notoriously difficult to communicate (Fisher, 1991). Tversky and Kahneman (1974) demonstrated that judgment becomes increasingly impaired as probabilities approach 0.01 (Tversky and Kahneman, 1974) and Prelec 1998 showed that individuals are more likely to overestimate small probabilities if they are associated with catastrophic events. Contributions from these areas are a vital step forward in advancing ethical risk communication as strategies must be ethically constructed and understood (procedural ethics) to be effective. However, one must pay close attention to substantive ethics, or the moral values that guide us, when crafting risk communication strategies in addition to procedural ethics as both influence our ability to achieve just outcomes (Sherwin, 2001). The following case helps to illuminate the differences between procedural and substantive ethics and the significance of the latter concept to the field of risk communication. It will demonstrate how ethically constructed strategies created by well intentioned analysts may still lead to unethical outcomes.

Imagine for a moment that this case takes place within A CULTURE¹⁴ that has major health disparities between its Aboriginal (approximately 5% of the total population) and non-Aboriginal citizens. For example, A CULTURE Aboriginal citizens experience higher rates of Fetal Alcohol Spectrum Disorder, a condition that describes a range of disabilities linked to alcohol exposure in the womb. Suppose that a risk communicator was hired by A CULTURE's Federal Health Department to communicate the ways in which an individual's risk for this disorder can be minimized. This risk communicator

¹⁴ I employ the convention A CULTURE to refer to a hypothetical specific culture.

truly wants to help the Aboriginal community address this health problem. She takes great efforts to construct a communication strategy that fits within the guidelines set by her region's strategic framework and is very thorough in her methods. She ensures that the materials she creates are effective in helping all interested citizens clearly understand the risk factors for Fetal Alcohol Spectrum Disorder and how to avoid them. Hence the risk communication process meets the test of procedural ethics and is unfolded by A CULTURE's Federal Health Department. However, the risk communication strategy outrages A CULTURE'S Aboriginal population. They explain that the strategy has stigmatized them as a people even though the disorder is not solely an Aboriginal health problem. They also point out that although they were consulted by the risk communicator *after* the health topic was picked, they would have suggested a different, and in their opinion, more important health issue if given the opportunity. So despite the fact that the risk communicator was motivated by good intentions and constructed an ethical risk communication strategy, the process does harm¹⁵ to the target population by failing to address their health concerns and ultimately stigmatizing them. It therefore violates many of the moral obligations and shared principles that both bioethicists and risk analysts hold dear (see section on the state of substantive ethics) and is thus substantively unethical.¹⁶

¹⁵ The concept of harm can also be difficult to characterize. While this term may imply physical bodily harm to some, others may argue that it should also include emotional and social impacts as outlined in the A CULTURE example.

¹⁶ The case presented here is intended to remind the reader of the infamous Nu-chal-nuth First Nations incident involving the unauthorized use of blood samples for research purposes (MacIntosh, 2005). Similar cases could be made for risk communication strategies focusing on products that caused great suffering in animals or those produced through child labour (see Sellnow et al, 2008 pg 150 for more on these examples).

The state of substantive ethics within risk communication: a few examples

Risk communication is the process of informing and at times directing human behaviour in ways that are perceived to be in the public interest. This desire to do what is in the best interest of the public is an example of substantive ethics. To determine this “good” risk analysts typically evaluate options according to criteria such as risks or costs and benefits, but some have moved beyond these metrics to examine what may motivate and obligate an analyst to communicate with citizens. Morgan and Lave argue that we can limit harms associated with persuasive efforts by ensuring that the goals of communication strategies are explicit, overt, and altruistic (Morgan and Lave, 1990). In this way, Morgan and Lave begin to move beyond procedural ethics by examining motivation. They state that a communicator’s motivations can be divided into two types: caring about how the strategy is used and not caring. The “caring” motivated risk communication messages can be further divided into covert or overt messages, which can be categorized as having either altruistic or selfish goals. These authors suggest that ethical dilemmas are *more likely* to occur when objectives of the risk communicator and target audience do not match and when the communicator produces covert, selfishly motivated messages. Although the authors do cover new ground in their paper, their arguments are somewhat problematic. First, it is not clear whose interests should be cared for in this framework and whose interests should be a priority. Secondly, Morgan and Lave would have us believe that overt messages are *more likely* to be ethical, provided that they were motivated by caring. The A CULTURE example above demonstrates how strategies created by caring analysts can nonetheless harm citizens. They are assuming that virtuous communicators are ethical communicators, but this is not always true.

Producing virtuous risk analysts who are ethically aware is certainly a good thing. However, such communicators may still create unethical strategies with the best of intentions if they do not understand and take into account the diverse interests and values of their audience, balance those interests in a fair and transparent manner, and determine a morally acceptable course of action. (Sellnow et al, 2008).

The broad ranging interests of a diverse public are explored by those who suggest that risk communicators are morally obligated to consult citizens regarding issues that substantially influence their lives (e.g., GMO foods, radon gas, and genetic science applications). Schrader-Frechette refers to this obligation among her four reasons for why managers ought to involve the public in risk analysis.¹⁷ She argues that it is ethical to involve the public when they have a stake in the consequences of an assessment (Schrader-Frechette, 1995). Burgess and Tansey make similar statements in their article on democratic deficits and the ethics of public engagement. They report that a democratic deficit occurs where there is unequal access to shape regulatory decisions (Burgess and Tansey, 2006). Others suggest that risk communicators are also obligated to help direct attention and limited financial resources on actual risks (Fisher, 1991). In other words, communicators must not allow public attention to shift from real to phantom risks. Fisher discusses this concept in her case analysis of tritium clean up after the Three Mile Island disaster. Residents objected to having this toxic water trucked away from the

¹⁷ Schrader-Frechette refers specifically to the risk assessment process but this argument can be appropriately applied to risk communication. Other motivations for including the public according to Schrader-Frechette are 2) logical, “uncertainty in risk assessments cause the invocation of value judgments”, 3) ontological “assessments affect many things like equity, future generations, civil liberties. They should not just therefore have scientific inputs or bounded scientific rationality”, and 4) democratic ideals “if the public cannot participate then it reduces democracy. It is not value neutral” See Schrader-Frechette, 1995.

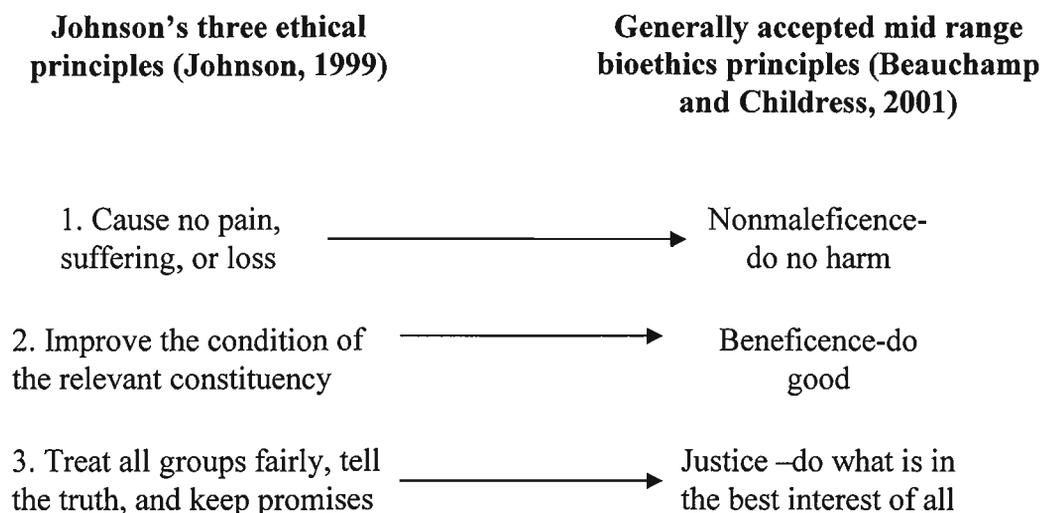
site despite the fact that releases were well below permitted levels. Not fully understanding the risks involved, they instead agreed to have it boiled, which released the tritium into the air. This option was not only more expensive, it was also more hazardous to the residents' health (Rasmussen, 1990).

Finally, Johnson creates a framework for identifying ethical issues in risk communication in a paper that responds to the earlier Morgan and Lave piece (see Figure 2.1). He argues that communicators must consider how each stage in his proposed framework¹⁸ “upholds or undermines” three general obligations (Johnson, 1999). These obligations relate to the commonly held mid-range bioethical principles of *autonomy* (self governance),¹⁹ beneficence (do good), non malfeasance (do no harm), and justice (do what is in the best interests of all) (Beauchamp and Childress, 2001). These principles are described as mid-range because unlike rules or specific moral judgments, they do not dictate a clear course of action (Dworkin, 1975 pg 1060). On the contrary, they are general, often conflicting with each other across contexts and in doing so, foster considered decision making by exposing tradeoffs and conflicting considerations (Keeney, 1984).

¹⁸ The stages include: identifying the issue, setting goals, knowing the issue, knowing the audience, knowing the constraints, assessing audiences, identifying messages, identifying methods, (after implementing a strategy) debriefing, and final evaluation.

¹⁹ Autonomy is not addressed in Johnson, 1999.

Figure 2.1 Ethical principles guiding risk communication²⁰



It is perhaps useful to return to the A CULTURE example at this point to help think through the ways in which risk communication could be improved by appealing to the shared substantive bioethics and risk communication principles discussed thus far. It would seem that a virtuous risk communicator would recognize the democratic deficit exposed by the A CULTURE situation, where Aboriginal citizens are clearly unable to influence health policy within their community. This virtuous analyst would be motivated

²⁰ Johnson's third principle encompasses a range of issues including truth telling and honesty but is nonetheless similar in nature to Beauchamp and Childress' description of justice. It should be noted that the list of bioethics principles presented here is not intended to be exhaustive. They are coherent with one another and represent a *common morality* (Marcum, 2008 and Schmidt-Felzmann, 2003). The principles are included here only to demonstrate that the most commonly accepted and cited principles in bioethics are already embedded within the work of most risk analysts. Other noteworthy ethics principles include The Belmont Report's basic ethical principles (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979); those discussed in the World Medical Association's (WMA) Declaration of Helsinki (The World Medical Association, 1964); and those highlighted in the World Health Organization's Pandemic Influenza Preparedness and Response document (World Health Organization, 2009).

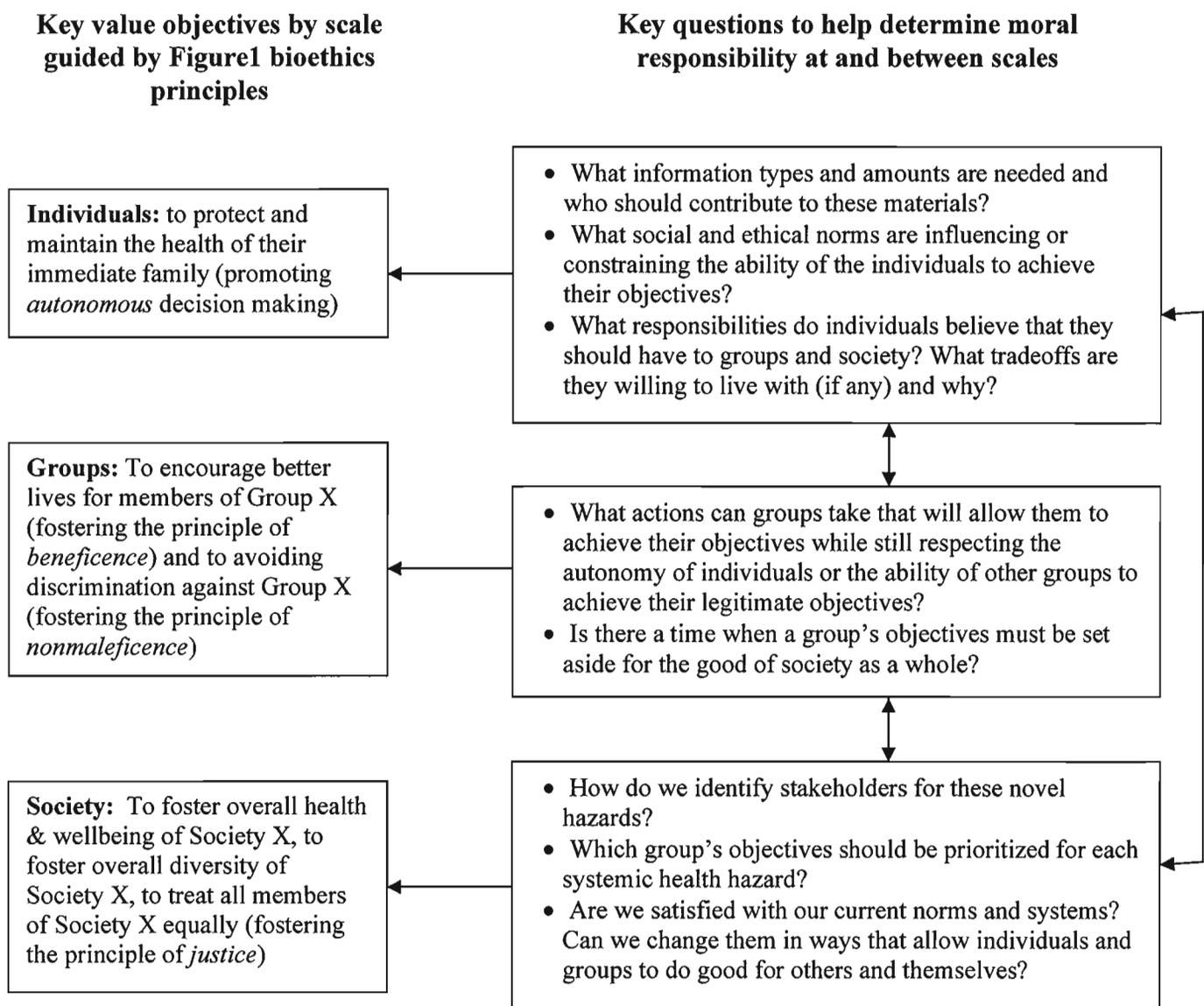
to help *direct public attention* to this important deficit by crafting persuasive strategies that accurately take into account and communicate the diverse interests and values of all A CULTURE citizens. Through employing the mid range principles in Figure 2.1, the communicator would first notice that the autonomy of A CULTURE Aboriginal citizens was being violated. Although they did participate in the risk communication strategy, they were not consulted early enough in the process. These citizens were therefore not given the opportunity to exercise self governance by directing attention to health topics of the greatest concern to their community. Although the research could benefit many individuals within this society (beneficence), these benefits must also be measured against harm done to the group in the form of stigmatization (non-maleficence). A simple weighing of net risks and benefits in cost-benefit form will not suffice here. The principle of justice requires that risks and benefits be distributed fairly across groups. Ultimately, the ends (reducing Aboriginal citizens' risks for Fetal Alcohol Spectrum Disorder) although important, may not justify the means (violating Aboriginal citizens' right to self governance). After considering all relevant issues discussed above, the analyst may advise A CULTURE's Federal Health Department to avoid targeted risk communication efforts for controversial topics in the future and instead focus on educating the entire citizenry about the risks of such disorders. She may also suggest additional public engagement activities around health priorities, especially for groups at increased risk.

Guidance from public ethics

Public ethics, as proposed by Sherwin, is a specific form of substantive ethics that probes moral responsibility at multiple scales of impact in relation to systemic hazards (Sherwin, 2008). This concept of a collective ethics represents a move away from a responsive ethics to a more proactive model. Specifically, she calls on her bioethics colleagues to address broader questions that tend to be overlooked when bioethicists respond to narrow, albeit significant, controversial questions surrounding issues such as rights of the fetus. Topics addressed through public ethics are unlike conventional bioethics topics in that they are unbounded, present novel ethical dimensions (e.g., “new oughts”), and involve cross-scale, ambiguous impacts for a wide range of stakeholders (Sherwin, 2008). For example, personal actions alone (e.g., using public transit, consuming local products) cannot mitigate the risks and benefits of systemic hazards (e.g., the effects of global climate change on a community). It could be argued that all actions (even those of powerful organizations) stem from a collection of individual personal decisions and that all citizens could theoretically unite to foster tremendous social change. However, this line of reasoning assumes that all citizens are equally powerful, able, and equipped to voice dissent within a society that privileges certain genders, physical abilities, worldviews, sexual orientations, and cultural groups, among other things. Alternatively, individual actions such as screening human embryos for disease may lead to unintended consequences for groups of people (e.g., stigmatization of people with disabilities) and alter the genetic makeup of society for all future citizens. Figure 2.2 below shows some of the key value objectives that are likely to be present at each scale for systemic hazards in the health domain. These objectives were derived through interviews with experts (see

chapter 3 of this thesis) and are guided by the bioethics principles shown in Figure 1. The figure also outlines a series of key questions that may help sort out moral responsibility at and between scales.

Figure 2.2 Examples of objectives and moral responsibilities by scale



* Arrows indicate pathways of influence

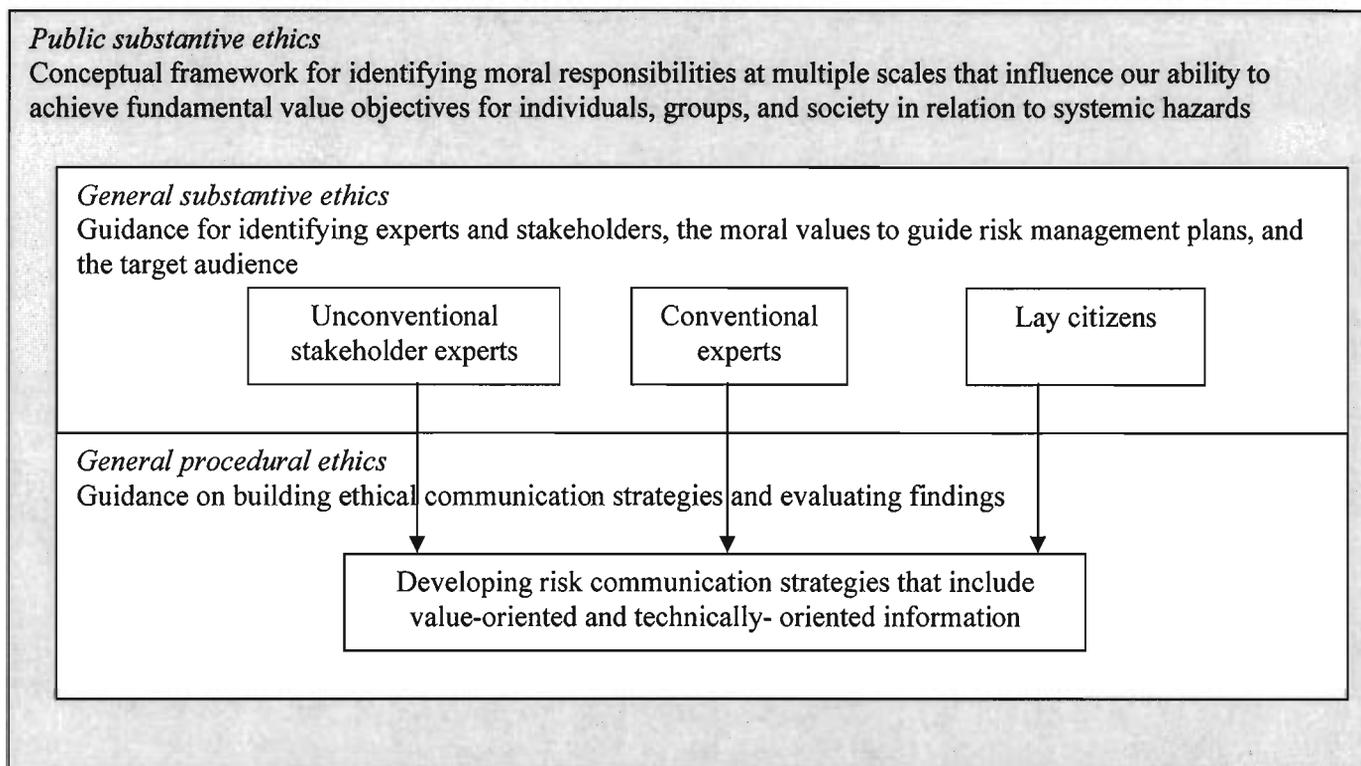
Sherwin seeks guidance from the work of other feminist scholars in her quest to pursue public ethics. One concept of particular influence is referred to as *relational* ethics (Sherwin, 1998). This term describes the idea that individuals, groups, and institutions are all connected to one another in our society. As shown in Figure 2.2, the ability to achieve key value objectives²¹ at each level are shaped (and constrained) by the moral responsibilities present at other scales of influence. Those studying through the lens of relational ethics examine the quality of decision making at the individual scale within in a wider social context that includes the influence of norms, regulations, responsibilities, culture, and other factors. Relational ethics is thus a political notion promoting autonomous decision making (Burgess and d'Agincourt-Canning, 2001). This is an idea that is also recognized within the field of health risk communication. In their discussion of genetic testing for cancer risks, Croyle and Lerman report that communication strategies should focus on both individual and family risk while discussing management plans (Croyle and Lerman, 1999). Ball, Evans, and Bostrom (1998) recommend encouraging doctor-patient “decision making partnerships” in order to expand the range of available options. Burgess and d'Agincourt-Canning have found that relational responsibility is a significant influence on an individual's decision to pursue genetic testing (Burgess and d'Agincourt-Canning, 2001). In other words, an individual's responsibilities as a caregiver, wife, mother, etc. may well influence and perhaps constrain the health related choices she ultimately makes.

²¹ Value focused thinking seeks to “clarify, define, and structure” an individual's fundamental values (in the form of objectives hierarchies) to guide decision making. Keeney argues that values are the fundamental component of decision-making and focusing on values as objectives can help one to achieve more desirable situations which he calls “decision opportunities” as apposed to “decision problems” (Keeney, 1992; Keeney, 1994, and McDaniels, 2000).

Employing bioethics guidance to communicate the risks and benefits of systemic health hazards

Figure 2.3 illustrates how lessons from the field of bioethics can inform and fortify risk communication strategies within the novel regulatory and decision making frameworks discussed below. Public substantive ethics, as described earlier, provides the conceptual framework for identifying moral responsibilities at multiple scales that influence our ability to achieve key value objectives for individuals, groups, and society when dealing with systemic hazards. More general substantive ethical considerations offer moral guidance for risk communicators such as the moral values that guide risk management plans, the target audience, and identifying the range of experts and stakeholders who will inform the strategy. For example, it is common and appropriate for risk communicators to seek the advice of conventional experts such as scientists and regulators who have cultivated a deep understanding of a particular hazard through study and analysis over time. However, in some cases, it may be important to include the views of unconventional stakeholders who also possess relevant as well as morally significant information (such as lived experiences). Such views, much like the views of conventional experts, are formed over many years, are often difficult for non stakeholders to anticipate, and cannot be assumed. Procedural ethics focuses on ways to build and evaluate ethical strategies.

Figure 2.3 Bioethics guidance for risk communication strategies regarding systemic hazards



Experts from both the fields of risk analysis and bioethics agree that systemic health hazards call for new approaches and methods (discussed below). This paper proposes ethically framed and constructed risk communication as a way of bridging the gap between what the individual can and ought to do and what we think our institutions and others can and ought to do in the face of systemic hazards. Schrader-Frechette (1995) and Burgess (2003), among others, argue that citizens have the right to determine the kind of society in which they want to live. Yet it is impossible for each individual citizen to directly shape the risk analysis processes for a given hazard.²² Risk communication efforts can gather groups of citizens together to examine systemic hazards in order to

²² Involvement here refers to meaningful and direct democratic participation in contrast to other democratic actions such as voting for elected officials.

provide public input into or oversight over each risk analysis phase.²³ The fundamental objectives of this approach to risk communication are therefore to (1) provide moral guidance for normatively ambiguous problems and (2) consider (and potentially mitigate) consequences associated with interpretative ambiguities that typically lead to multiple scales of impact for a broad range of stakeholders.²⁴ This holistic approach is inspired equally by the work of risk researchers and bioethicists who study similar problems yet rarely have the opportunity to collaborate. While risk analysts call for new regulatory and decision making frameworks capable of incorporating risk communication methods and findings, bioethicists provide advice on how to determine the range of moral responsibilities and values that ought to inform and guide those strategies.

Risk researchers recognize the fact that methods capable of addressing ambiguous problems are ineffective without appropriate support from regulatory and decision making frameworks. Marden and co-authors point out that current frameworks may not be structured to cope with particular risk communication outputs (e.g., the ethical dimensions of technologies) (Marden, Longstaff, and Levy, 2006 and forthcoming). For example, in Canada, existing regulations and laws are being stretched to cover ambiguous problems but these efforts have been controversial (e.g., regulating GM, farmed, and wild salmon under the Fisheries Act). McDaniels et al, and Renn therefore present new frameworks capable of considering, directing, and mitigating the consequences of ambiguous hazards while incorporating novel communication strategies. In his recent

²³ Typically, the public is brought into the risk analysis process only after hazards are identified and assessed.

²⁴ For example, lay participants can help clarify shared ethical and social norms. Diverse groups of citizens may also be able to draw on personal experiences and worldviews in order to anticipate the outcomes of systemic hazards for other individuals and groups.

2006 white paper, Renn proposes a new Risk Governance management framework to cope with ambiguous systemic hazards. Renn's framework includes five core processes, 1) pre-assessment, 2) risk appraisal, 3) tolerability and acceptability judgment, 4) risk management, and 5) risk communication. Significantly, risk communication is located at the centre of the framework influencing and influenced by all other processes. Of particular interest to communicators is the impact that communication is recommended to have on the pre-assessment phase, which includes problem framing, early warning, screening, and determination of scientific conventions. Renn also introduces readers to the concept of a Concern Assessment,²⁵ which includes gathering information on public risk perceptions, social concerns, and socio-economic impacts. This assessment is placed alongside the conventional risk assessment phase. Other examples of novel regulatory frameworks include the UK's Inter-departmental Liaison Group on Risk Assessment (ILGRA) Risk Communication Sub-Group's 1998 document "Risk Communication: A Guide to Regulatory Practice" (ILGRA, 1998), and the Canadian Government's 2000 Integrated Risk Management Framework (Treasury Board of Canada Secretariat, 2001). Both documents incorporate risk communication into every stage of the analysis process and could easily absorb communication methods and findings (Treasury Board of Canada Secretariat, 2001). McDaniels et al 2005 & 2006 propose a new risk management decision making framework capable of addressing the ethical and normative dimensions of multi-scalar systemic hazards (in this case salmon aquaculture). This framework involves (1) characterizing the regulatory context for a problem at each scale, (2) eliciting objectives from all affected parties at each scale, and (3) characterizing performance

²⁵ This is similar to Schrader-Frechette's probabilistic risk assessment in moral mathematics. See Kristin Schrader-Frechette, 1987.

measures for those objectives. McDaniels et al have found that even the most diverse groups often share the same fundamental value objectives for controversial hazards. Establishing these points of convergence can foster communication between groups and allow managers to arrive at decisions all stakeholders can live with.

For systemic ambiguous hazards, one must choose communication methods capable of addressing a broad range of individual, group, and societal risks and benefits that incorporate both technically-oriented and value-oriented risk information. Novel methods such as risk ranking and more conventional methods such as focus groups can be used to effectively engage citizens during such risk communication sessions. It is common during risk ranking exercises to ask diverse groups of participants to rate various management options associated with a hazard (EPA, 2005). However, this exercise can also be used to choose hazards that ought to be considered for risk assessments thereby including participant values and interests in the most preliminary stages of the risk analysis process. With systemic hazards such as genetic and genomic science applications, there is often substantial disagreement as to how or even if technologies or activities associated with these topics should be pursued thus taking the discussion beyond procedural ethics into the area of substantive public ethics. Participant recommendations may include additional research, additional regulations, or additional public input from other sub populations.

Interactions between diverse participants during focus groups or workshops can be used to expose society's ethics and reveal the norms that should guide risk communication strategies (Burgess and Tansey, 2006, Burgess, 2003). Communication efforts informed through such processes will therefore reflect the values of citizens and risk analysis

options will be justified by citizens and not just technical risk experts (Fung, 2003). Such discussions allow for greater representativeness and inclusiveness (Burgess and Tansey, 2005; Longstaff and Burgess, forthcoming) by allowing participants the freedom of expressing *under represented* or *unarticulated* opinions (Burgess, 2004). In this way, participants are able to “move beyond established notions of what is relevant” in order to “interrogate assumptions” (Levitt, Weiner, and Goodacre, 2005) and are thus capable of informing an ethical evaluation of the topic at hand (Burgess and Tansey, 2006). The results of these discussions allow citizens to consider the socially significant consequences of a hazard while determining the range of values that ought to shape risk analysis conclusions. Ethical decisions concerning the consequences of ambiguous systemic hazards must be “all things considered” judgments (McDonald, 2000). Methods that foster deliberative engagement encourage citizens to balance and even override self interest (even if this interest is very high) in favour of just policies for all (Ball, Evans, and Bostrom, 1998).

Conclusions

The objective of this paper was to show how lessons from the field of bioethics can help risk analysts cope with systemic hazards in the health domain through risk communication. This paper represents a preliminary step towards integrating a selection of complimentary theoretical concepts from both fields in order to foster communication between the two disciplines.²⁶ Much work remains to be done and progress in this area

²⁶ An additional step will involve writing a manuscript for the bioethics community from the risk analysis perspective. This paper will outline a series of insights that could be used to fortify bioethics research (e.g.,

will inevitably involve a number of significant challenges. McDaniels, Renn, and others present innovative ways of incorporating the moral dimensions of risk problems into regulatory and decision making frameworks while recognizing the consequences of ambiguous problems at multiple scales. However, it should be noted that overhauling current frameworks would be both difficult and expensive. For example, Renn states that risk communication under his framework should be performed by an interdisciplinary team of communicators, which would require additional training and perhaps even changes in personnel.

In addition, some risk communication methods such as focus groups and workshops are time consuming and expensive. A great deal of research needs to be accumulated to determine if these methods are in fact effective in providing moral guidance for and considering the consequences of systemic health hazards. Only a broad overview was provided here. A range of empirical data must first be collected before one can justify using such methods to inform actual policy. Questions of immediate concern include: approaches for blending value-oriented and technically-oriented risk informative for lay audiences in ways that are both informative and trustworthy; the range of stakeholders and experts that ought to inform risk communication materials for a particular systemic hazard; and the minimum amount of information that should be provided during risk communication sessions for systemic hazards that are invariably complex, to name only a few. Informational sufficiency or the functional aspects of the informed consent *process* has been a prolific area of research for the field of bioethics despite the fact that the social

empirical evidence on the effectiveness of communication methods, relevant risk perception findings, and the benefits of public engagement)

dimensions in which the informed consent process is embedded is often ignored (Corrigan and Williams-Jones, 2006) and there is a general “lack of consensus regarding the most appropriate method with which to communicate medical risks” (Ghosh and Ghosh, 2005). Nevertheless, it is now widely recognized that presentation of data has a strong influence on patient decisions (Mazur and Merz, 1993) and that decision theory can and should be used to improve the informed consent process (Holmes-Rovner and Wills, 2002). It appears that any decision aids, “regardless of the format or graphic representation of data” serve to increase patients’ knowledge (Holbrook et al., 2007) and that combining both quantitative and qualitative techniques is particularly effective (Ghosh and Ghosh, 2005). However, it is vital to point out that engaging citizens in deliberative risk communication efforts about emerging technologies is no substitute for patient centered risk communication efforts that seek to foster an informed consent *relationship* between a patient and a genetic counselor or physician. Informed consent directly involves an individual (or group in some cases) by requesting permission for an action that would not otherwise be permitted (e.g., a medical intervention). Deliberative risk communication on the other hand is performed at the social or aggregate level for collective decision making. While the objective of a deliberative exercise with citizens is to develop socially acceptable risk communication strategies, the intent of the informed consent relationship is to help patients make informed choices that they and their families can live with.

Lastly, bioethicists, risk communicators, and others need to be provided with opportunities to meet in settings that foster (and respect) an interdisciplinary approach to dealing with systemic hazards. Initiating such collaborations will likely be difficult given

the fact that communication between the groups rarely occurs despite the emergence of new interdisciplinary journals, funding opportunities, and degree programs at a variety of major academic institutions. Nonetheless, systemic health hazards must be confronted as they have the potential to significantly impact a broad range of stakeholders and systems. Meeting this new risk communication challenge is one way that communicators and bioethicists can come together to promote the overall health and wellbeing of individuals, groups, and society.

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Chapter three: Characterizing expert mental models for systemic hazards: the case of pre-implantation genetic diagnosis²⁷

Introduction

Characterizing how experts think about problems is an integral component of risk analysis for virtually any hazard. Individuals cultivate expert knowledge by working within a particular discipline or accruing specific skills or experiences over time. Risk analysts harness this expertise in several areas: probability elicitation, structuring risk assessments, developing modeling platforms, providing input on risk management decisions, and a range of other activities. The intention of this paper is to present a novel method of characterizing expert judgments about *systemic* hazards (as defined in the Introduction of this thesis) derived from mental model interviews in order to inform a participatory risk communication experiment.

Numerous approaches exist for eliciting expert information about potential hazards. The intention of most is to obtain judgments in formats relevant for policy-makers (De Bruin, 2006). Some methods can be described as consensus oriented (De Bruin et al., 2006; and Cooke and Goossens, 2004), which seek to clarify and obtain an integrated view of the facts of the matter or the breadth of issues relevant to the topic at hand. Such approaches work best for problems that draw on *cohesive* groups of experts with similar skill sets. However, new emerging hazards, referred to here as *systemic* hazards, involve uncertain outcomes at multiple scales, cross economic, social, ethical, technological and other

²⁷ A version of this chapter has been submitted for publication. Longstaff, Holly. Characterizing expert mental models for systemic hazards: the case of pre-implantation genetic diagnosis

domains, and are not bound by national borders (Renn, 2006).²⁸ These novel hazards require cooperation across sectors to support robust governance, risk management, and risk communication strategies (see McDaniels, Longstaff, and Dowlatabadi, 2006 and Renn, 2006 for examples²⁹). Communication strategies for these hazards often draw on heterogeneous expertise including from, at times, somewhat unconventional experts. In addition, it can be difficult for risk communicators to collate information across these diverse expert groups as there is often no consensus amongst heterogeneous experts about the nature, extent, and even the reality of systemic problems. It is asserted here that these new problems therefore require novel methods of eliciting and characterizing expert judgments capable of clarifying uncertainties and the full range of likely outcomes to relevant stakeholders. The need to identify new methods, theoretical perspectives, findings, and goals in the field of risk communication that are capable of coping with novel hazards is a new challenge for risk analysts. This challenge has been underscored in a variety of locations including a recent special edition of the *Journal of Risk Research* that presented a selection of papers from the “New perspectives on risk communication: uncertainty in a complex society” 2006 research conference that took place in Goteborg, Sweden (Boholm, 2008).

Systemic problems are unique in that they often involve both normative and interpretative ambiguity (Renn, 2006). Ambiguous risk problems differ from other complex hazards in

²⁸ Examples of systemic health hazards include: global climate change, genetically modified foods, biobanking and other genetic and genomic science technologies.

²⁹ In his recent 2006 white paper, Renn proposes a new “Risk Governance” management framework capable of handling ambiguous problems. Renn’s framework includes 5 core processes, 1) pre-assessment, 2) risk appraisal, 3) tolerability and acceptability judgment, 4) risk management, and 5) risk communication. Significantly, risk communication is central to the framework influencing and being influenced by all other processes. Of particular interest to communicators is the influence that communication is recommended to have on the pre-assessment phase, which includes problem framing, early warning, screening, and determination of scientific conventions.

that there is typically substantial disagreement as to how or if technologies or activities associated with these problems should be pursued at all.³⁰ Ambiguous risk problems require cooperation and engagement across sectors, expert groups, and civil society to determine an appropriate course of action. As such, these problems call for new participatory risk communication methods and approaches that reflect a range of social values (Renn and Klinke, 2004). The fact that a topic is normative (e.g., walking on the right side of the sidewalk) does not justify pursuing participatory risk communication. Normative ambiguity occurs in the “absence of a strong normative standard” (e.g., where there is no clear right side to walk on) (Burgess and Williams-Jones, in progress). Interpretative ambiguity occurs when it is unclear as to how the consequences of a potential risk will be experienced by individuals and groups at multiple scales and across domains. Participatory risk communication can be used to promote democratic public oversight or input for every phase of risk analysis (Renn, 2006 and Powell & Leiss, 1997).³¹

Systemic hazards³² are ripe with interpretative ambiguity. For example, health biotechnologies like pre-implantation genetic diagnosis (PGD) may lead to a range of multi scalar physical, emotional, ethical, economic, and social impacts that should be considered by decision makers. Pre-implantation genetic diagnosis may pose risks and benefits to *individuals* who undergo or have PGD performed on them (e.g., unknown long-term health outcomes for children born following the procedure and women who

³⁰ Take for example the ambiguous risk problem of genetically modified foods and activities associated with this topic such as mono-culture and mega-farming.

³¹ Unlike other approaches in which the public is brought into the risk analysis process only after hazards are identified and assessed.

³² Pre-implantation genetic diagnosis is used to analyze and screen genetic material from fertilized human embryos during in-vitro fertilization (see study context section.)

undergo PGD), individuals who *do not* undergo PGD (e.g., denial of insurance coverage to people who neglect testing and thus “choose” to bear children with disabilities), *groups* (e.g., by further *medicalization* of the pregnancy experience), and *society* (e.g., through economic impacts on the Canadian health care system).

Hoffmann et al report that most approaches for aggregating diverse expert judgements can be characterized as either behavioural (e.g., Delphi³³) or mathematical (e.g., probabilistic decision modeling) (Hoffmann, et al., 2006). These manipulate analytic languages derived through quantifying expert judgments (Fischhoff, 1989). Characterizing the risks and benefits of systemic hazards, such as PGD, call for a systematic method of eliciting expert information that can also account for distinct communication patterns and skill sets of conventional (e.g., genetic counsellor, physician) and unconventional experts (e.g., those living with disability, caregiver perspective). It is for this reason that the methods described here were based on a behavioural approach known as the mental models method as described by Morgan et al. (2002).³⁴

³³ *Delphi method* is an expert decision making model where participants revise answers in response to group feedback in rounds (if necessary). The views of earlier rounds inform each successive round until participants come to agreement (Dalkey, 1969).

³⁴ Morgan and co-authors explain that an individual’s mental model is informed by that person’s life experiences or worldview and help the individual to navigate through a very complex world. The mental models method recognizes that the minds of laypeople are not homogenous. Instead, this approach makes allowances for a person’s individuality while disseminating information in a systematic and ethical way. Each individual will use a set of ideas or mental models to predict the world around them and incorporate these ideas into their decision making processes. The dissemination process is designed to allow participants to examine a wide range of risks and benefits of a topic thereby allowing that participants to determine which options align with their values and beliefs (Morgan et al., 2002).

A mental model is a collection of thoughts and beliefs that a person holds concerning the functioning of the world (Morgan et al., 2002).³⁵ During the first stage of the mental models approach for risk communication, expert information is organized into a format that speaks to these models by addressing major uncertainties or points of common interest. The approach calls for a broad range of experts to be interviewed to minimize interviewer bias. One potential drawback associated with techniques typically used for characterizing expert judgments is that they often rely on quantitative methods, such as questionnaires, that cannot make allowances for diverse communication patterns of participants (See for example Bruine de Bruin et al., 2006 and Goossens, et al., 1998). In addition, experts run the risk of operating at one level or in one domain and can only report on their side of the problem. For example, a physician who conducts PGD develops a deep understanding of the technical and perhaps ethical dimensions of this technology and how successful this procedure can be in avoiding particular disabilities in the biological children of their patients. However, this expertise cannot be substituted for the *lived experience* of someone who cares for children with screenable disabilities (who we are attempting to avoid) or who has lived with that disability all their life. On the other hand, it is inappropriate for a risk communicator to allow the lived experience of disability to replace expertise concerning the technical and other dimensions of PGD when crafting their communication strategies. For the case of systemic hazards that involve multiple scales of impact across multiple domains, it is important for risk communicators to promote a holistic view amongst experts in order to characterize the full range of risks and benefits posed by the hazard in question (Renn and Klinke, 2004).

³⁵ It should be noted that the concept of a mental model can be traced back even earlier to the field of cognitive psychology (Holland et al, 1986; Johnson-Laird, 1983; and Gentner & Stevens, 1983)

The mental models method employs charts³⁶ that show deterministic decision pathways including uncertain outcomes (Morgan et al., 2002). While other studies (e.g., Willems et al., 2005) have employed charts to elicit judgment from homogenous expert groups, using charts to collate the judgments of a heterogeneous group of experts for systemic hazards is a novel use of these decision-making tools (Willems et al., 2005). In the experiment discussed here, literature findings regarding the risks and benefits of PGD were captured in a series of charts that were used to explore expert mental models throughout a series of individual interviews. Using charts allows the interviewer and participant to systematically explore the full range of risks and benefits of PGD at each scale and domain but does not constrain the responses or communication styles of the expert.

This paper focuses specifically on the ways in which the author characterized expert mental models of PGD and is one component of a larger research project.³⁷ The following section includes background information on PGD, the topic of interest for this study. The next section presents the results of an extensive literature review that sought to clarify risks and benefits at the family, group, and societal scales according to literature produced by experts relevant to PGD. The author's approach to characterizing expert mental models is described in the following section. This was accomplished through a series of expert interviews that were intended to confirm and supplement the literature review findings. Key insights and conclusions are presented in the final section.

³⁶ The book by Morgan et al uses the term *influence diagram* to refer to these figures. However other writers see influence diagrams as more formalized and with somewhat different conventions than seen in the Morgan work (e.g., Clemen, 1997). I use the term *charts* to avoid confusion.

³⁷ Phase one of this project was approved by the University of British Columbia's Behavioral Research Ethics Board (ID#H07-02574).

Study context: pre-implantation genetic diagnosis

Pre-implantation genetic diagnosis is used to analyze and screen genetic material from fertilized human embryos during in-vitro fertilization (IVF).³⁸ During PGD, cells (called blastomeres) or the polar body (structure extruded from the egg or embryo after fertilization that contains a copy of the maternal genetic material) are extracted from the fertilized embryo at day 3 when the embryo has 8-10 cells (Chen, 2005). DNA from these embryos is then multiplied thousands of times to identify specific genes. Embryos that do not carry genetic markers for a specific condition³⁹ are selected and implanted into the uterus of the female patient. Pre-implantation genetic diagnosis has a very high barrier for entry in Canada and only affects a very small proportion of live births. In Canada, approximately 12% of the population identifies with a disability and only about 3% of disabilities are solved through tests like PGD. Currently, fewer than 20 children have been born following PGD in Canada but over 1000 have been in the world (Health Canada, 2005). Under Canadian law, embryos that are not selected can be destroyed or donated to stem cell research, provided that the donors have given their free and informed consent and that no part of the embryo or the embryo as a whole was obtained through *commercial transactions* (CIHR, 2005).

There are three main applications for PGD, all of which are controversial for various reasons. The first application involves using the procedure to diagnose genetic conditions or chromosomal abnormalities through two different types of tests. The first detects

³⁸ It is important to note that although PGD must occur in conjunction with IVF, individuals pursuing IVF treatment are not required to undergo PGD.

³⁹ It is also possible to select FOR specific conditions such as deafness (Robertson, 2003).

irregularities in specific genes or DNA segments to avoid conditions such as cystic fibrosis or Tay-Sachs syndrome. The second test detects irregularities in the structure or number of chromosomes in order to avoid conditions such as Down Syndrome. The condition of having too many or too few chromosomes is known as aneuploidy. The test for aneuploidy is also called genetic screening because one is not testing for any specific marker. Some physicians hope that using PGD to detect aneuploidy in an embryo during IVF will also help to avoid first trimester pregnancy losses in women who may have otherwise experienced miscarriages due to chromosomal abnormalities or problems associated with age related infertility (Chen, 2005).

The second application for PGD is to determine the sex of an embryo. Sex selection can be used to avoid male embryos and instead, select female embryos that are less likely to be affected by sex linked disorders such as Duchenne muscular dystrophy or hemophilia. Individuals may also choose the sex of their embryo for non-medical reasons including “family balancing”. However, sex selection for this purpose is banned in Canada under Section 5 (1) (e) of the Assisted Human Reproduction Act (AHR Act) (Department of Justice Canada, 2004).

The final application for PGD is tissue typing or human leukocyte antigens (HLA) matching of tissue. During this process, PGD is used to select a *saviour sibling* or an embryo that is a tissue match for an existing sick child. The chance of rejecting donated tissue (i.e., bone marrow, umbilical cord blood) is significantly reduced if the donor’s antigens are similar to those of the older sibling (Devolder, 2005; and Wilkinson, 2004).

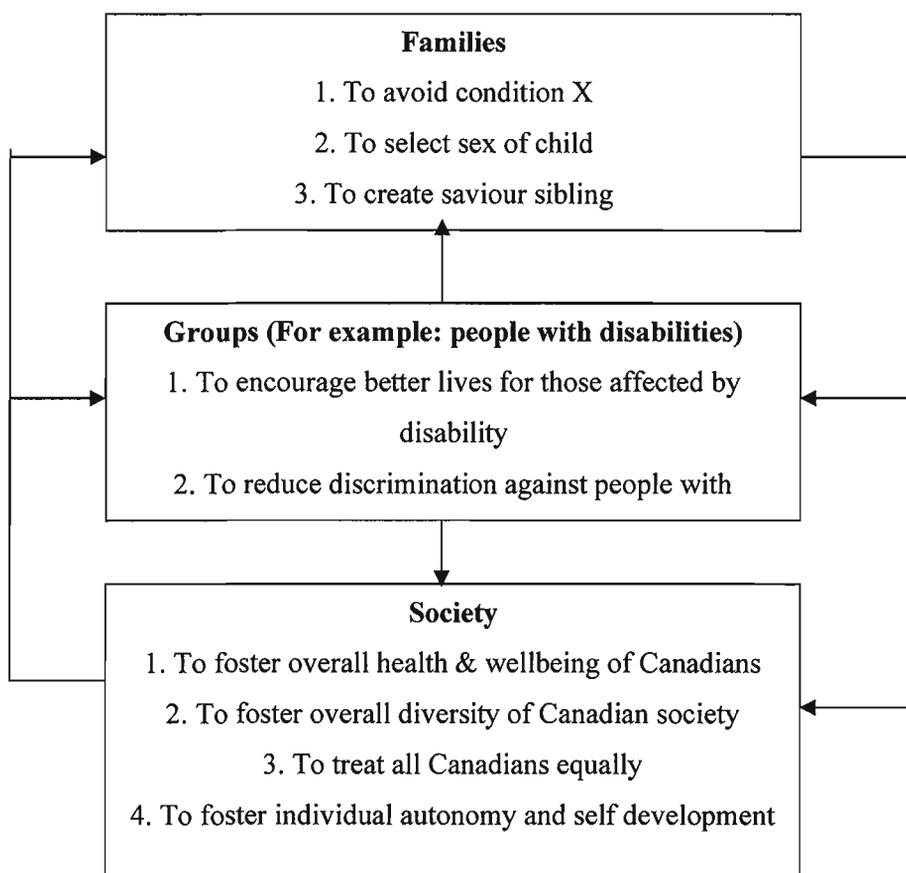
The expert literature review: clarifying risks and benefits for systemic hazards

The Mental Models Approach recommends seeking out a diverse range of experts when characterizing the known risks and benefits of a hazard. However, identifying relevant experts for the topic of PGD is not a straightforward task. Conventional approaches to stakeholder mapping are typically used to characterize stakeholders in order to predict their ability to influence the daily functions and key objectives of an organization, thereby addressing Freeman's (1994) "Principle of Who or What Really Counts." Although legitimacy is a key concern in such processes, some stakeholder groups that have morally legitimate claims may be inadvertently overlooked. Stakeholder mapping approaches are extremely effective in helping businesses to identify the most disruptive groups by mapping stakeholders according to criteria like power and interest (Gardner et al., 1986) or power to influence, legitimacy of the relationship, and urgency of the claim (Mitchell, Agle, and Wood, 1997). Determining "power positions" through the "systematic classification of entities of interest" (Sharma, 2003) help organizations to *manage* stakeholders (Newcombe, 2003). However, many unconventional stakeholders of PGD technology (e.g., people with disabilities, caretakers of children with disabilities) are neither powerful nor influential. In addition, their small numbers and limited influence is likely to only decrease if PGD becomes socially acceptable and used with increased frequency. Although PGD is a medical procedure performed by physicians, a thorough literature review of this technology revealed that the risks and benefits of PGD could be experienced at multiple scales, or levels of impact, by families, groups, and society. In other words, the risks and benefits of PGD stretch beyond the potential for PGD technology to achieve successful outcomes and the physical risks or benefits that

this procedure may pose to the women who use it and the children who are born following it. To identify or map stakeholders and experts groups that include both the relatively powerful (e.g., physicians who perform PGD and control access to it) and the relatively powerless (e.g., caretakers of children with screenable conditions), it is therefore necessary to employ different means of characterizing expertise.

Some potential decision objectives for PGD at various scales are shown in Figure 3.1 below. For the case of PGD, constraints set at broader levels (e.g., regulations) are intended to shape behaviour at narrower scales. However, the ideal of autonomous decision making promoted within the Canadian health care system (outlined in the section on risks and benefits at the group and societal scales) and the objectives of special interest groups (e.g., people with disabilities) also constrain the decision making system. It is necessary to find a way to integrate all of these ethically fraught decisions about a single technology into one systematic risk communication strategy. This goal was achieved here by conducting a thorough literature review of documents produced by experts relevant to PGD technology and confirming and supplementing these findings during expert mental model interviews.

Figure 3.1 Selected key objectives and the potential influence pathways of decisions at each scale.



The following section discusses sources for the information in Figure 3.2. It clarifies that risks and benefits posed by PGD technology at the family scale, and the group and societal scales. The information presented here is based on a thorough literature review of position statements and information produced by the National Society of Genetic Counsellors and the American Board of Genetic Counseling, academic papers written within the last five years and included on PubMed, and policy documents regarding PGD.

Clarifying risks and benefits at the family scale

The literature review began by identifying the risks and benefits of PGD at the family scale or the risks and benefits that the technology may pose to a woman's body and to the embryo, fetus, and child. Many of the issues discussed in this section would be similar to those addressed by a genetic counsellor⁴⁰ and can be characterized as primarily physical, technical, or psychological. Physical risks associated with PGD are often related to IVF, which, as previously mentioned, must be conducted in conjunction with PGD. For example, hormone injections that stimulate ovulation and the egg retrieval process during IVF are both physically invasive and will pose some risk to a woman's body. Other short-term risks that families must consider include Ovarian Hyperstimulation Syndrome (OHSS) and infections. There are also benefits associated with PGD and IVF (other than producing a biological child). For example, IVF lowers the risk of ectopic pregnancies or pregnancies that occur outside the uterus, which can endanger a woman life, cause severe bleeding and pain, and can lead to the death of a fetus. That said, the background risk of ectopic pregnancy is small (less than 2% in Canada).⁴¹

One significant physical risk associated with IVF, and therefore PGD, is multiple births, which is linked to the age of mother, the number of embryos implanted, and the quality of those embryos. Risks that multiple births pose to women include premature labour, difficult deliveries, physical and emotional stress. Risks to fetuses and children who are twins, triplets, etc. include increased risk of prematurity, neonatal mortality, SIDS, birth

⁴⁰ All those pursuing PGD must (1) be diagnosed with or be a carrier for a serious genetic condition and (2) consult with a genetic counsellor.

⁴¹ Statements derived from expert interview conducted during phase 1 of this project. Statistics Canada, Health Statistics Division reports that approximately 1.2% of pregnancies in Canada were ectopic in nature in 1994. For more on ectopic pregnancy rates in Canada please see Public Health Agency of Canada, 2002.

defects, developmental disabilities, and child abuse (Multiple Births Canada, 1998). Conducting single embryo transfers (often referred to as SET) during IVF for best candidates⁴² helps to eliminate this risk but also reduces the chance of becoming pregnant because fewer embryos are implanted overall.

It is also important to mention that PGD cannot guarantee a “normal” embryo. There are a series of technical challenges inherent to PGD that “can lead to a misdiagnosis of the embryo” and result in an abnormal fetus and child (Hudson, 2004). Testing occurs under strict time constraints and in addition, only small amounts of DNA are examined. Also, there is the potential for the child to carry or develop conditions that were *not* screened out through PGD.

Still other risks and benefits associated with PGD are psychological in nature. The psychological benefits of avoiding a dreaded condition must be weighed against a number of additional factors. In some cases, the biological father and not the woman who undergoes PGD will actually be the carrier of the genetic disorder being avoided. Perceived or actual resentment and guilt associated with this reality could increase stress levels experienced by family members. In addition, families may be asked to submit to additional tests throughout a pregnancy after PGD has occurred. Tests such as amniocentesis or CVS are often used to detect misdiagnosis (stemming from some of the technical challenges discussed earlier) and health of the fetus over time. A recent study determined that 96% of surveyed American IVF clinics either recommended or required

⁴² Younger woman under 35 who have good quality embryos among other things are typically defined as the best candidates for SET (Kissin et al., 2005).

such additional tests (Baruch et al., 2008). Continued or repeated testing may induce a sense of prolonged uncertainty and increase stress levels for family members.

Clarifying risks and benefits at the group and societal scales

Most would likely agree that there can be great social and biological pressure to reproduce. Yet families may suffer with infertility, have difficulty conceiving, or experience miscarriages and infant deaths (Franklin and Roberts, 2006). Those who are fertile may have an inheritable genetic condition that makes it almost impossible to have their own biological healthy children. Families in this situation may feel pressure to pursue technological solutions such as PGD to solve their fertility dilemmas and may fail to consider other alternatives such as adoption.⁴³ Some view entitlement over reproduction as an extension of one's entitlement to control his or her body. In addition, it may be asserted that parents should be entitled to a healthy child through whatever means possible (Leader, 1999). These views likely stem (in part) from the emphasis that Canadians and our Canadian health care system places on the bioethical principle of autonomy.⁴⁴ As explained by Sherwin (2000), patient autonomy is a "central value within virtually all health care ethics feminist or otherwise."

⁴³ But is adoption really a practical alternative for Canadians? Public adoption, or adoption through a government agency, for **an infant with no "special needs"** may take up to 8 years. Private adoption may take less time but can cost anywhere from \$10,000-\$18,000. Costs for international adoption may also take less time but are also costly varying from \$15,000 in Haiti, to \$30,000 in Guatemala, and as high as \$50,000 in the US (Canada Adopts, 2001).

⁴⁴ Autonomy is defined as the ability to govern one's own actions without interference from others (Beauchamp and Childress, 2001).

The prevailing norm within the health care system is to view competent patients as autonomous individuals who purchase health care services and actively participate in (or even dictate) the management of their own health care. This concept of the autonomous decision maker can be found in the National Society of Genetic Counsellor's (NSGC) Code of Ethics and Position Statements and literature produced by the American Board of Genetic Counselling (ABGC) as well as in the ethical codes of many other health practitioners (i.e., Canadian Nurses Association Code of Ethics for Registered Nurses (Canadian Nurses Association, 2002), Canadian Medical Association Code of Ethics (Canadian Medical Association, 2004)), and policies and legislation of various Canadian provinces (i.e., The Ontario Consent to Treatment Act, the Substitute Decisions Act, and the Advocacy Act, The BC Health Care (Consent) and Care Facility (Admission) Act, the Yukon Territory Care Consent Act, The Québec Civil Code and the Act Respecting Health Services and Social Services (Manitoba Law reform Commission, 2004)). While respecting an individual's autonomy is desirable in a health care setting, we must also consider how actions at the family scale may potentially harm citizens at broader levels by thinking through other generally accepted ethical principles such as distributive justice.⁴⁵

PGD technology may affect groups and society as well as individual families. For example, decisions made about this technology at the family scale may have an effect on groups such as all those who chose to give birth and people with disabilities. At the present time, PGD is rarely used in Canada; but suppose it were to become a standard part of prenatal care. When new technologies that screen and perform diagnostic tests on

⁴⁵ Distributive justice can be understood as the fair distribution of risks and benefits across all groups (Beauchamp and Childress, 2001).

fetuses are made widely available and used with increased frequency, these procedures may become standard practice and therefore difficult for all families to refuse (Shakespeare, 2005). Couples may not understand that they have the option of refusing standardized tests or screens and the range of potential consequences associated with these procedures may be masked.⁴⁶ A good example of this phenomenon is ultrasound technology.

Ultrasound is now standard practice for pregnancies in Canada and is typically viewed as an opportunity to see and bond with the fetus (Cook, 2003; Mitchell, 2001; Rothman, 1989; and Taylor, 1998) rather than as a medical screening procedure to detect abnormalities. Williams et al, 2005 report that many women are not prepared for negative results associated with this routine procedure and do not adequately consider the consequences of potential negative risk estimates in their decision to pursue ultrasound. This research team also found that many individuals falsely believed that negative results could be addressed by medical experts through processes like *in vivo* surgery (Williams et al., 2005). In reality, additional information cannot necessarily mitigate negative outcomes. Lastly, some women were found to experience long term anxiety from false positive problematic screens (Tymstra, 1986; and Weinans et al., 2000).

Another potential outcome of using PGD is that there will be fewer people born who have genetic disabilities. Some may argue that this will result in a net economic benefit for the Canadian health care system. Some are concerned that if PGD is viewed

⁴⁶ However, others are quick to point out that currently, most people are not eligible for PGD (as it has a high barrier for entry) and additional tests are not an option for those who oppose abortion. In other words, the reason some couples choose PGD in the first place is because it happens *before* pregnancy occurs. They do not want to use prenatal tests such as CVS or amniocentesis and then abort affected fetuses.

favourably in this way, then perhaps Canadians will begin to experience social pressure to submit to such technologies and remain consumers of genetic tests throughout their pregnancies. Pursuing technologies that screen for disability may also influence how we view all people with disabilities. Perhaps PGD will reduce our society's overall compassion for people with disabilities when they are viewed as undesirable. Society may even become less tolerant, or "try less" for adults with disabilities who already exist.⁴⁷ This outcome not only affects people with disabilities, it helps to shape the social and ethical norms of society. In short, it is in everyone's best interest to create a society that fosters diversity and compassionate behaviour towards all citizens.⁴⁸

The interviews: characterizing expert mental models

This section discusses the process of characterizing expert mental models for PGD. The first section describes the interview process while the second presents the final products of those interviews.

Experts interviews

The first step in phase one of this project was to complete a thorough literature review regarding the risks and benefits of PGD across domains at multiple scales (family, group, society) (see expert literature review section). These findings were then transformed into a series of charts that recorded major themes and possible outcomes. The charts were

⁴⁷ Statement derived from expert interview conducted during phase 1 of this project.

⁴⁸ For more on disability rights critiques of prenatal testing and screening please see Shakespeare, 1998 & Parens and Asch, 2000

organized around key themes regarding the technological and social risks and benefits of PGD. There were 6 charts in total, two of which (regulatory considerations and conditions screened for by PGD) were added in accordance with expert advice (see Appendix D to view charts and Appendix B for expert interview questions). The next step was to identify and recruit experts to evaluate these charts. Experts were selected to represent the major themes that emerged from the literature review. Additional experts were also added to this group based on recommendations by two or more participants. This review, which also served as one of the comprehensive exams for my doctoral program, was quite extensive in nature. It covered a vast array of information including position statements and information produced by the National Society of Genetic Counsellors and the American Board of Genetic Counseling, academic papers written within the last five years and included on PubMed, and policy documents regarding PGD. It was also informed by disability studies research and an extensive qualitative ethnographic study of couples who have undergone PGD (Franklin and Roberts, 2006). All who participated in this study are widely acknowledged as experts in this narrow field. Maintaining confidentiality of interview findings was therefore a particularly important and challenging experience.

The study topic draws on a diverse range of experts that include some lay stakeholders who have specialized knowledge of PGD (e.g., parents of children with disabilities). Even characterizing risks and benefits at the family scale involved a somewhat diverse group of medical experts who could help families work through the physical, psychological, and technological issues surrounding PGD. Table 3.1 illustrates the wide

range of expertise that was represented by the expert group. In total, eight experts were interviewed with a fairly even gender split.

TABLE 3.1 Overview of interviewee expertise

Experts	Ethical, economic, legal, & social dimensions	Reproductive medicine, genetics & genetic counselling	Other science	Disability rights advocacy	Parental perspective and lived experience
1. Mr A	√	√			
2. Mr B	√		√	√	√
3. Ms C	√	√			
4. Ms D				√	√
5. Ms E				√	√
6. Ms F	√				
7. Ms G	√	√			
8. Mr H		√			√

Risks and benefits at the family scale drew primarily on experts in reproductive medicine, genetics & genetic counselling, and the experience of living with or caring for someone with a disability. Major topics associated with the group and societal scales called for experts in the ethical, legal, economic, and social dimensions of PGD and disability rights advocacy. As shown in Table 3.1, most of those who participated in these interviews represented multiple fields of expertise.⁴⁹

The interviews were intended to provide some in depth analysis of key literature review findings. Including unconventional experts such as those with the lived experience of disability provided new insights and information that was not addressed by other experts. For example, the spectrum of conditions chart shown in Appendix F was created in

⁴⁹ It is worth noting that the author was unable to secure a policy expert for this phase of the project due to the fact that the Canadian policy framework for PGD is currently in flux. Policy experts considered participation inappropriate at this time. As a result, information regarding the Canadian policy context for PGD was gathered from web published reports and information.

response to unconventional expert advice and was a key component of the risk communication workshops for participants. It is worth noting that recruiting experts in PGD was a very difficult process as this topic is highly personal for many unconventional experts and highly political for most conventional experts. Some potential experts such as specialists employed by fertility centres refused to participate. In addition, those who have actually undergone PGD are difficult to locate in Canada as this procedure is rarely performed at present. It could be argued that additional or different experts may have modified the content of materials that were ultimately used to inform the risk communication workshops. Testing this hypothesis requires additional studies that compare the results of risk communication workshops informed by differently composed expert groups and employ innovative expert recruiting techniques that overcome some of the challenges faced during this study.

The expert interview phase of the study was broken into three steps. First, the expert was contacted via email to request their participation in this project. During this first email exchange, the expert was provided with a brief overview of the entire project and their potential role in this phase of the study. If the expert agreed to participate, they were then sent a more detailed explanation of their responsibilities, the charts, and a consent form. Each individual was given at least a week to review the charts, make comments, and prepare for the interview, which would take place in person, over the phone, or via email depending on their preference and location. Four of the experts were interviewed over the phone, one was interviewed via email, and the remaining three were interviewed in person. Interviews lasted approximately one hour on average.

Each expert was interviewed individually instead of in a less private format such as a focus group or panel. It was assumed that group discussions that included representation from the full range of expertise relevant to PGD may hinder participation from less conventional experts. Individual interviews (Fern, 1982) and discussion groups are both effective methods for generating ideas on a topic. It is also well documented that one of the strengths of group discussions is the interaction that occurs between participants, which is useful in exposing motivations or reasons behind opinions (Carey 1994, Carey & Smith 1994, Morgan & Krueger 1993). However, methods that fostered internal interrogation seemed inappropriate for a heterogeneous expert group that included both highly educated medical and academic participants and participants whose expertise was drawn from living with disability or caring for people with disabilities. Although all those interviewed for this portion of the study are recognized experts in domains relevant to PGD, they do not share similar educational backgrounds or communication styles in most cases. For example, an expert in caring for children with a disability screened for by PGD and a physician who has uses PGD technology to help patients avoid that disability in their future child both accrue their expertise over many years. However, conventional experts (e.g., a physician) are highly respected and powerful members of our society. Such experts have been trained to communicate their point of view clearly and confidently on a daily basis. On the other hand, unconventional experts (e.g., caregivers for the disabled) typically have no such training or social power. These individuals may find it difficult to argue against or challenge more powerful others. Milgram's research (as discussed in Cassell, 2005) demonstrates the human tendency to "obey the commands of an authority even when they conflict with our expressed desires or moral principles". Experts in this study were interviewed separately to avoid power issues. The goal of this

process was not to arrive at a convergence of views but instead to understand the diversity of perspective and variety of views held by experts in PGD technology. During the interview process for this study, all participants had the opportunity to reflect individually on the design of the study, the accuracy and completeness of the charts, suggest additional key readings, and tell stories. A few also sent additional documents and videos that were ultimately incorporated into phase 2 and 3 of the study where appropriate.

Final products

Experts were originally sent four charts that illustrated the risks and benefits that PGD may pose across domains at multiple scales of societal impact. These charts would act as a knowledge framework for choices about PGD technology. The charts indicating risks and benefits at the family scale focused on the consequences of PGD to a woman, and an embryo, fetus, and child and how these outcomes (characterized as primarily physical, technical, or psychological) may influence families. The charts indicating risks and benefits at group and societal scales focused on how PGD may pose risks and benefits for groups of people (e.g., people with disabilities, all pregnant women) and society in general (e.g., concerns regarding eugenics, how our society views and treats people with disabilities). Later on, two additional charts were created in accordance with advice offered during the expert interviewing process. One of these charts outlined a few of the issues that ought to be considered for the Canadian regulatory system. The other described the spectrum of conditions currently detected and avoided through PGD, which included non-fatal, fatal, early onset, and late onset conditions.

All of the charts were revised considerably during the first few interviews. For example, the chart illustrating the technical risks of PGD to the embryo, fetus, and child initially contained four major concerns after the literature review was complete and before the first expert was interviewed. By the end of the final interview however, this figure grew to contain eight major items and a significant amount of supplemental information (see Appendix E for an example of how this chart was revised in response to expert feedback). Bowen (2008) explains that data saturation is reached when “nothing new” appears to be emerging from a data set and no new categories can be added. In other words, all additional information can be fit into existing categories. Theoretical saturation, on the other hand is reached when no new themes or issues regarding a category are revealed. As interviews conducted for this study progressed, fewer and fewer changes were requested and eventually no new themes, issues (Strauss and Corbin, 1990) or categories (Morse et al, 2002) were presented. It was determined that data saturation was therefore sufficient in terms of breadth and novelty of expressed opinions to move forward to the risk communication stage of this study. (Guest et al, 2006). Experts interviewed during early in the process were also given the opportunity to review and comment on subsequent revisions. The final revised charts include comments from all eight experts who were interviewed during phase one of this study and became the basis for all materials used during subsequent phases of the project. While charts indicating risks and benefits at the family scale included information on quantitative details such as probabilities and background risks, charts illustrating risks and benefits at broader scales focused more heavily on ethical outcomes, and other social risks and benefits (see Figure 3.2). The intention of the charts is to outline decision pathways and points of shared uncertainty.

Figure 3.2 illustrates a series of uncertain consequences and considerations at the societal scale that stem from and interact with decision pathways regarding PGD at the group and family scales. The information contained within the figures represents the diversity of opinion expressed by the expert group. Disagreement is represented within the chart nodes. For example, all experts who participated in this study agreed that in theory, ethical dilemmas may emerge if “diagnostic tests on fetuses were to become “standard practice””. However, some were careful to add that currently, “very few are eligible for PGD and would not have additional tests anyway.”

Figure 3.2 Chart indicating social risks and benefits of PGD

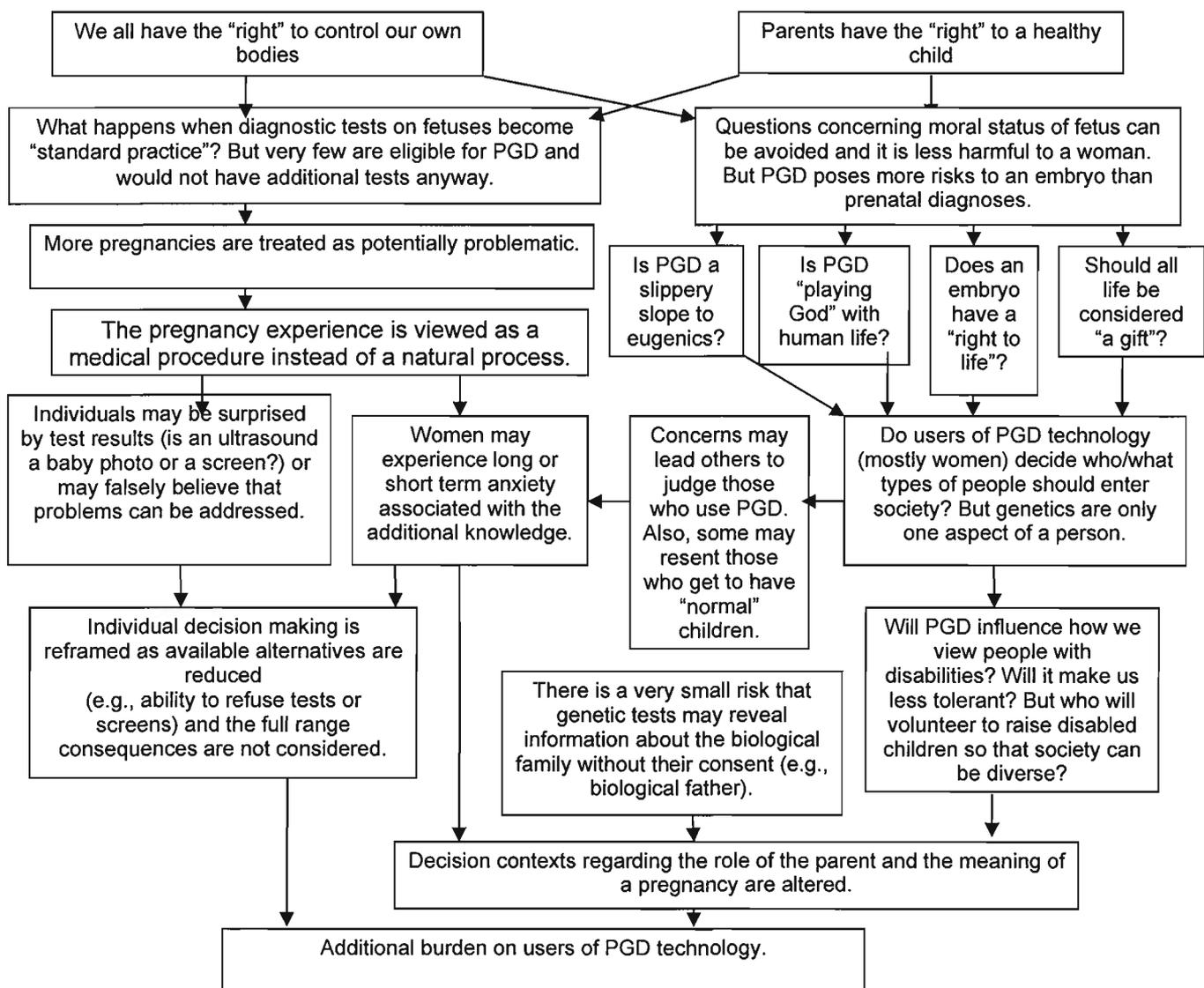


Figure 3.2 provides a knowledge framework for choices concerning PGD. This figure illustrates how perceived “rights” such as the *right* to control one’s own body coupled with the *right* to a healthy child can lead to implications for groups of people. For example, new reproductive technologies can modify medical norms as acceptance of these procedures by experts and lay users grows. These tests may even become

standardized, or a standard part of medical care, in some cases. Standardized reproductive tests (e.g., ultrasound) have an effect on all those who wish to conceive a child when they must accept the additional risks and benefits associated with these tests (e.g., how to make sense of and deal with the additional knowledge they produce).

Pre-implantation genetic diagnosis may successfully avoid certain long standing ethical debates in reproductive medicine such as the moral status of the fetus because it is conducted before pregnancy occurs. However, the technology raises new moral dilemmas for some (e.g., playing God with human life (Cole-Turner, 1999), rights of the embryo (Human Research Project, 2006)). In addition, questions arise concerning who should have the responsibility for determining what types of embryos should be allowed to develop in our society and how these decision makers will then be perceived by other non-users of PGD technology. While PGD may pose a very small risk to some who may not have consented to this procedure (Dugan et al., 2003 and Tassicker, 2003), it is argued that PGD poses a significant risk to existing and future people with disabilities (Knoppers, Bordet, and Isasi, 2006). For example, there are concerns that PGD technology may normalize discrimination against people with disabilities by expressing the view that the lives of those with disabilities are not worth living (Buchanan, et al., 2000 and Albert, 2004). All of these collective outcomes have the propensity to change current decision making contexts regarding the role of the parent and the meaning of a pregnancy and will ultimately place a great deal of additional pressure on users of PGD technology.

Conclusions

The objective of this paper was to share a novel method of eliciting expert judgement. The approach described in this paper is effective for systemic hazards (like PGD) that draw on diverse heterogeneous groups of experts. It allows for qualitative feedback capable of incorporating a range of discrete skills sets and communication styles unlike conventional methods that embrace quantitative measuring tools like questionnaires. In addition, characterizing the mental models of experts through a series of charts was effective in fostering “all things considered” judgments for an ethically continuous issue (McDonald, 2000). The interviews confirmed and corrected many literature review findings but more importantly, supplemented these findings with personal, value-oriented messages communicated by those deeply engaged in PGD research.

This study topic draws on a diverse range of individuals that include conventional medical experts, lay advocates, and experts in the ethical, legal, and social dimensions of novel technologies. It was therefore necessary to produce interviewing methods that could accommodate diverse modes of communication and skill sets. Using charts to illustrate decision pathways and points of shared uncertainty for PGD technology across domains and at multiple scales allows for experts to deliver judgments in a qualitative fashion using a range of communication styles. While some experts interviewed during phase one of this study used information contained in each text box to constrain discussion, others used this information as starting off points for story telling. Unlike survey instruments, the charts are fluid, robust documents that are modified continually

after each interview until they accurately reflect persistent disagreements and the range of views expressed by a group of diverse experts.

Pre-implantation genetic diagnosis can be described as a systemic risk topic because the outcomes of this technology extend beyond the families who use it to potentially influence groups and society. The technology also involves many ethically contentious issues related to eugenics, quality of life, and reproductive rights to name only a few. Bioethicists and risk analysts alike have called for “all things considered” judgments when approaching such topics (McDonald, 2000; Sherwin, 2008; Renn, 2006; and Renn and Klinke, 2004). In other words, we must consider all relevant scientific, social, ethical, environmental, and economic aspects of the issue and how these outcomes play out at multiple scales while making our decisions. The charts produced for this study foster holistic judgments because each expert who views them is encouraged to systematically consider the web of decisions that stem from each decision surrounding PGD, instead of the details pertaining solely to their area of expertise.

The information gathered through these interviews was compiled and transformed into materials that were eventually used during phase 2 and 3 of this project (discussed in Chapters 4 and 5 of this thesis). Phase 2 of this project invited lay citizens to participate in mental models interviews about PGD. During the interview process, individual participants were asked open ended questions that helped them to explore their own mental model of PGD. Findings from these interviews were then used to complement and inform phase 3 results. Phase 3, the final phase of this project, was a risk communication experiment. The objective of this experimental workshop was to have lay citizens

evaluate and create risk communication strategies for PGD after learning as much about the relevant risks and benefits of this technology as possible. The underlying assumption of this study is that technologies like PGD have the potential to produce both harms and benefits to individuals, groups, and society. Lay citizens who comprise our society should therefore have a say in how we develop risk communication strategies for these novel hazards. The workshop accomplished a number of tasks. First, participants filled out a pre-deliberation questionnaire that tested their knowledge of the risks and benefits of PGD. They then received information about PGD in different risk communication formats during a 35 minute power point presentation. After the presentation and a short break, they deliberated in order to develop risk communication strategies for PGD. Treatment A participants deliberated in conventional focus groups while treatment B participants deliberated in structured decision making discussion groups. After the group discussions were concluded, all voted privately on their preferred risk communication strategy in their workbooks. The final task was to complete the post-deliberation questionnaire, which tested a number of outcome variables (i.e., learning, changes in confidence levels). Anonymized study results will be presented on a password protected website for expert and lay participants from all phases of the project to view. It is hoped that findings gleaned from this project will help to inform standards and methods of communication for other systemic hazards within the health domain.

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Chapter four: Learning about systemic hazards through a risk communication experiment: the case of pre-implantation genetic diagnosis⁵⁰

Introduction

Pre-implantation genetic diagnosis (PGD), or the genetic screening of fertilized human embryos before implantation, poses significant challenges to the field of risk communication. It is an ethically contentious reproductive technology that leads to a range of ambiguous and uncertain outcomes at multiple scales (e.g., family, group, societal). Potential stakeholders for this systemic hazard⁵¹ include a wide range of citizens such as disability activists, bioethicists, geneticists, those living with disability, childbearing women, and genetic counsellors, to name only a few (See Chapter 3 of this thesis). Information concerning the risks and benefits that this technology may pose to this unconventional group of stakeholders is frequently value laden, controversial, and extremely complicated. Risk communication strategies that attempt to disseminate this information must therefore carefully address a wide range of multi-scalar outcomes with both technically -oriented (e.g., probabilities of negative health outcomes for individuals) and value-oriented (e.g., value based concerns of disenfranchised groups) information.

Fortunately, the social dimensions of risk (including affect and values) have been an important area of study in the field of risk communication for some years and many important contributions have been made over the past few decades (McComas, 2006). The influence that social and cultural factors have on risk perceptions is well documented

⁵⁰ A version of this chapter has been submitted for publication. Longstaff, Holly. Learning about systemic hazards through a risk communication experiment: the case of pre-implantation genetic diagnosis.

⁵¹ Please see the Introduction of this thesis for more on systemic hazards.

(see for example Douglas & Wildavsky, 1982; Short, 1984; Kasperson et al, 1987; and Slovic & Gregory, 1994). In addition, emotions have been shown to play both a significant and necessary role in decision making processes. The risk as feelings hypothesis suggests that cognitive factors and emotions such as dread and worry play a complimentary role in risk decision making (Loewenstein et al, 2001). Griffin and colleagues' Risk Information Seeking and Processing or RISP Model helps to explain how individuals come to understand and cope with risk messages (Griffin et al, 1999). The influence of emotions and feelings in decision making is also explored in Slovic et al (2005), Klein (1999), and in Clore, (1992). Clore's affect-as -information hypothesis models how feelings influence social judgments.⁵²

The study described in this thesis contributes to this area of analysis by conducting a mental models risk communication experiment about PGD that includes both value-and technically-oriented components (Morgan et al, 2002). The thesis contribution is unique in both topic and method. While many experiments are conducted in the field of risk communication, experiments that test structured decision making approaches are rare (Arvai et al, 2001). The study employs a within-subject,⁵³ before and after comparison experiment that analyzes how participants learn about the ethically contentious and novel risks and benefits associated with PGD. The fundamental objective is to gather empirical evidence that shows lay citizens can in fact learn a great deal about a range of technically and value-oriented risk/benefit messages. Furthermore, it will be demonstrated that

⁵² These are of course of mere selection of research studies focusing on affect and decision making. A more detailed bibliography can be found on Decision Research's Affect and Emotion publication list at <http://www.decisionresearch.org/research/affect/publications.html>

⁵³ This term is used to describe studies in which repeated measurements are taken from the same participants.

citizens can consider these messages in ways that enhance (not replace) their own views, which are likely to be largely normative and value based. The research questions specifically addressed are shown below.

1. Can conventional risk communication methods such as the mental models approach be used effectively for unknown hazards like PGD?
2. How much can we expect lay participants to learn about an unknown systemic hazard during one 2.5-hour workshop?
3. Does the knowledge provided to participants increase their overall confidence levels?
4. Which risk communication methods do participants prefer and find the most trustworthy for systemic hazards?
5. Do participants believe that it is sensible to rely on collaborative risk communication processes that include perspectives from both lay and expert citizens?
6. Is it ethical to include value-oriented messages when considering the risks and benefits of systemic hazards or are these messages unjustifiably persuasive?

The following sections describe the topic for this study and the study context including a description of the lay participant samples. The next section outlines the mental models method and interview results followed by a discussion of the workshop methods and results. The final section discusses study results in light of the research questions shown above and offers conclusions.

The topic: pre-implantation genetic diagnosis

Pre-implantation genetic diagnosis is used in conjunction with in vitro fertilization (IVF) to screen in vitro fertilized human embryos. The three main applications for PGD are (1) to detect abnormalities or irregularities in specific genes or DNA segments to avoid particular genetic conditions, (2) to determine the sex of an embryo, or (3) for tissue typing or human leukocyte antigens (HLA) matching of tissue. This third application is

also sometimes described as creating a “saviour sibling” for an existing sick child (Devolder, 2005). All applications of this technology are contentious for various reasons. For example, the concept of sex selection is so controversial in Canada that it has been banned under Section 5 (1) (e) of the Assisted Human Reproduction Act (AHR Act). Direct connections with other divisive scientific areas (such as stem cell research) may also fan controversies surrounding PGD. After the PGD process is complete, it is possible for families to donate unused embryos to stem cell research. Although stem cell applications offer tremendous hope for some (e.g., patient groups), they also involve a range of serious ethical concerns (CIHR, 2005 and Giacomini, Baylis, & Robert, 2007). These issues, among others, are complicated by the fact that the outcomes of PGD can be difficult to anticipate in some cases.

Pre-implantation genetic diagnosis can be characterized as a systemic hazard because, like many other genetic and genomic science applications, it crosses technological, economic, social, and ethical domains and leads to an ambiguous range of outcomes at multiple scales for a wide range of stakeholders. This reproductive technology affects *individuals* who use it and the children who are born following it, *individuals* who do not use it who may feel pressure to screen their embryos, *groups of citizens* who believe that this technology may normalize discrimination against people with disabilities or further medicalize the pregnancy experience for all women, and *all citizens* who are affected by a technology that has the propensity to substantially influence societal and ethical norms (for more on PGD as a systemic hazard please see the Introduction to this thesis).

Study overview and samples

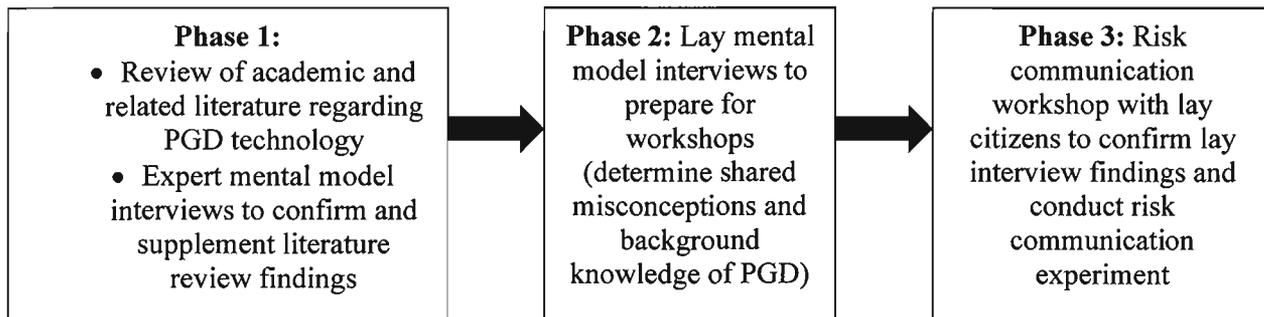
This research project included three phases with each subsequent phase building on information gathered during earlier stages (see Figure 4.1).⁵⁴ The first task was to undertake an extensive literature review of the risks and benefits of PGD at multiple scales. Findings from this review were then evaluated and supplemented during a series of expert mental model interviews (phase 1).⁵⁵ Phase 1 results can be found in Chapter 3 of this thesis. The second phase⁵⁶ comprised a series of mental models interviews with lay citizens. Expert information from phase 1 was used to guide questions and the purpose of the interviews was to determine participants' general understanding of PGD technology and common misconceptions that would have to be addressed during the workshop (Phase 3). All information disseminated to lay participants during the risk communication experimental workshops was based on phase 1 and 2 results.

⁵⁴ Other public engagement efforts about PGD in Canada include the Federal Health Canada (2005) initiative and Orchids theater project (Cox, Kazubowski-Houston, and Nisker, 2009).

⁵⁵ The first phase of the study was reviewed and approved of by the University of British Columbia's Behavioural Research Ethics Board (BREB) (H07-02574)

⁵⁶ The second and third phases of this study were also reviewed and approved of by the University of British Columbia's BREB (H08-00700)

Figure 4.1 Conceptual framework for study



This chapter focuses on Phases 2 and 3 of this study or the results of lay mental model interviews and experimental risk communication workshops conducted with lay citizens of Vancouver, British Columbia, Canada. The lay interviews and workshops took place over the summer and fall of 2008. Sixteen individuals participated in the interview process⁵⁷ while fifty-seven participated in one of eight 2.5- hour workshops. All were recruited through poster advertisements and were randomly assigned to be either interviewed or participate in one of two workshop treatment groups. The recruitment goal was not to represent any specific group or population but instead to test learning outcomes and differences between treatments (structured and unstructured decision making) during a risk communication experiment. The participant samples for both methods are therefore not representative of the greater Vancouver population. The workshop participants represented a wider range of cultural and employment

⁵⁷ Interviews typically lasted between 45-60 minutes.

backgrounds (among other things) than those who participated in the mental model interviews⁵⁸ (see Table 4.1).

Table 4.1 Demographic statistics of interview and workshop participants

Demographic statistics	Interview participants	Workshop participants
Gender		
Female	69%	60%
Relationship status		
• Married	6%	16%
• In a relationship	19%	26%
• Single	69%	53%
• Divorced	6%	5%
Children		
Yes	13%	18%
Age		
• Under 30	50%	47%
• 31-50	50%	46%
• Over 50	---	7%
Self identified cultural background		
• Caucasian	13%	23%
• Asian	50%	21%
• Canadian	13%	14%
• English/Scottish /Irish	6%	9%
• Muslim /Hindu/Indian	---	7%
• Black/African	6%	4%
• Brazilian	---	4%
• Eastern European	19%	4%
• First Nation, urban/rural, Turkish, Central European, or unspecified international	---	11%
• No response	---	5%
Occupation		
• Student/graduate student	50%	33%
• Artist /writer /film maker/actor/musician /jeweller/dancer	6%	18%
• Customer service /food server /bank teller /landscaping/ administrative	---	14%
• Teacher/instructor /social worker/librarian	6%	14%
• Researcher /analyst /consultant	19%	5%
• Non profit /fundraising /government	---	5%
• Home maker	---	4%
• Unemployed/on disability	19%	4%
• Natural medicine /healing consultant	---	4%

* percentages may not equal 100% due to rounding

⁵⁸ Each workshop consisted of a mix of the above demographics with no more than 2-3 students per group.

Mental model interviews

Methods

Lay interviews were based on the Mental Models Approach as described by Morgan, Fischhoff, Bostrom, and Atman (Morgan et al, 2002)⁵⁹. Morgan and his colleagues believed that it was possible to improve the overall effectiveness of risk communication by developing a more systematic approach that acknowledged the influence that an individual's pre-existing knowledge structures and beliefs can have on how she learns new information. A mental model includes a person's knowledge, attitudes, beliefs, values, perceptions, ethics, and inference mechanisms regarding a hazard (Slovic, 1992 and Morgan et al, 2002). As explained by Morgan et al, each individual has (or attempts to form in real time) mental models of how their complex world operates. This set of ideas is incorporated into an individual's decision making processes and is used to help predict and cope with the world around them.

The interviewing method employed in this thesis resembles the mental models method as explained by Morgan and colleagues but also differs in a few key ways. The format of a mental model interview is similar to a long open ended conversation. Although the same set of questions is asked to each individual, the process is largely participant driven. The participant is encouraged to speak to each topic for as long as they wish with minimal interference from the interviewer. The questions that guide the process are intended to

⁵⁹ The concept of a mental model can be traced back even earlier to the field of cognitive psychology (Holland et al, 1986; Johnson-Laird, 1983; and Gentner & Stevens, 1983)

probe the participant's awareness of the hazard in question and its associated risks and benefits in order to identify significant misconceptions that may hinder the comprehension of new information and shared knowledge gaps, among other things. For the case of PGD, it is important to determine if participants are aware of this technology or others like it and what risks and benefits may be associated with this procedure at multiple scales for a diverse range of stakeholders. A selection of lay mental model interview questions used in phase two of this project is provided in Table 4.2 below (see Appendix C for the complete list). Pre-testing of 3 individuals to prepare for the mental model interviews confirmed that most citizens have very minimal awareness or knowledge of PGD technology (as discussed below in the interview result section). In some cases, probing with more familiar terms that are related to PGD such as genetic testing, IVF, and prenatal testing helped participants to explore issues relevant to all such technologies. However, probing mental models related specifically to PGD was impossible and very frustrating to the participant without some kind of additional information from the interviewer. This study therefore took the unusual step of providing the interview participant with definitions of IVF and PGD after all conversation had been exhausted. Both pre- tested and formally interviewed participants found it extremely helpful to hear these definitions. Participants were then asked about more specific risks, benefits, and stakeholders for PGD technology to determine awareness of or ability to anticipate information included in the finalized expert charts.

Table 4.2 Selected introductory mental model interview questions for PGD technology

1.	Have you ever heard of pre-implantation genetic diagnosis or PGD?
2.	a) [If yes] Please tell me everything you know about it. b) [If no] What do you think this term means?
3.	How did you come to learn this information?
4.	Have you ever heard of in vitro fertilization or IVF?
5.	a) [If yes] Please tell me everything you know about it. b) [If no] What do you think this term means?
6.	How did you come to learn this information?

The mental models approach is mostly known for its effectiveness in addressing familiar hazards⁶⁰ (Byram, Fischhoff et al, 2001). It is likely that most lay citizens will be aware and have at least some background knowledge of such hazards, although serious misconceptions may also be present. For example, research on breast implants determined that women participants tended to worry about phantom risks (e.g., implants rupturing due to airbag deployment during motor vehicle accidents or mammography) at the expense of actual risks (e.g., undetected leakages) (Byram, Fischhoff et al, 2001). Byram et al addressed these embedded misconceptions and through reflective discourse, helped participants to develop personal risk management plans in line with their health objectives (e.g., requesting specialized mammography procedures).

Interview results

Past research has suggested that the North American lay public has very little awareness of PGD. In 2003, researchers at Johns Hopkins University conducted 21 focus groups

⁶⁰ Examples of other familiar hazards include radon gas (Morgan et al, 2002) or global climate change (Bostrom et al, 1994).

with 181 participants from 5 American cities as part of their “Reproductive Genetic Testing: What America Thinks” project. They found that most of their participants were not familiar with PGD (Genetics and Public Policy Centre, 2003). Phase 2 mental model interview results confirmed the 2003 finding. Nearly all reported that they had never even heard of the term pre-implantation genetic diagnosis or its acronym PGD. It may therefore seem curious to conduct mental model interviews for this unfamiliar topic. One might assume that it would be impossible to explore a person’s mental model of a virtually unknown technology. However, interview findings did indicate that although participants did not have any significant background knowledge of PGD specifically, they were familiar with IVF, which must occur in conjunction with PGD. Understanding IVF is a vital step in understanding PGD as these two technologies share many of the same risks and benefits (e.g., risk of Ovarian Hyperstimulation Syndrome, lowering the risk of ectopic pregnancies, increased risk of multiple births,). Pre-implantation genetic diagnosis is a complicated systemic hazard involving a vast array of anticipated outcomes at multiple scales. Identifying areas of pre-existing relevant knowledge that can be supplemented is an important step in any efficient risk communication effort.

The mental model interviews also revealed a series of concepts that were particularly difficult for most participants to grasp. It is vital for risk communicators to clarify these misconceptions before participants may consider the full array of risks and benefits of PGD technology. First, interview participants had a very difficult time anticipating the stakeholders of PGD technology or those who may be affected by the outcomes of this procedure. Even after being provided with a description of PGD and consistent interviewer probing, participants were generally unable to conceptualize the full multi-

scalar outcomes of PGD.⁶¹ Most identified women, families, physicians, and scientists as stakeholders but very few identified groups such as people with disabilities or society as having a vested interest in this technology, contradicting popular expert views on the matter. For example, it is argued by some that PGD technology has the potential to normalize (Shakespeare, 2005) discrimination against people with disabilities by expressing the view that the lives of those with disabilities are not worth living (Buchanan et al, 2000 & Albert, 2004). If participants cannot identify major stakeholders for a technology, then they cannot accurately consider the full range of risks and benefits of that technology at multiple scales.

Another significant misconception involved the relationship between PGD and IVF. Most individuals who pursue PGD technology are not actually infertile like users of IVF technology. Instead, these individuals must submit themselves to the risks and benefits of IVF only so that they may screen their embryos. In other words, users of PGD technology are submitting themselves to unnecessary risks and benefits (in a sense)⁶² as they are not necessarily infertile. Most could conceive a child naturally, although that child may: be born with a genetic or chromosomal abnormality; not be their preferred sex; or may not be a tissue match for their existing sick child. Many interview participants assumed that users of PGD technology were infertile.⁶³

⁶¹ Difficulties in conceptualizing complex systems are referred to as *systemic blind spots* (McDaniels, 1998).

⁶² Of course those who pursue PGD technology would likely believe that benefits associated with screening their embryos far outweigh any additional risks posed by IVF.

⁶³ The assumption that PGD users were infertile was likely due to participants conflating PGD with the more familiar IVF technology, which is intended to help people with infertility.

Risk communication experimental workshops

Methods

Risk communication experimental workshops (the third and final phase in this study) took place in August and September, 2008 with a diverse sample of lay citizens. There were eight in total and each 2.5-hour workshop included 4 parts: a 20 minute pre-deliberation questionnaire; a 30 minute presentation of background information concerning PGD; a one- hour small group deliberation with all participants; and a 30 minute post-deliberation questionnaire (see Table 4.3). Half of the workshops included a structured decision making component while the others did not. The structured decision making component in the form of consequence matrixes were shown only to randomly assigned treatment B workshop participants (to view all matrices please see Appendix F). Treatment A participants received no information regarding the objectives and alternatives for PGD in terms of consequence tables, and were therefore considered the control group. Differences in deliberation outcomes between these two treatments will be the focus of Chapter 5 and will not be discussed here. Workshops results most central to this paper include the ability of participants from both treatments to learn about various aspects of PGD.

Table 4.3 Workshop format

Workshop agenda	Purpose
1. Pre communication questionnaire	<ul style="list-style-type: none"> • To determine background knowledge • To confirm mental model interview findings
2. Risk communication materials in different formats	<ul style="list-style-type: none"> • To learn about risks and benefits of PGD at multiple scales
2.b *Structured decision making exercise for treatment B only*	<ul style="list-style-type: none"> • To learn about key value objectives and alternatives for various stakeholders through consequence table
3. Group deliberation	<ul style="list-style-type: none"> • To explore potential risk communication strategies while drawing on information presented during workshop
4. A) Private vote	<ul style="list-style-type: none"> • To privately describe recommended strategy
B) Post communication questionnaire and workshop evaluation questions	<ul style="list-style-type: none"> • To determine how much participants learned over the workshop and how their opinions may have changed. • To rate workshop according to criteria
* Each workshop also included a short break.	

The pre-deliberation questionnaire provided an overview of participants' baseline understanding of the risks and benefits of PGD at multiple scales. It also sought to confirm lay mental model interview findings (see Figure 4.2).

Figure 4.2 Selected question from pre and post deliberation questionnaire

4) As far as you know, what are the applications of PGD?

(Feel free to circle more than one response)

- a) PGD is used to diagnose genetic conditions or chromosomal abnormalities.
- b) PGD is used to help **infertile** couples achieve pregnancy.
- c) PGD is used to determine the sex of an embryo.
- d) PGD is used to diagnose abnormalities **during** pregnancy.
- e) PGD is used to match tissue to create compatible cells for an existing child.
- f) Don't know

26) Who would likely be the most affected by the use of PGD?

(Feel free to circle more than one response)

- a) Families
- b) Women
- c) Children
- d) People with disabilities
- e) Disability activists
- f) Families affected by disability
- g) Religious groups
- h) All Canadians
- i) Others (please name) _____
- j) Don't know

The background PowerPoint presentation provided lay participants with the expert information collected during phase one of the study in a variety of formats including: Frequently Asked Questions (FAQ's), newspaper stories, videos, audio recordings, and charts. The FAQ's were generated by the author and addressed technically-oriented information about PGD that experts deemed significant. The charts discussed the technical risks of PGD to the embryo, fetus, and child; medical risks of PGD to a woman; and social risks of PGD. They were all generated by expert participants and the audio recording was based on the charts (see Appendix H for audio scripts and Appendix D for

charts). All these items emphasized technically-oriented information. The newspaper stories were published accounts written by journalists and recommended by experts (see Appendix I). They emphasized value –oriented information as did the videos. The 2 videos were recommended by experts and created and published by (1) Nova Scotia Down’s Syndrome Society and (2) the National Tay-Sachs & Allied Diseases Association (PSA) (see Appendix J). After a short break, participants received some additional background about the field of risk communication and then participated in a small group deliberation. The objectives of the deliberation were to discuss their views on preferred risk communication strategies for PGD and evaluate workshop materials and methods. Participants also discussed who should communicate these risks and benefits and potential target audiences. It is important to note that participants were not asked to consider individual choices or opinions during the discussion (e.g., would *you* use PGD technology?). Instead, the intention was for participants to offer advice regarding socially acceptable risk communication strategies for PGD. In other words, participants were asked to consider what information *should* be available for Canadians and in what format. To accomplish this task, participants would need to consider the consequences for relevant stakeholders, (especially unanticipated stakeholders identified through mental model interview findings and highlighted in the consequences matrixes introduced to half the groups) in light of the participant group’s ethics and norms.

The last step in the workshop was to complete a post-deliberation questionnaire. To minimize social pressure, this second questionnaire gave participants the opportunity to write down their preferred risk communication strategy for PGD (that need not agree with any group decisions). The questionnaire also duplicated all questions from the first

survey to test learning and preference changes over the course of the workshop. Evaluation questions that pertained specifically to the workshop methods and goals were also included (see Figure 4.3).

Figure 4.3 Selected rating questions from post-deliberation questionnaire

For the following questions, please check off \checkmark only one response

Of all the information provided to you today, which was the...

Information types	3) most important when considering your private vote? ⁶⁴	4) least important when considering your private vote?
a. The presentation of FAQ's about PGD		
b. The audio recordings that discussed the technical risks of PGD to a woman		
c. The charts that discussed the technical risks of PGD to a woman		
d. The audio recording that discussed the technical risks of PGD to the embryo, fetus, and child		
e. The charts that discussed the technical risks of PGD to the embryo, fetus, and child		
f. The audio recording that discussed the social risks of PGD.		
g. The charts that discussed the social risks of PGD.		
h. The videos that talked about different types of conditions.		
i. The news articles that talked about different types of conditions		
j. The small group discussion		
k. The opinions that I held before the workshop.		
l. Other _____ _____		

16) In your opinion, is it sensible for risk communicators to rely on a process like this one when determining risk communication strategies for PGD?

(Please circle one)

YES

NO

Don't know

⁶⁴ This was the portion of the workshop where participants had the opportunity to "vote" and explain their preferred risk communication strategy for PGD.

Workshop findings

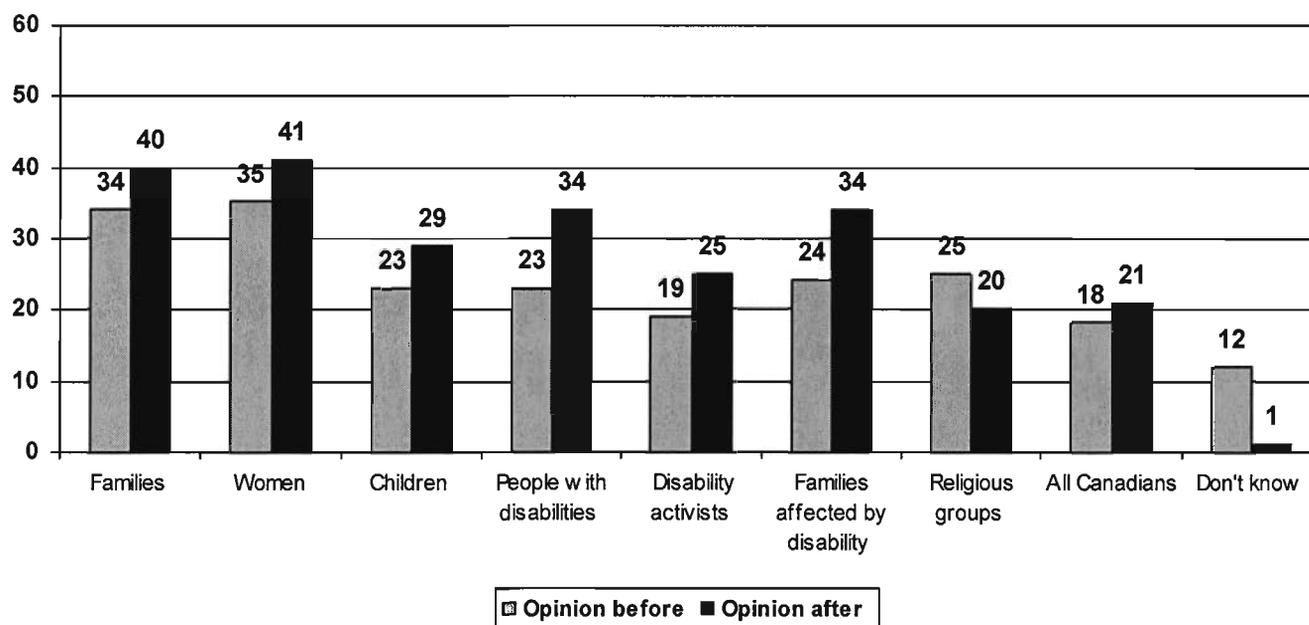
Confirmation of mental model interview findings

Workshop results confirmed the lay mental model interview findings discussed above in the larger workshop sample of lay participants. Nearly all (93%) workshop participants reported that they had never heard of the term pre-implantation genetic diagnosis or PGD. However, workshop participants, similar to their lay mental model interview counterparts, were familiar with in vitro fertilization or IVF. Most (88%) had heard of the IVF technology and when asked to describe the process, nearly three quarters (74%) provided a correct description before receiving any risk communication materials on the subject. When asked where they had learned about IVF technology the most popular responses were the television news, followed closely by the newspaper, the Internet, and in a magazine and through friends and family (these last two options were tied in popularity). A few participants also mentioned some additional sources on IVF including popular television shows and books (fiction and nonfiction) suggesting that the topic of IVF has entered and permeated public discourse concerning reproduction.

As mentioned previously, one must be able to anticipate the range of stakeholders for a systemic hazard to contemplate the full range of risks and benefits that the technology may pose at multiple scales. However, lay interview participants found it difficult to imagine stakeholders for PGD technology outside the individual or family scale. This finding was confirmed in the larger workshop sample of participants (see Figure 4.4). Before receiving risk communication materials, workshop participants anticipated that

families and women would likely be the most affected by PGD technology. After reviewing risk communication materials, participants still believed that families and women would be the groups most heavily affected by this technology. However, fewer reported that religious groups would be the most affected and a statistically significant number anticipated that people with disabilities, disability activists, and families of those affected by disability would also be affected.⁶⁵ Slightly more also recognized the societal scale outcomes that PGD technology could potentially have on all Canadians.

Figure 4.4 Most affected stakeholders of PGD technology

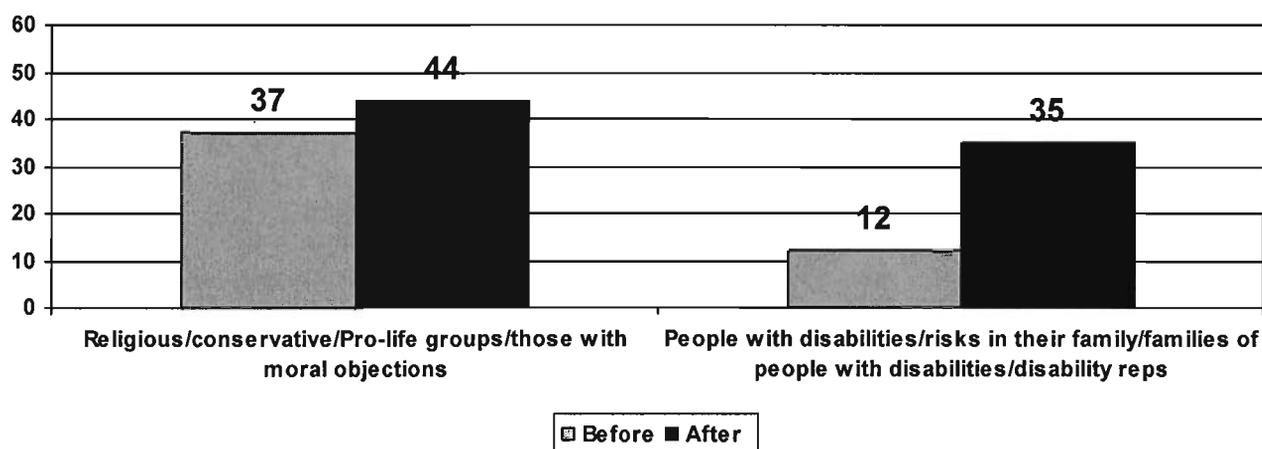


When asked to name individuals or groups who might be concerned about the use of PGD technology in the pre-deliberation questionnaire, the most common responses were

⁶⁵ Statistical significance was determined using the McNemar test for the significance of changes at a 95% confidence interval (Sirkin, 1995). This formula measures the number of individuals who respond differently after being exposed to new information or a new condition (Daniel, 1990).

religious and conservative groups. However Figure 4.5 shows that the risk communication workshop was successful in correcting a popular misconception concerning stakeholders. After receiving information on the variety of citizens potentially affected by PGD technology and the range of risks and benefits that the technology may pose at multiple scales, a statistically significant majority of participants (61%) reported that they now viewed people with disabilities, their families, and organizations representing people with disabilities as a concerned stakeholder for PGD technology.

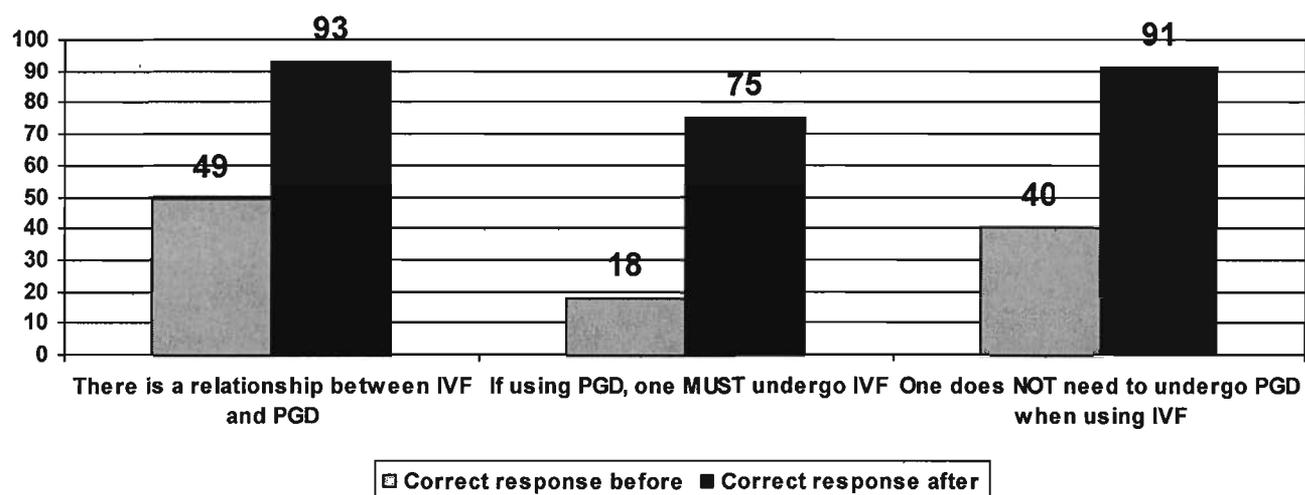
Figure 4.5 Individuals and groups who would be most concerned about the use of PGD: coded results of open ended responses from workshop participants



The final misconception identified through the lay mental model interviews involved the relationship between PGD and IVF technologies. It is important for participants to understand that those who wish to screen their embryos through PGD take on extra risks associated with IVF when they are not necessarily infertile. Figure 4.6 shows responses from the pre and post deliberation questionnaires on this topic. The risk communication materials were helpful in correcting this misconception but even by the end of the

workshop, some participants still found it difficult to sort out the relationship between IVF risks and those posed by PGD. Most understood that there was a relationship between the two technologies by the end of the workshop and that one need not screen their embryos when using IVF technology. However, one quarter (25%) still did not understand that IVF was a prerequisite for screening embryos and therefore a procedure that subjects individuals to the risks of IVF even though they are not necessarily infertile.

Figure 4.6 Understanding the relationship between PGD and IVF (shown in percentages)



Learning new information

Workshop materials were successful in teaching a range of technically-oriented information about PGD technology. Figure 4.7 shows that a statistically significant number of workshop participants could correctly describe PGD and IVF by the end of the workshop. A significant majority could also identify the applications of PGD technology,

which are to (1) diagnose genetic conditions or chromosomal abnormalities; (2) determine the sex of an embryo; (3) and match tissue to create compatible cells for an existing sick child. Over a quarter learned that it was actually quite difficult to access PGD in Canada as it currently has a high barrier for entry and most understood that it was an infrequently used technology in Canada at this time.

Figure 4.7 Correct responses about general background before and after reviewing risk communication materials (shown in percentages)

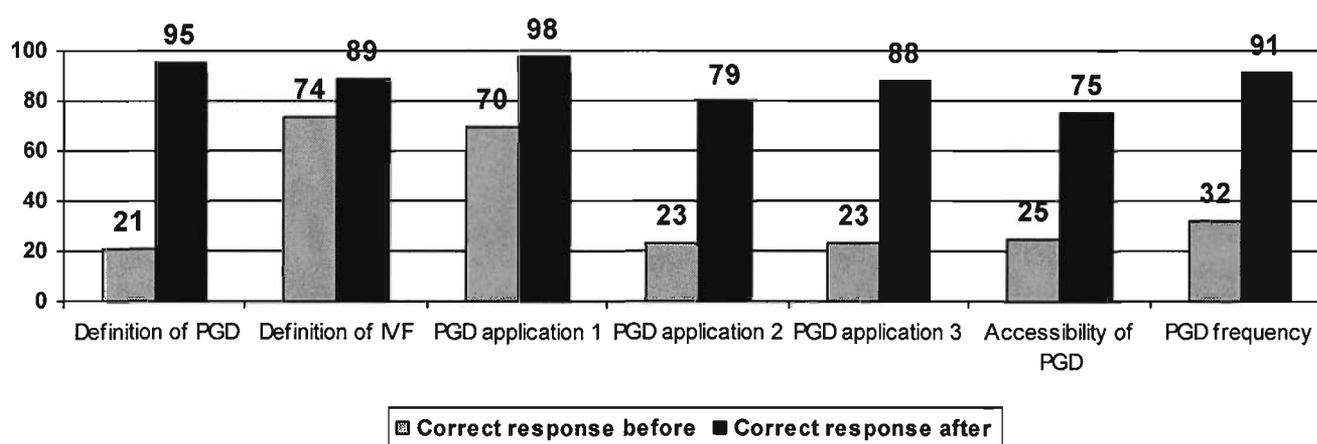
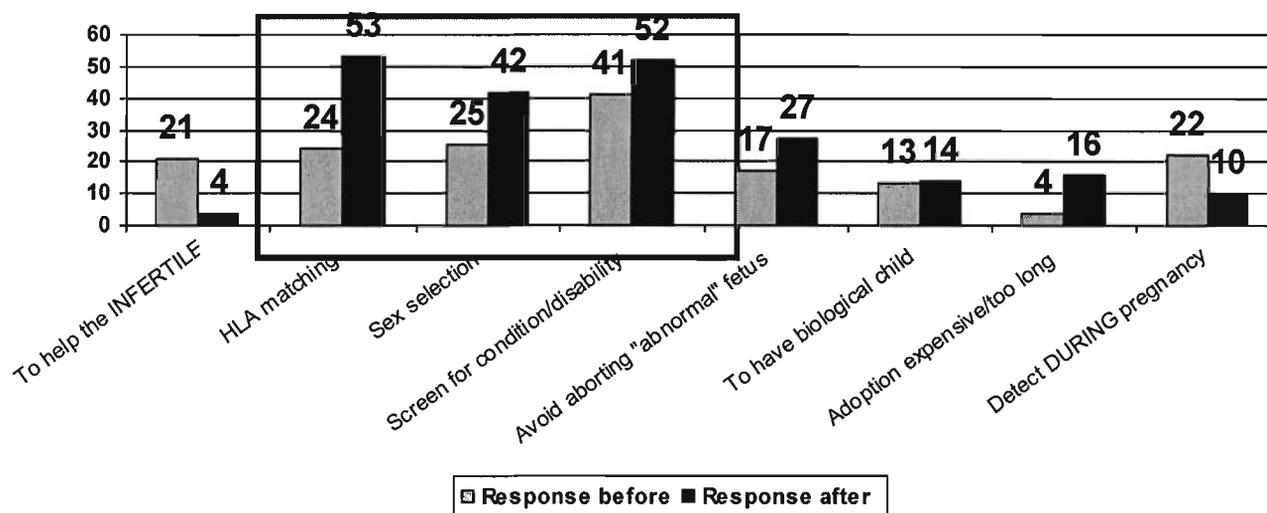


Figure 4.8 shows a selection of motivations for why people might choose to pursue PGD. Only the first and last options are actually inaccurate (PGD is used to help *infertile* people achieve pregnancy,⁶⁶ PGD is used to detect abnormalities *during* a pregnancy) and fewer participants did choose these options after examining the risk communication materials. The second, third, and fourth options (circled) are the applications of PGD. This response pattern reflects those shown in Figure 4.7, which also indicates that a statistically significant number of participants were successful in learning about these applications. However, the desire to have a biological child, avoiding abortions for

⁶⁶ However, PGD may also be a viable alternative for those who experience recurrent miscarriages (See Chen, 2005)

“abnormal” fetuses, and challenges associated with adoption, were also presented as motivations for PGD during the workshop. More participants chose these options in the post deliberation questionnaire but many had difficulty learning about these additional background motivations.

Figure 4.8 Motivations for pursuing PGD

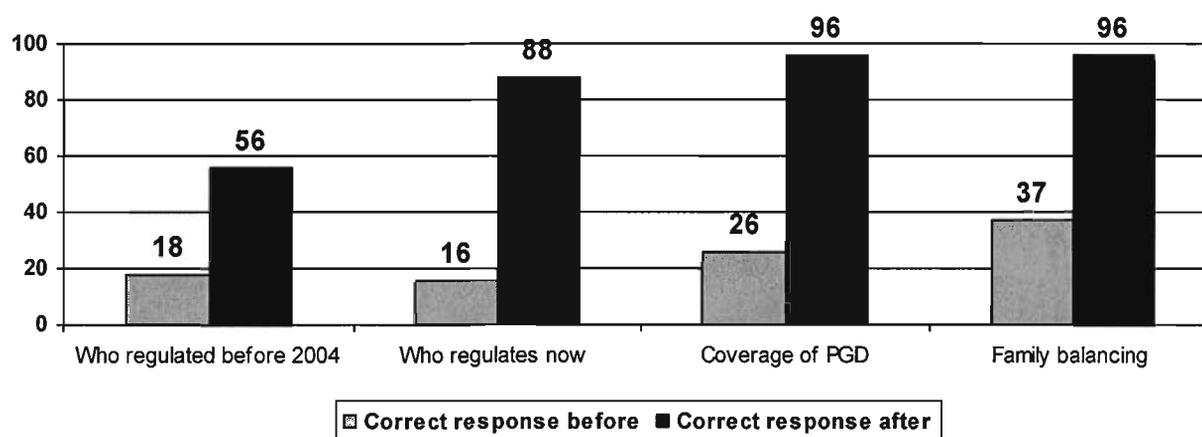


A significant portion of participants were also able to learn a great deal about the regulatory framework surrounding PGD in Canada. By the end of the workshop, most understood that an agency called Assisted Human Reproduction Canada regulates PGD in Canada; the technology is not covered under the Canadian health care system; and using PGD purely for “family balancing” is illegal in Canada. However, only 56%⁶⁷ could correctly report that there were no regulations, standards, or professional guidelines

⁶⁷ The question format could be partly blamed for this particular finding. In this case (and in only this case), participants should have identified two correct options within one question (see Appendix G to view entire workshop workbook).

for the use of PGD in Canada before 2004 in the post-deliberation questionnaire (see Figure 4.9).

Figure 4.9 Correct responses about regulatory framework before and after reviewing risk communication materials (shown in percentages)



Participants were asked to speculate about the specific risks and benefits that PGD may pose to (1) a woman, (2) an embryo, fetus, and child, and (3) society before reviewing risk communication materials. In this section of the questionnaire, participants were asked to explain unaided as many risks and benefits as possible for each scale (see Table 4.4).

Table 4.4 Unaided question format concerning potential risks and benefits that PGD may pose to a woman.

- 2) What risks and benefits might PGD pose to **a woman**? Please list as many as you can. Point form is okay.

Risks	Benefits

Many initially provided incorrect responses, which would be anticipated as 93% participants were unfamiliar with the technology before the event. However, participants also provided a great deal of general hopes and concerns that they maintained and supplemented throughout the workshop.⁶⁸ Pre-communication reported benefits to women included risks to the physical body, complications associated with a medical procedure, and anxiety or other psychological stresses. Benefits included the potential for healthy babies, and increased knowledge or better decision making. When asked to report on the risks that PGD technology may pose to women after reviewing risk communication materials, the most common response was psychological stress and anxiety. However, many also mentioned more specific risks such as OHSS/hormonal complications associated with the IVF process, multiple birth situations, and the potential for misdiagnosis. The most common response when reporting potential benefits to women was the opportunity to have a normal healthy child, free of serious disease. Many

⁶⁸ The concept of collecting participant hopes and concerns is based on Burgess, 2004.

also once again mentioned the additional information/knowledge produced through PGD as a benefit. Some stated that PGD benefited women by offering them more control or peace of mind. Also mentioned was the opportunity to save a sick sibling.

The most common risks reported about the embryo, fetus, and child during the pre-deliberation questionnaire were harms associated with a medical procedure, although a few mentioned eugenics and killing embryos as potential risks associated with PGD. Even fewer reported that the child born following PGD would have no choice in how they came into being and that the child may experience discrimination during their lifetime. The most commonly reported benefit was the potential to have healthier children with two participants mentioning knowing the child's sex as a benefit. After reviewing the risk communication materials, the most commonly reported risk was the potential to terminate an embryo during PGD. Many also mentioned that PGD had the potential to accidentally turn genes off or on, and that there was a lower chance of successful pregnancy through using PGD. Participants also noted that children would be at risk for disorders not screened out by PGD, the health risks associated with multiple births, and the future social or psychological risks to a child born following PGD, which may include suffering because of their role as a saviour sibling. The most common response concerning benefits for the embryo, fetus, or child was the ability to live a healthier life, free of fatal diseases or genetic disorders. Some also mentioned benefits associated with saving a sick sibling.

Participants reported on a wide range of potential risks and benefits that PGD may pose to society before reviewing communication materials. Potential risks to society included

general ethical and medical risks, eugenics and designer babies, and the fact that PGD may not be accepted by religious groups or conservatives. Others reported that there was a risk that PGD may be imposed on people and that the technology involved interfering with evolution or natural selection, playing God, and was unnatural. Others viewed stigmatization or discrimination against groups (including those who use PGD technology) as potential risks. Benefits included the possibility of producing healthy children, less disability overall and the associated burden that disability may lead to for social systems, an increased use of PGD,⁶⁹ better decision making or more reproductive options, decreased pain and suffering, improving society's gene pool, increased quality of life, and the advancement of science.

After reviewing the communication materials the most commonly reported risk that PGD may pose to society was to people with disabilities (or other groups) who may be discriminated against further. Participants reported that PGD may lead to decreased tolerance or compassion overall in society and that the aforementioned groups may experience a loss of voice and feel alienated. Other commonly mentioned risks were eugenics, narrowing genetic and social diversity, and choosing the sex of future offspring. Most of the comments regarding benefits at the societal scale in the post-deliberation questionnaire were divided between (1) more money for the health care system or less stress on government systems including decreased health care costs due to decreased disability and (2) an improved system for others and a healthier overall population with less disease.

⁶⁹ Those that expressed this particular benefit were also proponents of PGD technology.

Questionnaire responses also confirmed an important misconception concerning the motivations for PGD. Figure 4.8 shows that over one third (22) of participants initially believed that PGD could detect abnormalities *during* pregnancy similar to a genetic test (e.g., amniocentesis). Many reported in the pre-deliberation questionnaire that PGD could be used by couples to help prepare for a child with a disability (perceived as a potential benefit) or abort an abnormal fetus (perceived as a potential risk) in this unaided section of the questionnaire. This is an important misconception to address as PGD technology is used to avoid embryos with abnormalities altogether, a fundamentally different purpose. Less than half (n=10, a statistically significant portion) of those who initially reported this motivation for PGD still mistakenly believed that it was correct in the final questionnaire as shown in Figure 4.8. Similarly, when asked unaided about the potential risks and benefits of PGD in the final questionnaire, very few maintained the misconception that PGD could be used to help prepare for life with a disabled child or abort an abnormal fetus.

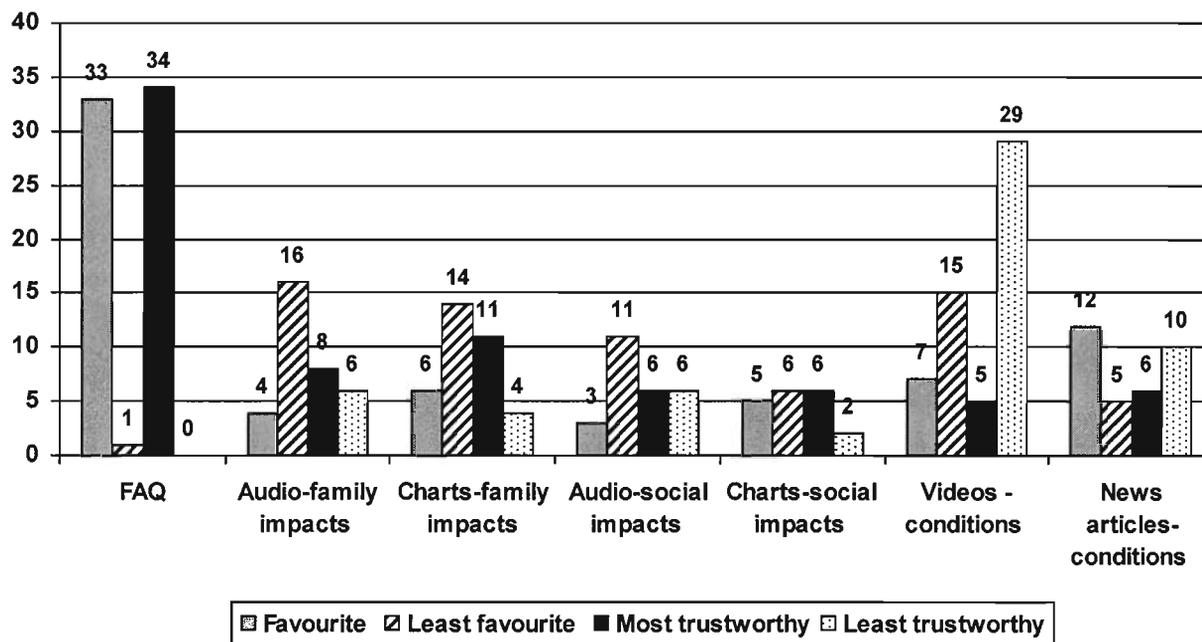
Rating the risk communication strategies

Participants were asked to rate all risk communication materials used during the event in the post –deliberation questionnaire.⁷⁰ The most popular and most trustworthy strategy

⁷⁰ The experiment in this workshop involved offering SDM materials in the form of consequences matrices to participants of only 4 of the eight workshops, in keeping with the experimental design. In the future, it would also be interesting to experiment with the communication tool, using different methods to communicate the same information. Participants in the workshops described here were shown a great deal of information and exposed to an array of communication formats and asked to evaluate them. By making this process transparent (as opposed to part of the experiment), participants were able to offer advice such as switching the content of one approach with another, or ruling out one method but not its contents, etc.

overall was the power point presentation of background information about PGD in the FAQ format (see Figure 4.10). Previous studies also confirm the popularity and effectiveness of this method (Longstaff, 2005). The least favourite risk communication strategies with participants were the audio recordings and charts of risks and benefits that PGD may pose to a woman and embryo, fetus, and child; the videos that discussed different types of conditions screened for with PGD; and the audio recording of the risks and benefits that PGD may pose to society. The videos were also rated as the least trustworthy method overall.

Figure 4.10 Rating the popularity and trustworthiness of workshop risk communication strategies



Discussion and conclusions

The results of this study demonstrate that the mental models approach is effective not only for communicating the risks and benefits of familiar hazards but also for novel hazards that are virtually unknown to most citizens. In this case, the approach helped to expose relevant pre-existing knowledge regarding IVF that could be supplemented, thereby optimizing the efficiency of the risk communication experimental workshop. Mental model interviews with lay citizens also helped to identify points of common confusion. These assumptions would hinder a participant's ability to understand the broad range of risks and benefits potentially posed by PGD. Mental model interviews suggested, and workshop results confirmed, that many participants had difficulty anticipating the multi-scalar nature of this technology. People with disabilities, their families, and organizations that represent these groups are generally recognized by relevant experts as a major stakeholder for this type of reproductive technology although they do not always appear as such in policy documents. As pointed out by Knoppers et al, "One policy issue that is not explicitly mentioned in the legislation (related to PGD) of any of the surveyed countries (12 including Canada) is the potential for discrimination against disabled people, despite a heated controversy." (Knoppers et al, 2006). Similarly, lay participants of the mental model interview process did not initially anticipate this potential stakeholder group although they did view religious organizations, conservative groups, families, and all women as potential stakeholders. Workshop materials were therefore created to help address this misconception (among others) and by the end of the event, participants did come to understand the views of many different stakeholder groups including those affected by disability. Participants

recognized that people with disabilities, their families, and disability activists may be affected by PGD technology and were likely concerned about its usage. Participants were also successful in learning about the potential societal outcomes of this technology. Many (58%) came to believe that information regarding PGD should be communicated to all Canadians as the outcomes of this technology were considered to be significant to many and broad in scope.⁷¹

However, aspects of certain misconceptions were particularly difficult for some participants to overcome. Most did come to understand that there was a relationship between IVF and PGD and that users of IVF were not obligated to use PGD technology. However, one quarter failed to learn that IVF is always a pre-requisite for PGD and therefore an additional risk that these individuals accept despite the fact that they are not necessarily infertile. Most were also able to overcome an important misconception concerning the timing of PGD technology. Many initially believed that the procedure could be used to help prepare for life with a disabled child or to abort an abnormal fetus. By the end of the event, most had learned that PGD was used to avoid abnormal embryos altogether as the screening process takes place before a woman becomes pregnant.

The risk communication workshop was also successful in teaching a range of technically-oriented information about a virtually unknown systemic hazard. A significant number of participants were able to learn a great deal about the PGD process, the various applications of this technology, and the Canadian regulatory

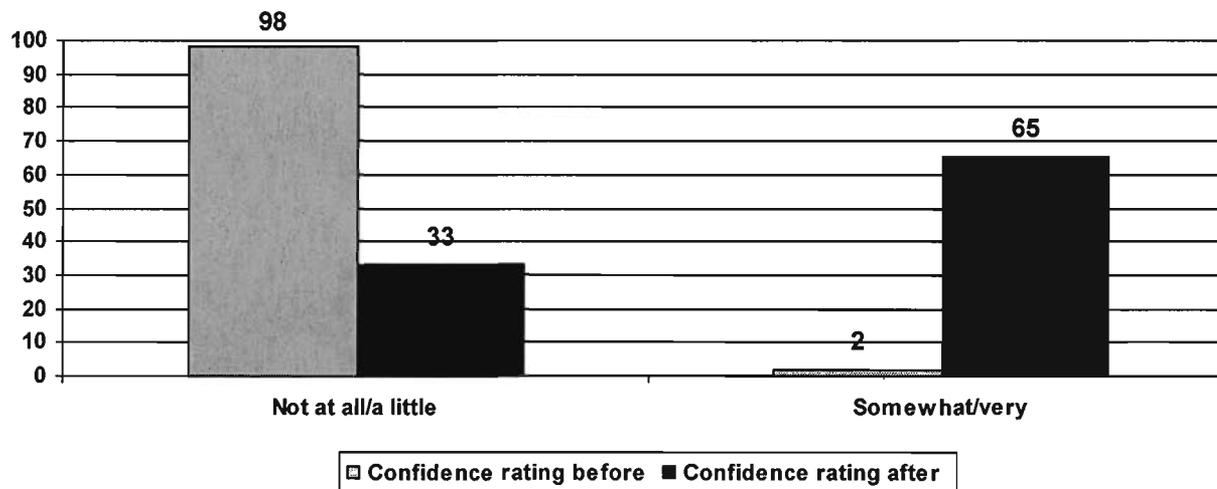
⁷¹ When asked to identify the target audience for PGD risk communication protocols in Canada

framework that oversees it. Participants were even able to learn about very detailed risks and benefits that this technology may pose to women, an embryo, fetus, or child, and to society. However, many anticipated risks and benefits of this technology were maintained throughout the workshop. In other words, participants used the expert information to supplement their own views, not replace them.

Participants worked very hard during the 2.5 hour risk communication workshop. They considered a wide range of information, evaluated numerous risk communication methods, participated in a group deliberation, and completed two difficult surveys. At the end of the event, participants were successful in learning a great deal of information about a previously unknown topic, and felt confident in their newfound knowledge. Figure 4.11 shows that nearly all participants stated that they were either “a little” or “not at all” confident in their knowledge of the risks and benefits of PGD before the event, while two thirds were either “somewhat” or “very confident” by the end. Most reported that the workshop had been a valuable learning experience. A significant majority (84%) also reported that they would be “very” or “definitely likely” to attend a workshop like this again in the future. Most also agreed that it was sensible for risk communicators to rely on a collaborative process like this one when determining risk communication strategies for PGD.⁷²

⁷² In total, 46 participants agreed that it was sensible, 7 said they did not know, and 3 reported that it was not.

Figure 4.11 Confidence in knowledge of the risks and benefits of PGD (shown in percentages)



Workshop findings also revealed a major challenge for those who communicate the risks and benefits of systemic hazards. As mentioned, it is important for lay citizens to consider both value-oriented (e.g., the values of relevant stakeholders, ethical and social outcomes of PGD) and technically-oriented (e.g., regulatory frameworks, PGD process and applications) information when considering systematic hazards. Participants agreed that value-oriented information concerning the social risks and benefits of PGD and the perspectives of those influenced by disability was important to consider (see excerpt from one Down Syndrome Society video discussion shown below). They also learned a great deal about the social risks and benefits of PGD at multiple scales.

[While] ...its okay, disabled children with Down Syndrome, they can live happy lives...they have a place in society. -Annie

I think that's important when considering this procedure, because some things might be called a disease or a disability, but if the person is living a healthy life with no real discomforts or pain, or issues within themselves, is it okay to call it a disease or a disability? (Workshop #8 participant exchange)-Bill

However, participants did not particularly like or trust the vehicles used to deliver certain aspects of this information. The short films used for this workshop included a (1) video produced by the Nova Scotia's Down's Syndrome Society that included photographs of children living with this type of disability superimposed with text messages and (2) short public service announcement (PSA) about genetic testing from the National Tay-Sachs & Allied Diseases Association. Over half rated these videos as the least trustworthy of all the methods used during the workshop. Discussions during the mid-event deliberation confirmed this finding where participants referred to these methods as "biased", "too emotional," and "too polarized", among other things.⁷³

Many experts in PGD technology suggest that the *lived experience of disability* is a key message that should be communicated during this type of event. However, it is difficult to imagine how this message could be communicated through conventional, more preferred methods such as FAQs. Recall that participants preferred the FAQ format and also found it the most trustworthy communication method overall. The newspaper articles, which also addressed the lived experience of disability, were viewed more favourably than the videos but many also found them to be untrustworthy when compared to the other risk communication methods.

In any case, this outcome could also be viewed positively. Some risk communicators are concerned about the ethical dimensions of including value-oriented risk messages in their protocols as they have the potential to unjustifiably appeal to participants' emotions and

⁷³ These comments are taken from deliberations that occurred during the 5th workshop. However, they accurately represent a theme that crossed all discussions. These findings are also similar to those of other studies that involve the communication of emotional information. For example, see discussions of fairness and bias in Cox et al, 2009.

values (McComas, 2006). Yet, for the case of PGD, it would seem unethical not to include perspectives on the lived experience of disability, among other things, given the range of influence that this reproductive technology may have on the lives of individuals, groups, and society. In addition, workshop deliberations and questionnaire results revealed that participants were quite critical of such messages precisely because of their ability to persuade. It would seem then that including value-oriented risk messages (such as those expressed in the videos and news media articles) is appropriate if participants are given the opportunity to critically evaluate them in a transparent manner. In this study, participants openly discussed and evaluated all risk communication strategies and messages during a short deliberation with other participants and through questionnaire feedback.

In conclusion, more empirical research should be conducted to determine best practices for communicating all aspects of value-oriented and technically-oriented information regarding systemic hazards. Such research should focus on identifying methods of communicating value-oriented information that are both effective and trustworthy. For example, it would be interesting to experiment with a variety of message types in which the value-based components can be included in one treatment and removed in another. This would allow the communicator to test the degree to which emotive elements in each method actually influence participants' understanding of risk and sense of trust during risk communication efforts instead of depending solely on self reported views.

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Chapter five: Using structured decision making to help communicate information about controversial technologies: The case of pre-impantation genetic diagnosis⁷⁴

Introduction

Public engagement models are relatively new to science communication yet continue to increase in popularity (National Research Council, 1996; Rowe and Frewer, 2005; Longstaff and Burgess, forthcoming; Dietrich and Schibeci, 2003; Fukuyama and Furger, 2007).⁷⁵ This *dialectical* approach to communicating risk (Juanillo & Scherer, 1995) attempts to “engage audiences in the content” (McComas, 2004) to help foster deliberative and informed decision making (see for example Arvai et al, 2001 and O’Doherty & Burgess, 2008). Public involvement is now supported by many government agencies at all levels in both the United States and Canada and is legislated in some cases (e.g., US National Environmental Policy Act and Canadian Environmental Protection Act, 1999). However, relatively little empirical evidence has been collected to support the effectiveness and quality of these efforts (National Academy of Sciences, 2008; Rowe and Frewer, 2000; Sunstein, 2002).⁷⁶ More specifically, very few studies have focused on analyzing the merits of various processes used to engage the public.

Proponents argue that deliberative methods will enhance overall societal participation by helping to achieve significant democratic ideals such as better informed and more robust,

⁷⁴ A version of this chapter has been submitted for publication. Longstaff, Holly. Using structured decision making techniques to help communicate information about controversial technologies: The case of pre-impantation genetic diagnosis.

⁷⁵ Recent examples include: the 2001 Canadian Public Consultation on Xenotransplantation; 2002 UK GM Nation; Danish Board of Technology’s 2005 Citizen Jury assessment of transgenic crops; UK government’s Nanotechnology Engagement Group; New Zealand Bioethics Council’s 2007 Who gets born? Pre-birth testing deliberative dialogue; and CaliforniaSpeaks 2007(for more on these events please see Walmsley, 2009,).

⁷⁶ Exceptions include Beierle and Cayford, 2002; National Academy of Sciences, 2008; and National Research Council, 1996.

inclusive decisions. However, critics respond that methods used during these expensive and time consuming events are ultimately unable to produce meaningful outcomes (National Academy of Sciences, 2008). For example, some argue that lay citizens are unable (or unwilling) to accept the difficult tradeoffs inherent to complicated problems (Zeckhauser and Viscusi, 1996). Others suggest that public engagement activities are easily manipulated by outgroups,⁷⁷ political symbolism, and additional factors that may lead to polarized, trivial, or generally biased decisions (Sunstein, 2002; Dryzek, 1990; Bohman, 1998; and Gutmann and Thompson, 1996).

The main objective of this paper is to evaluate the quality of lay participant decision processes associated with a series of deliberative risk communication experimental workshops conducted in 2008 in Vancouver, British Columbia. The criteria used to evaluate these processes were introduced in the recent National Academy of Sciences, 2008 report (pg 71) on public participation (see Table 5.1)

Table 5.1 National Academy of Sciences, 2008 criteria

Outputs to indicate quality	Performance measures
Quality of decisions processes	<ul style="list-style-type: none"> • Information was added /considered in the process • Outputs reflected a broad view of the issues that participants believed were important • Innovative ideas were generated for solving problems
Capacity for future decision making	<ul style="list-style-type: none"> • Became better informed about relevant issues • Scientists gained understanding of public concerns • Participants gained skills
<p>*Note that indicators of legitimacy of process and decisions discussed in NAS 2008 were not addressed here because this was an experiment and not a participation process with an official mandate</p>	

⁷⁷ An outgroup can be described as a group of citizens organized around a particular issue (e.g., political, religious) that by nature of their shared interest, place themselves in opposition to others (Sunstein, 2002)

This study focused on communicating the risks and benefits of a controversial reproductive procedure to lay citizens. Information about the risks and benefits of novel technologies is particularly difficult to communicate because it must draw on a great deal of complex scientific information. Analysts working in this area must also struggle to address socially and ethically contentious issues without unfairly characterizing or simplifying the views of diverse stakeholders. The example addressed in this study is pre-implantation genetic diagnosis (PGD) or the genetic screening of in vitro human embryos for particular genetic conditions or abnormalities during in vitro fertilization (IVF). This process may lead to many controversial outcomes for individuals, groups, and society. Some of the more notable considerations include physical risks to women's bodies, emotional benefits to families, and the social stigmatization of certain groups (e.g., people with disabilities, all pregnant women).⁷⁸ The next section provides additional background about the risk communication experimental workshop concept and design. The following section provides an overview of workshop findings including participant recommendations for risk communication strategies about PGD technology. The next section evaluates the workshop findings using the National Academy of Sciences, 2008 criteria and the final section revisits the study research questions shown above while offering conclusions.

⁷⁸ Suppose that PGD technology were socially accepted and used frequently. In that world, people with disabilities may be stigmatized if others view them as undesirable or preventable. Again, in that world, all pregnant women could conceivably suffer from stigmatization if they do not comply with the now standard medical procedure that is viewed to be in the best interests of their future child.

Experimental design

Concepts

One of the fundamental objectives of the risk communication experimental workshops was to examine whether a structured decision making (SDM) approach to risk communication would affect how participants processed ethically and socially contentious information about a complicated novel topic. The SDM components specifically employed by this study were a series of 3 consequence tables derived from expert interview findings. These tables summarized decision contexts, objectives, alternatives, consequences, and tradeoffs for stakeholders of PGD at multiple scales (e.g., family, group, societal). In other words, they summarized the kinds of information required for responsible decision making (Hammond et al, 1999 and Clemen & Reilly, 2000).

Structured decision making refers to a version of decision analytic practice that uses concepts and tools to clarify choices in difficult problems (Hammond et al, 1999). The steps involved in SDM help to expose assumptions thereby allowing decision makers to find more innovative solutions to complicated dilemmas (Keeney, 1992, Gregory, McDaniels, and Fields, 2001; McDaniels and Gregory, 2004; McDaniels, 2000). These steps are intended to clarify significant aspects of the problem at hand including the decision makers' objectives, the range of available alternatives, the consequences of those alternatives, important value tradeoffs inherent to particular choices, and performance measures for gauging progress over time. Hammond, Keeney and Raiffa

1999 provide a clear introduction to the steps of the SDM approach, which they capture through the acronym PrOACT.⁷⁹ The concept of integrating values and technical information within a decision analytic framework is well established in the field of risk communication and risk management (Keeney, 1992; Bohneblust & Slovic, 1998) and has been employed in a number of previous studies, most frequently in the environmental domain (e.g., Arvai et al, 2001; Gregory & Keeney, 1994; Gregory et al, 1993). Employing a consequence table is a basic tool of good decision process as it requires that key steps of the SDM PrOACT approach be completed. For example, a specific decision context must be selected; objectives and performance measures must be defined; alternatives must be defined; consequences of the alternatives in terms of the objectives must be summarized, and tradeoffs are exposed. The value components include selecting the decision context and specifying the objectives, while the technical components include identifying the alternatives and their consequences.

Since the 1970's, SDM has been used by a range of interested parties in both private industry and government agencies (Keeney, 1982). It is now also used in conjunction with stakeholder processes or citizen engagements. Rowe and Frewer's process evaluation criteria for effective public participation refer to decision analytic approaches (Rowe and Frewer 2000) and the recent National Academy of Sciences report evaluating citizen involvement is strongly oriented toward decision making (National Academy of Sciences, 2008). Structured decision making often involves interested parties throughout a whole decision making process, from expressing values to creating alternatives, to organizing information to aid in comparing and selecting among alternatives (Keeney et

⁷⁹ PR=Problem, O=Objective, A=Alternatives, C=Consequences, and T=Tradeoffs

al, 1990; .McDaniels, 1996; Gregory et al, 2001). In addition, it is recognized that sometimes addressing only parts of a decision process (or partial decision analysis) can be helpful to provide structure for ongoing debate about policy issues (Keeney, 1982). For example, it can be useful to identify what aspects of a lengthy process can be condensed to provide insights with less time and effort.

However, experiments on construction of preferences demonstrate the pitfalls of unstructured decision making (Payne, Bettman, & Johnson, 1992; Slovic, 1995) and the difficulty most of us have when considering complex value laden tradeoffs (Bohneblust & Slovic, 1998; Zeckhauser and Viscusi, 1996). An experiment conducted by Arvai, Gregory, and McDaniels (2001) addressed many of these challenges through using SDM materials to determine whether participants made better decisions during a deliberative risk communication experiment. The materials summarized the pros and cons of a decision in terms of a consequence table, or objectives by alternative matrix. The experiment discussed in this chapter builds on the work of Arvai et al. by employing a workshop format that also included workbooks, group deliberations, and consequence tables to help participants make difficult decisions in 4 of the 8 workshops. However, instead of environmental policy decisions regarding hypothetical river systems, participants of this thesis study were asked to provide risk communication advice about a highly controversial and largely unknown emerging technology within the health domain (PGD). Of primary interest was whether SDM materials could help participants conceptualize difficult tradeoffs and make good, inclusive decisions in politically, ethically, and emotionally charged cases.

Research design

The workshops employed a *between subject* design with two treatments. Treatment A included standard risk communication materials while treatment B included these same materials, plus a SDM component. The SDM treatment component used in half the workshops acted as a counterfactual experiment with two alternatives where only treatment B participants received special training in elements of SDM. This type of experimentation was called for in National Academy of Sciences, 2008 (page 68). The SDM component of treatment B workshops included a brief introduction to consequence tables. These tables illustrated objectives by alternatives for individuals, groups, and society concerning PGD technology (see Figure 5.1 for societal scale example). The objectives shown across the top are examples of the key value objectives held by that particular group (Keeney, 1992). The alternatives shown in the column along the far left side of the table outline a range of potential alternatives including the option of PGD. Learning about alternatives through the lens of the value objectives at each scale clarifies important tradeoffs inherent to each choice. For example, allowing individuals at the family scale to avoid a child with a particular genetic condition through PGD may involve trading off important value objectives at the group scale such as reducing perceived discriminatory practices towards people with disabilities and the societal scale such as fostering overall diversity of Canadian society. Some may view this as a justified tradeoff while others may not.

Figure 5.1 Consequence tables for PGD at the *societal* scale: objectives by alternatives

Alternatives	Key objectives of society		
	1) To foster overall health & wellbeing of Canadians	2) To foster overall diversity of Canadian society	3) To treat all Canadians equally
Natural : status quo	Some natural pregnancies will result in children with disabilities who may or may not experience short lived or painful lives.	Some natural pregnancies will result in children with disabilities who contribute to the diversity of our society.	Supporting natural pregnancies and therefore not supporting techniques that assist in reproduction means that some Canadians will not be able to have their own biological “normal” children.
PGD: testing fertilized embryos before they are implanted in the female patient	PGD will reducing the overall number of those born with specific conditions and will therefore increase the overall number of healthy babies.	Reducing the overall number of people with disabilities will reduce the genetic and cultural diversity of our Canadian society.	Part of treating Canadians equally means that there should be equitable access to government services. However PGD is expensive and currently only available to some. If PGD is made available to all, other services will have to be reduced.
Prenatal diagnosis: a variety of tests that are used to determine the health and condition of an unborn fetus (e.g., ultrasound, amniocentesis, chorionic villus sampling)	Prenatal diagnosis can help families prepare for life with children affected by disabilities or avoid affected fetuses who would experience short lived or painful lives.	Prenatal diagnosis can help families prepare for life with children affected by disabilities. However, it may also lead some to abort affected fetuses, which may reduce the overall genetic and cultural diversity of our Canadian society.	Part of treating Canadians equally means that there should be equitable access to government services. However, prenatal diagnosis techniques are expensive. If they are made available to all, other services will have to be reduced.
Adoption: private, public, or international	All types of adoption should be encouraged so that all of us have the opportunity to be raised by loving families.	If adoption becomes socially desirable and popular, it may become more acceptable to adopt children with “special needs”, which will increase the overall genetic and cultural diversity of our Canadian society.	All types of adoption should be encouraged so that all of us have the opportunity to be raised by loving families.

The workshops described here took place in the summer and fall of 2008 on the University of British Columbia campus in Vancouver, Canada. Fifty-seven lay citizens

were randomly assigned to one of eight 2.5- hour workshops. Mental model interviews with lay citizens that took place prior to the workshops revealed a number of significant information gaps. For example, participants generally knew little about PGD. In particular, participants had a difficult time identifying the stakeholders of this technology or those who may be influenced by the outcomes of this procedure.⁸⁰ If participants cannot identify major stakeholders for a technology, they are not in a position to consider the full range of risks and benefits of that technology. The research questions motivating the use of SDM techniques were based on these earlier study results as well as popular critiques (raised earlier) of deliberative engagement activities (see Table 5.2).

Table 5.2 Workshop research questions

1. Can SDM materials help to produce better informed and more robust, inclusive decisions (e.g., understanding range of stakeholders and their hopes and concerns ⁸¹)?
2. Can SDM materials help participants to conceptualize the difficult tradeoffs inherent in complicated problems?
3. Can SDM materials help to overcome the influence of controversial and political symbols (e.g., anti/pro abortion rhetoric) invoked by PGD so that participants can make more considered, inclusive decisions?
4. Are including SDM materials in risk communication workshop worth the extra time and effort they require?

Participants in both treatments were asked to complete a questionnaire at the beginning of the workshop (see Figure 5.2).⁸² The surveys included questions regarding the individual's relevant background knowledge and opinions concerning PGD and were based on the results of expert interviews (see Chapter 3 of this thesis) and mental model interviews with other lay citizens (see Chapter 4 of this thesis). All participants then had

⁸⁰ There were also significant information gaps (see Chapter 3 of this thesis).

⁸¹ The concept of collecting participant hopes and concerns is based on Burgess, 2004.

⁸² The experiment also involved a within subject before/after comparison that focussed on learning outcomes (see Chapter 3 of this thesis).

the opportunity to learn about the various risks and benefits of PGD through a range of different communication methods including a power point presentation of Frequently Asked Questions (FAQs), audio recordings, charts, news articles, and videos. The only difference between the two treatments occurred after participants received all risk and benefit information. Participants in treatment B workshops observed a short presentation on consequence tables (step 3 in Figure 5.2) while participants of treatment A workshops moved directly to the facilitated group deliberation. After the deliberation, all participants were asked to vote on their preferred risk communication method(s) for PGD. They also completed a second questionnaire to test how much they had learned over the course of the workshop and how their opinions changed, if at all. This second survey contained the same questions as the first in addition to a series of workshop evaluation questions.

Figure 5.2. Workshop format

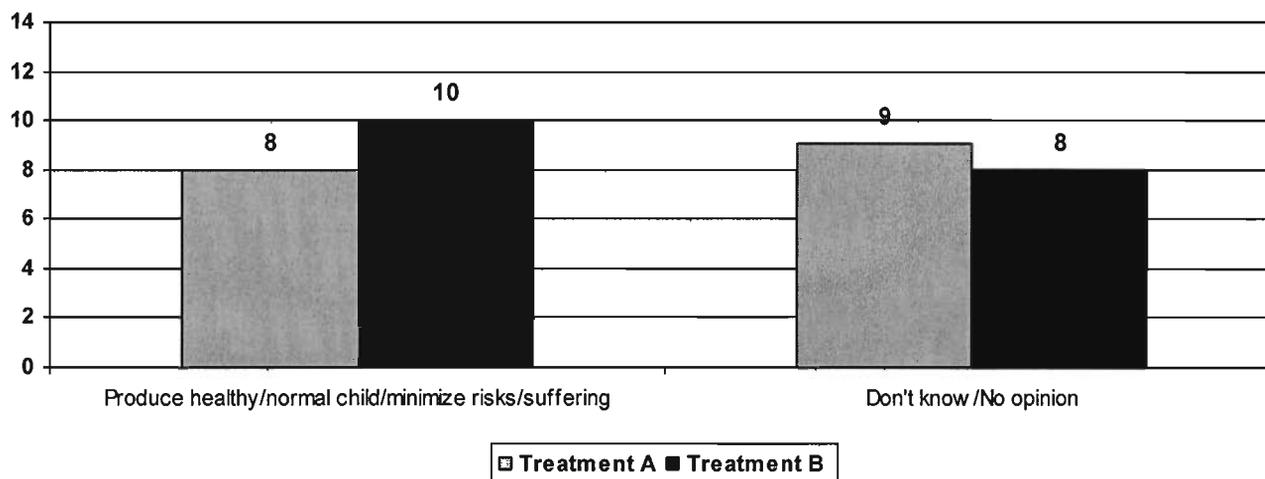
Treatment A	Treatment B
<ol style="list-style-type: none"> 1. Pre communication questionnaire 2. Risk communication materials in different formats 3. Group deliberation 4. Private vote 5. Post communication questionnaire and workshop evaluation questions 	<ol style="list-style-type: none"> 5. Pre communication questionnaire 6. Risk communication materials in different formats 7. *Structured decision making exercise* 8. Group deliberation 9. Private vote 10. Post communication questionnaire and workshop evaluation questions

Risk communication experimental workshop results

Reported hopes and concerns for PGD technology

Participants were asked to identify their biggest hopes for PGD technology in the pre and post communication questionnaires. Before receiving any risk or benefit information about PGD, the most common hope stated by participants in both treatments was that PGD would lead to the production of healthy, normal children and would help to minimize risks and suffering (see Figure 5.3). About the same number of participants in each treatment could not state any hopes for this technology before reviewing risk communication materials.

Figure 5.3 Survey 1 results: reported hopes for PGD technology



After reviewing the risk and benefit information, the most commonly reported hopes for treatment A workshop participants (those who did NOT review SDM materials) could be collected under four main headings shown in Figure 5.4. Shared hopes for participants in treatment B workshops (those who DID review SDM materials) were more diverse in

nature. While shared responses from treatment A participants centered mostly on disease prevention and decision making, shared responses from treatment B participants also covered additional topics such as public education and funding arrangements (see Figure 5.5).⁸³

Figure 5.4 Survey 2 results for treatment A participants: reported hopes for PGD technology

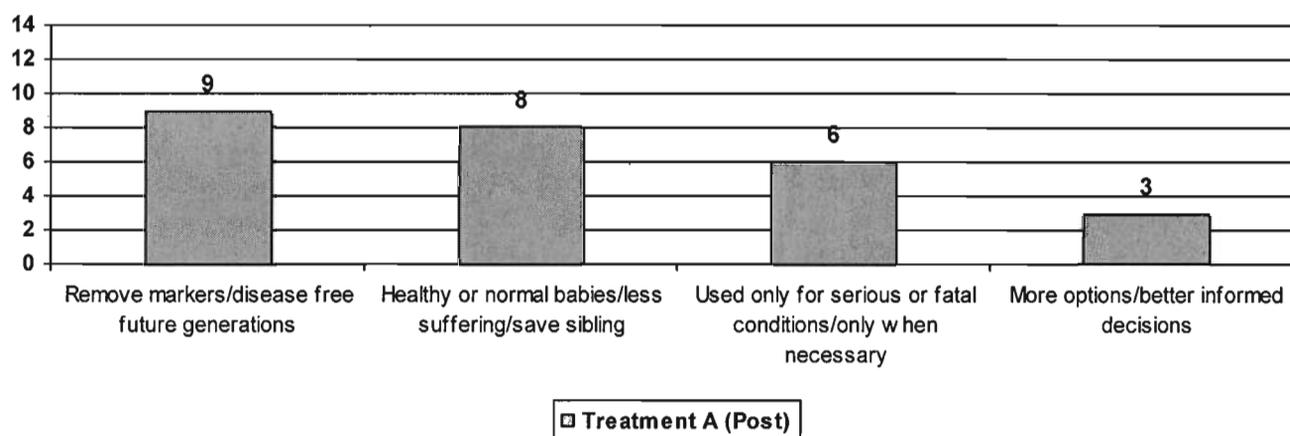
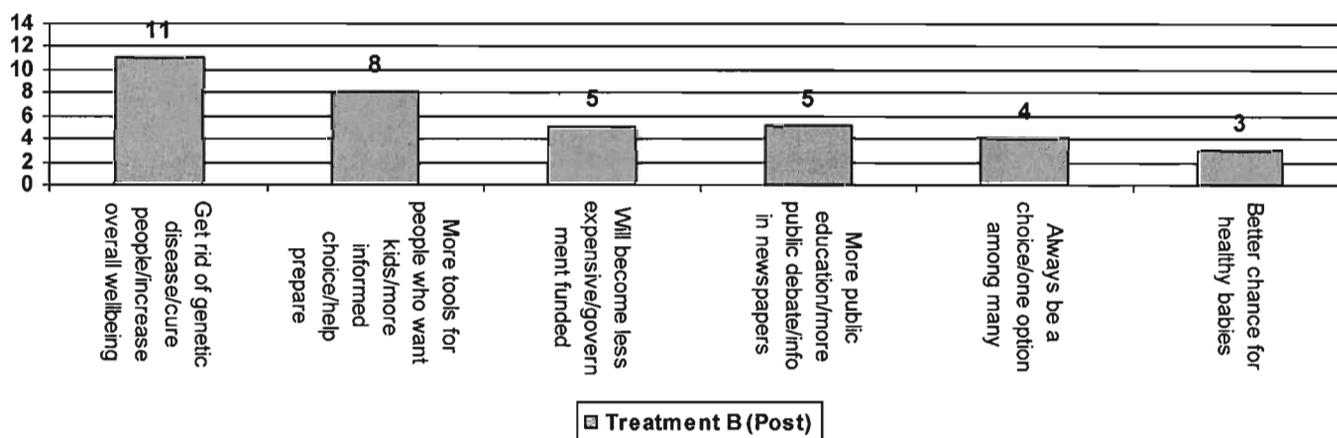


Figure 5.5 Survey 2 results for treatment B participants: reported hopes for PGD technology

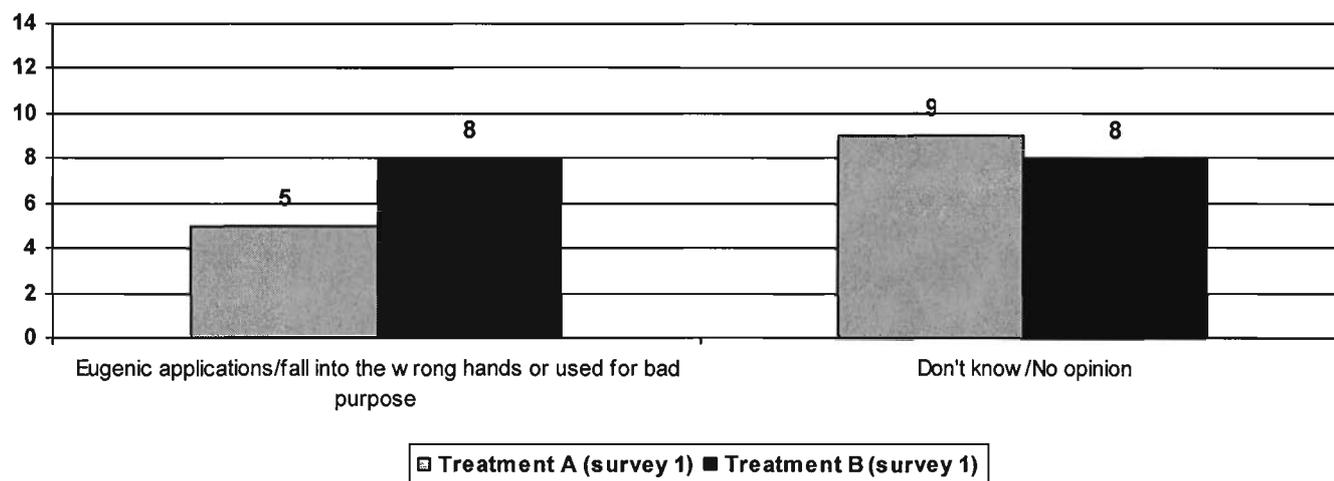


Before reviewing any risk communication materials, many participants also had difficulty reporting anticipated concerns for PGD technology (see Figure 5.6). The most common

⁸³ Note that hopes and concerns had to be reported by more than 2 people to be considered “shared”.

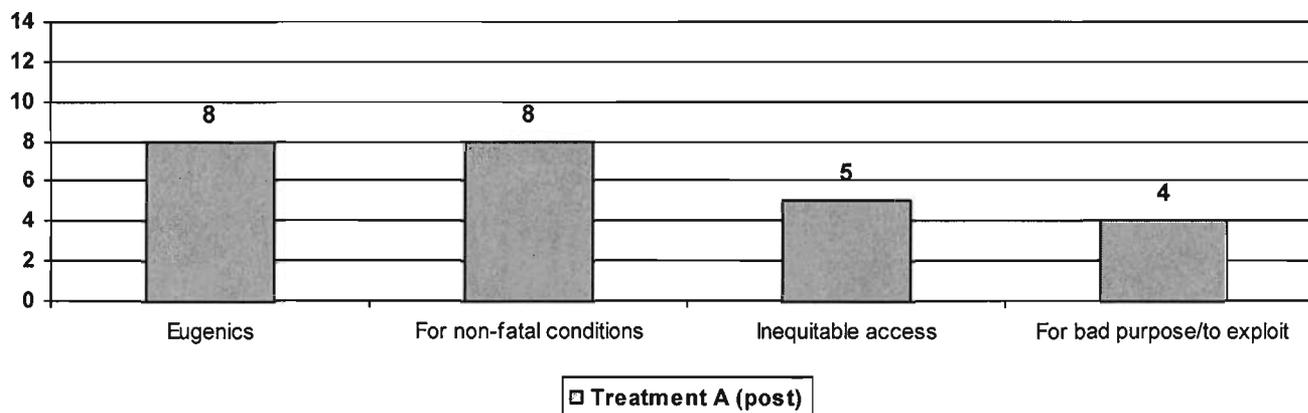
reported concern was that PGD would lead to eugenic applications such as designer babies, fall into the wrong hands, or be used for other unethical purposes.

Figure 5.6 Survey 1 results: reported concerns for PGD technology



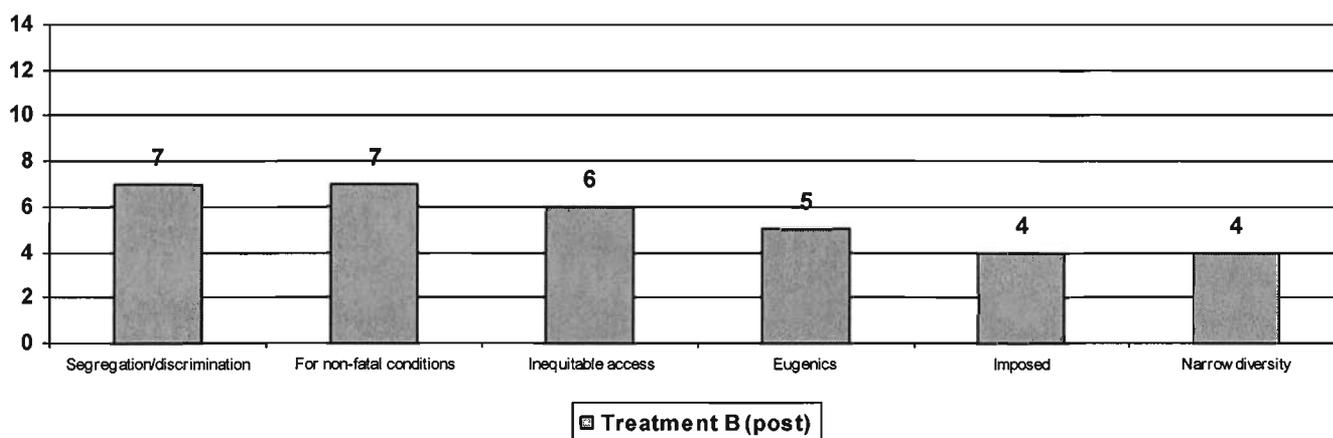
In the post communication questionnaire, the most common concern for treatment A participants was still eugenic applications. Some also remained concerned about PGD being used for some general bad purpose or to exploit an unidentified group. However these participants were also now concerned about unnecessary applications for PGD such as sex selection and for other non-fatal conditions, as well as inequitable access to the technology (see Figure 5.7).

Figure 5.7 Survey 2 results for treatment A participants: reported concerns for PGD technology



Treatment B participants also maintained eugenic concerns but the leading concern after reviewing communication and SDM materials was now the potential for PGD to lead to segregation and discrimination, unnecessary applications (e.g., screening for non-fatal conditions and sex selection), and inequitable access (see Figure 5.8). They were also concerned about the technology becoming imposed on individuals and the ways in which the PGD may narrow diversity for Canadian society.

Figure 5.8 Survey 2 results for treatment B participants: reported concerns for PGD technology



Differences also emerged between treatment A and B participants for questions regarding anticipated stakeholder concerns. When asked about stakeholders and PGD technology before receiving risk and benefit information in the first questionnaire, participants from both treatments most commonly reported that stakeholders would likely be primarily concerned about PGD because of religious convictions, general ethical beliefs, because they perceived PGD as “playing God”, etc (see Table 5.3). These were still the most commonly reported stakeholder concerns after receiving risk and benefit information for treatment A participants (those who did NOT review SDM materials). However, in the second survey, or after reviewing risk and benefit information and SDM materials, the most commonly reported anticipated stakeholder concerns for treatment B participants were that PGD may ostracize some, create class differences, and discriminate against people with disabilities or infringe on their rights.

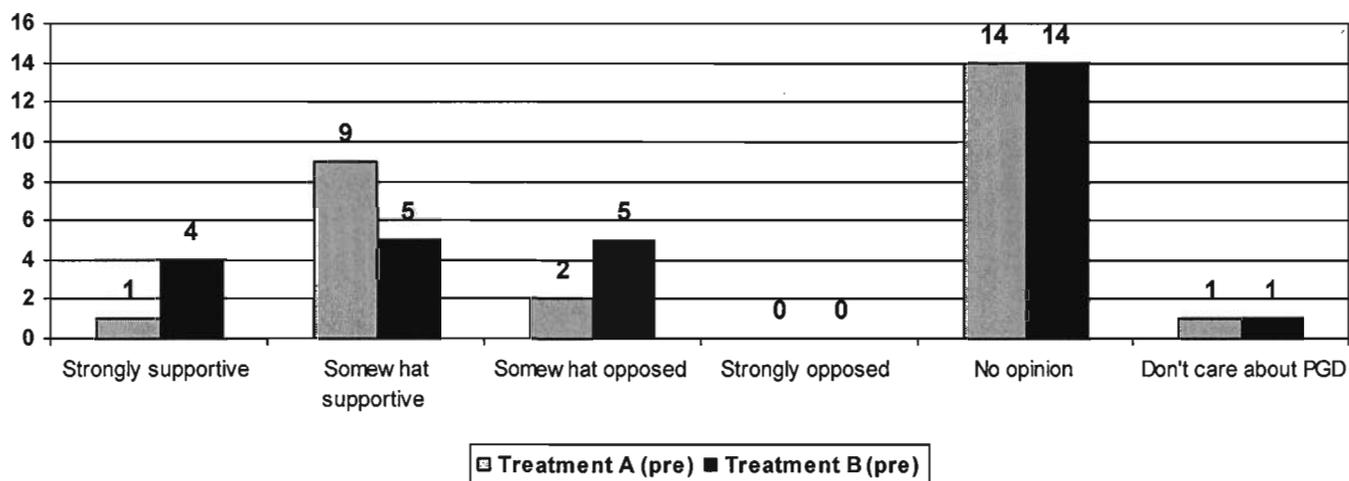
Table 5.3 Reported stakeholder concerns: most common response by treatment

Survey 1: most popular response for treatment A participants	Survey 1: most popular response for treatment B participants
Because it goes against how they want others to live /goes against their convictions/playing god /murdering embryo (n=7)	Erosion of faith in god /ethics/religious reasons/playing god (n=12)
Survey 2: most popular response for treatment A participants	Survey 2: most popular response for treatment B participants
Ethical /religious reasons/ eugenics/playing god/different values (n=16)	Ostracization /creating class differences/discrimination against people with disabilities/infringe on their rights (n=12)

Participant opinions regarding PGD technology

Most participants in both treatments reported that they had no opinion regarding PGD in the first questionnaire (see Figure 5.9). This is unsurprising given that most were unfamiliar with this technology before the workshop. Nearly all (93%) participants stated in the first questionnaire that they had never heard of the term pre-implantation genetic diagnosis or PGD.

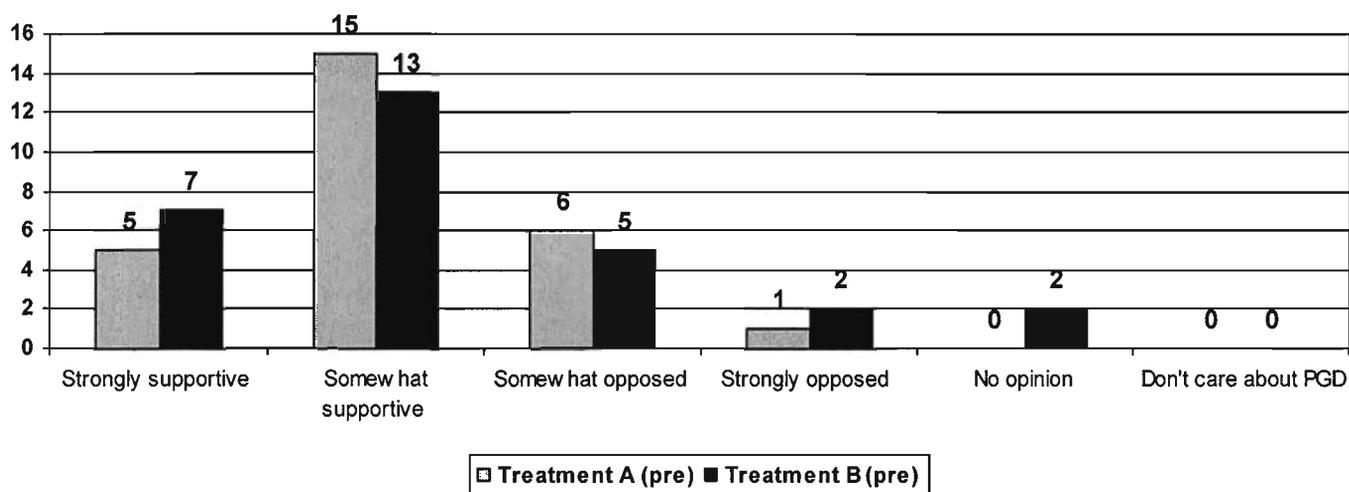
Figure 5.9 Survey 1 results: Opinions of PGD technology (shown in percentages)



Overall opinions did not vary significantly⁸⁴ by treatment by the end of the workshop (see Figure 5.10). In the second questionnaire, only two participants reported that they still had no opinion of PGD and most reported that they were now either somewhat or strongly supportive of this technology.

⁸⁴ Statistical significance was determined using the McNemar test for the significance of changes at a 95% confidence interval (Sirkin, 1995). This formula measures the number of individuals who respond differently after being exposed to new information or a new condition (Daniel, 1990).

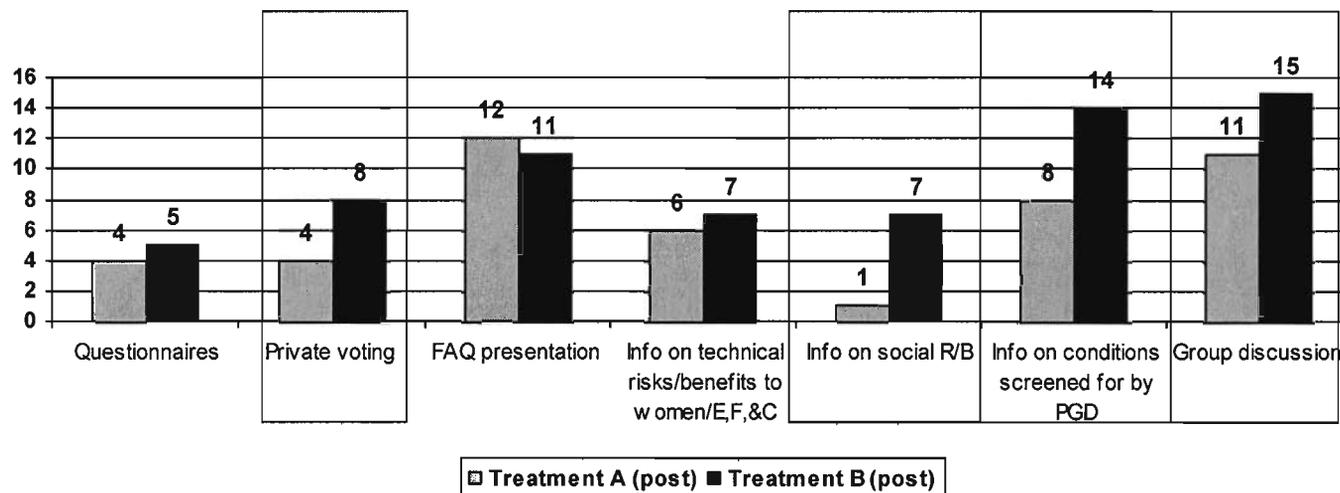
Figure 5.10 Survey 2 results: Opinions of PGD technology



Rating the workshop

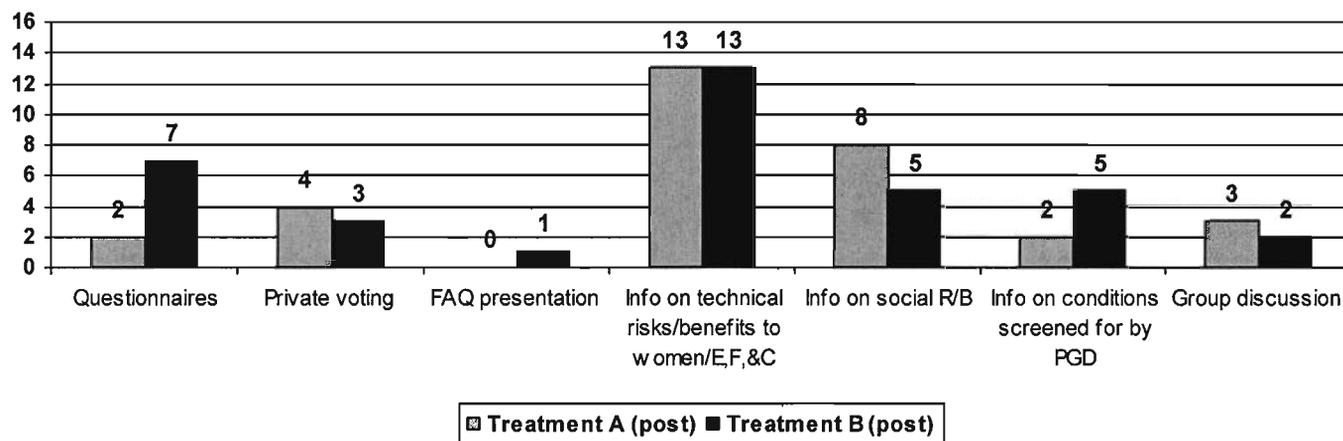
Differences between treatments emerged when participants were asked to rate their favourite part of the workshop (see Figure 5.11). Participants from each treatment favoured the questionnaires, general background information presented in FAQ's, and information on the technical risks and benefits to women, embryos, fetuses, and children equally. However, participants from treatment B (those who DID review SDM materials) were somewhat more likely to prefer the private voting process and the group discussion and significantly more likely to prefer strategies that focussed on the social risks and benefits of PGD and the conditions screened for by PGD.

Figure 5.11 Survey 2 results: Favourite part of the workshop



When asked to identify their least favourite part of the workshop most participants in both treatments stated that the information presented on the technical risks and benefits of PGD to women, embryos, fetuses, and children was their least favourite part (see Figure 5.12). Treatment B participants were also significantly more likely to pick the questionnaires as their least favourite activity.⁸⁵

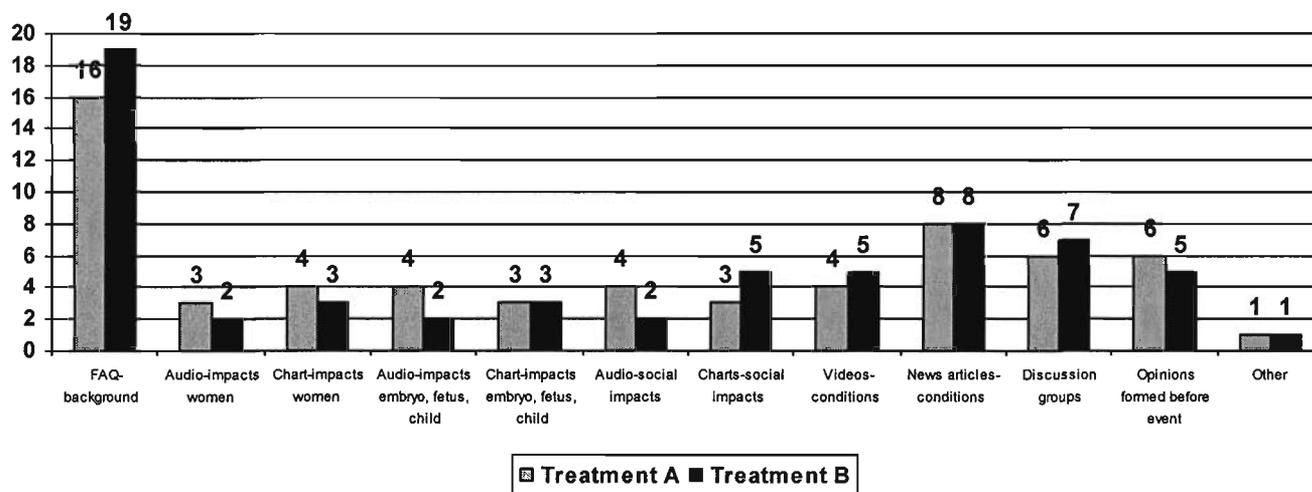
Figure 5.12 Survey 2 workshop ratings: Least favourite part of the workshop



⁸⁵ It is possible that treatment B participants rated the questionnaires as their least favorite part of the workshop because they preferred the group discussion portion. They might have believed that if the workbook exercises were reduced, they would have been able to engage in a longer discussion. These were also the participants who viewed the SDM materials so therefore had to wait much longer before they were allowed to discuss the issues with other participants (when compared to treatment A participants).

Participants in both treatments reported that the most important factor informing their private vote, or their recommendations for risk communication strategies, was the general background information about PGD addressed in the FAQ power point presentation (see Figure 5.13). Nineteen participants from treatment B and 16 from treatment A stated that this information source influenced their decision the most. The second most important source of information for participants was the news articles that described aspects of PGD from the viewpoint of those personally affected by disability. Responses concerning the least important factors influencing participants' final vote also showed very few significant differences between treatments.

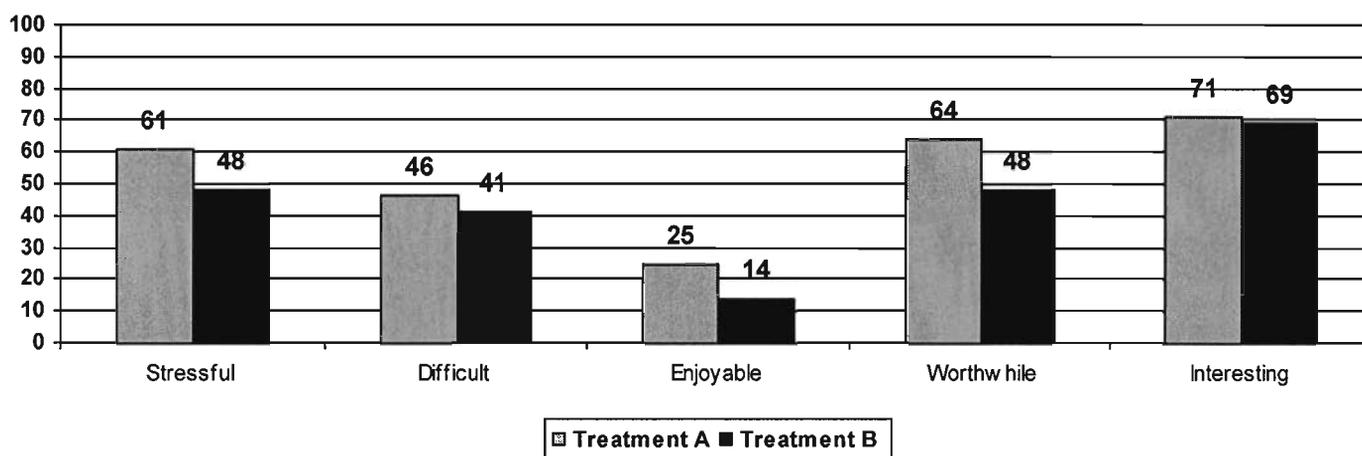
Figure 5.13 Survey 2 workshop ratings: Most important factor influencing recommendations



Finally, participants were asked how stressful, difficult, enjoyable, worthwhile, and interesting they found the workshop on a four point scale. Figure 5.14 shows those who offered extreme responses of 1 or 4 out of four. Those who did NOT receive SDM materials in treatment A had a higher percentage of participations who rated the

workshop as extremely stressful, enjoyable, and worthwhile. Ratings for extreme difficulty were similar for both treatments as were the percentage of those who reported that the workshop was extremely interesting. It is worth noting that extreme percentage ratings for treatment B participants were lower overall for this set of questions.

Figure 5.14 Survey 2 workshop ratings: Extreme ratings by treatment (shown in percentages)



Recommendations from participants

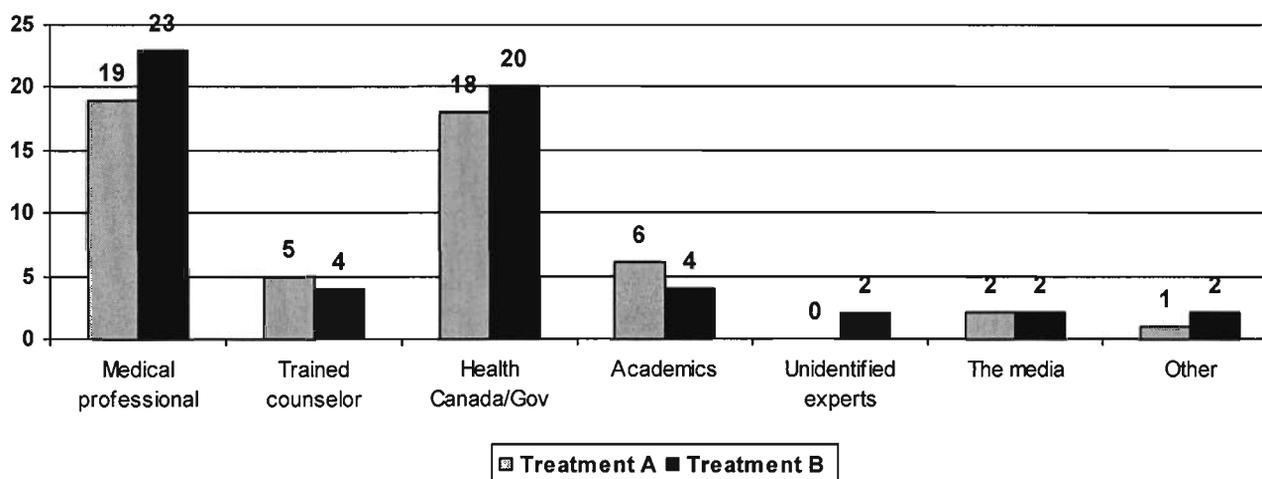
After reviewing all risk communication information (and SDM materials for the case of treatment B participants), participants engaged in a facilitated group discussion that asked them to provide risk communication recommendations.⁸⁶ Participants were asked to consider: who should communicate information about PGD; who should comprise the target audience; preferred risk communication strategies for PGD; and what information should be included in those strategies. After the group discussion on these issues was

⁸⁶ A brief overview of risk communication practices and objectives was provided before each group discussion.

complete, participants were then asked to fill out the second questionnaire, which included a voting section where they could privately write down their recommendations. They were explicitly told that their private vote need not agree with any recommendations reached during the group discussion.

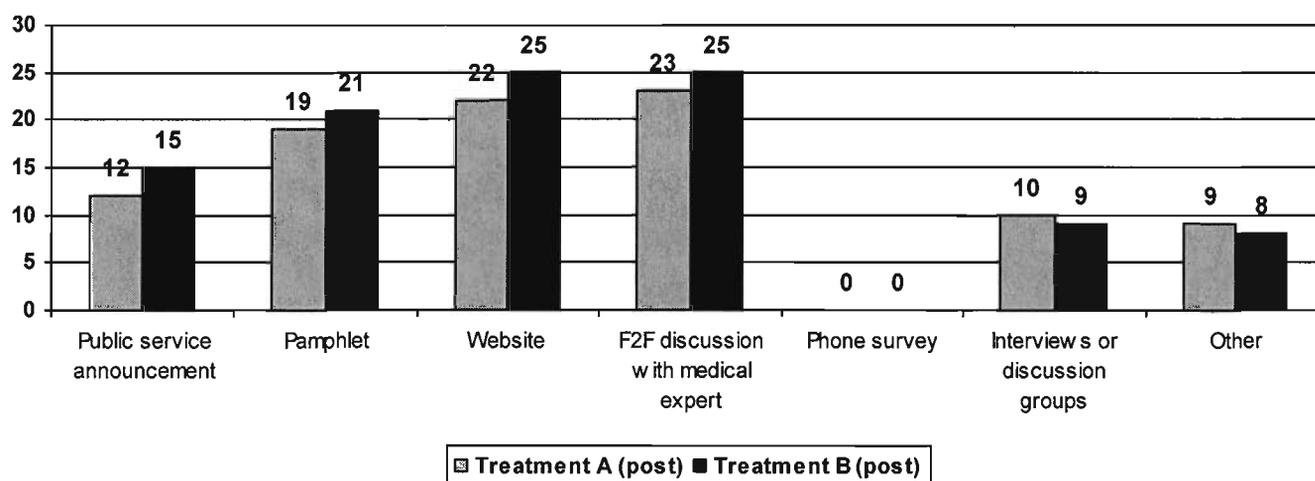
Recommendation responses revealed no significant differences between treatments. Participants from both treatments agreed that risks communicators for PGD should be both medical professionals and a federal department such as Health Canada. Group discussions revealed that participants had come to view PGD as a multi-scalar hazard that posed risks and benefits to individuals (e.g., families who want to have children), groups (e.g., those who can afford PGD), and society (e.g., all Canadians). They believed it was therefore appropriate to use different communicators (see Figure 5.15) and strategies (see Figure 5.16) to reach each of these target audiences (see Figure 5.17).

Figure 5.15 Recommendations: Who should communicate information about PGD?



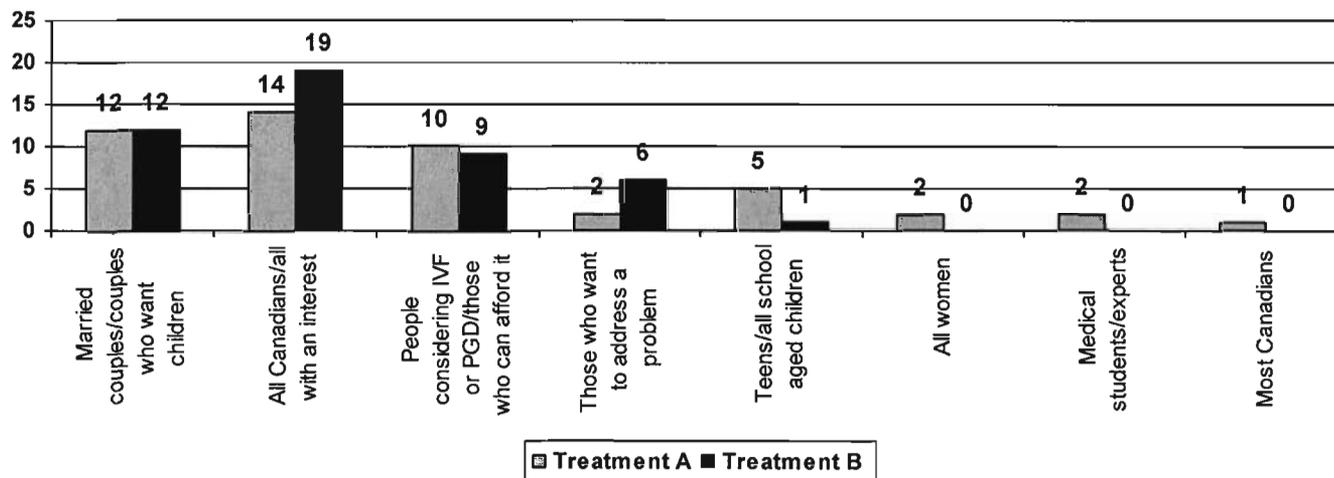
The most popular proposed risk communication methods for all participants were a face to face discussion with a medical expert and a website, which correlates well with the recommended risk communicators. Pamphlets were also a popular choice. The telephone survey was the only method to receive no votes by participants from either treatment.

Figure 5.16 Recommendations: Proposed risk communication strategies for PGD



Recommended target audiences were also similar for participants in both treatments. The most popular choice was all interested Canadians although treatment B participants were slightly more likely to choose this audience than their treatment A counterparts. The second most popular choice for all participants was married couples who want to have children followed by people considering IVF or PGD and who can afford it.

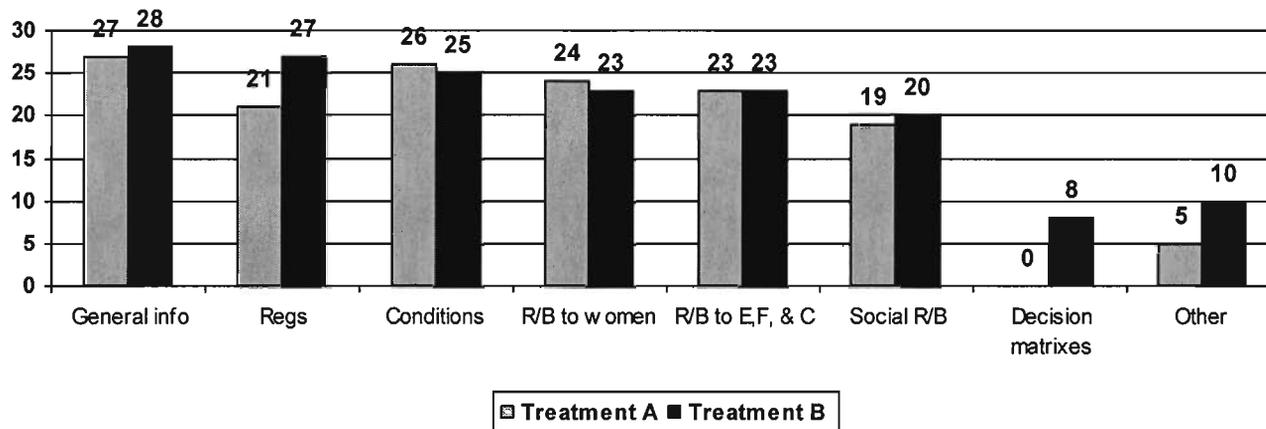
Figure 5.17 Recommendations: Who should comprise the target audience for risk
 communion strategies about PGD?



Participants from both treatments also agreed on the types of information that should comprise risk communication strategies for PGD (see Figure 5.18). They agreed that just about all information types presented during the workshop should be included although a significant number of treatment B participants reported that information about PGD regulations were more important than the others. In addition, only a few treatment B participants believed that the consequence tables (SDM materials) were important to include.⁸⁷

⁸⁷ Participants were asked to consider difficult tradeoff during the workshop. They understood that they were supposed to recommend key items (e.g., components, information types) that ought to be included in all risk communication strategies about PGD. They were aware that including certain items meant that others would have to be left out as it is unrealistic to retain the large amount of detail included in the workshop. It is the author's assumption that participants left the matrices out because they likely viewed the matrices (which took up to 20 minutes to discuss) as a simple way of reducing the amount of information for a future strategy. Also the value of the matrices is not obvious to those involved in the experiment.

Figure 5.18 Recommendations: What types of information should comprise risk communion strategies for PGD?



Voting confidence levels were also very similar for participants of each treatment. In total, 86% reported that they were either somewhat (61%) or very confident (25%) in their vote.

Evaluating the decision making process

This section employs the 2008 Academy of Sciences criteria to evaluate the quality of decision processes for participants of the deliberative risk communication workshops about PGD. The focus is specifically on process related quality or the effect (if any) that SDM applications had on how participants managed complex information about a novel, controversial topic. The first key finding to introduce is that differences between the two treatments could be easily overlooked if only major workshop outcomes were examined. For example, participant final recommendations for risk communication strategies about PGD revealed very few differences between treatments with most agreeing on who should communicate this information, preferred risk communication strategies and the

types of information that ought to be included in those strategies, and preferred target audiences. Overall, opinions of PGD did not vary significantly by treatment by the end of the workshop and confidence levels in participant generated recommendations were also very high and consistent across treatments. Differences emerged only when examining the hopes and concerns and perspectives that informed key workshop outcomes.

Quality of decisions

Information was added and considered in the process

At the beginning of the workshop in the first questionnaire, almost one third of participants (30%) failed to identify any particular hopes or concerns for PGD technology. However, treatment B participants reported on a more complex and wider network of hopes and concerns by the second questionnaire. While shared post questionnaire responses from treatment A participants centered mostly on disease prevention and decision making, shared responses from treatment B participants also covered topics such as public education and funding arrangements. Eugenic applications were one of the leading concerns for treatment A participants both before and after reviewing communication materials. However, over the course of the workshop, the leading concern for those who had viewed SDM materials (treatment B) became the potential for PGD to lead to segregation and discrimination. Common concerns for treatment B participants also included additional topics such as PGD technology becoming imposed on individuals and the ways in which the technology may narrow diversity for Canadian society.

Outputs reflected a broad view of the issues that participants believed were important

Participants agreed that the issues presented to them throughout the workshop were relevant and thus important to include in any future risk communication strategies with the exception of the SDM materials. Suggestions for additional information to include in forthcoming risk communication strategies mostly called for supplementary details on topics already covered during the workshop as opposed to new items (e.g., information on other conditions screened for by PGD, more stories from the perspective of people with disabilities). Most agreed that it was sensible for risk communicators to rely on a collaborative process like this one when determining risk communication strategies for PGD.⁸⁸

Innovative ideas were generated for solving problems

Participants were given the opportunity to describe their vision of a risk communication strategy for PGD in the voting section of the second questionnaire. Many innovative and extremely detailed strategies were proposed and a few even included intricate diagrams and figures. Some of the more notable suggestions included a 1-800 hotline number for risk and benefit information about PGD; a documentary film about PGD produced for CBC television and schools; videos to be aired on YouTube; webcasts; referendums on PGD policy; and chat rooms for those going through the PGD process.

⁸⁸ In total, 46 participants agreed that it was sensible, 7 said they did not know, and 3 reported that it was not.

Capacity for future decision making

Participants became better informed about relevant issues

Mental model interviews with lay citizens that took place prior to the workshops revealed that participants had very little background knowledge of PGD and had a difficult time anticipating particular stakeholders of this technology. All participants were successful in learning a great deal about PGD during the workshop (see Chapter 4 of this thesis). However, participants who reviewed SDM materials (treatment B) had an easier time identifying with the concerns of people who may be discriminated against through this technology (e.g., PGD may ostracize some, create class differences, discriminate against people with disabilities, or infringe on their rights) in addition to other stakeholders. People with disabilities are often identified as a major stakeholder group for PGD technology but were overlooked by most mental model interviewees during phase 2 of this study. Interestingly, those who reviewed SDM materials were more likely to prefer information on the social risks and benefits of PGD and on the conditions screened for by PGD when compared to their treatment A counterparts. Perhaps treatment B participants favoured this information because they were able to identify with a wider range of stakeholder groups.

Scientists gained an understanding of public concerns

The workshops described here have no official mandate. However the recommendations produced by participants could be easily communicated to scientists, policy analysts, and regulators working in this area. The final step in this project is to share anonymized

findings on a password protected website accessible to all experts and lay citizens who participated in various study phases.

Participants gained skills

Two of the new skills gained by all workshop participants were learning how to participate in a deliberative group discussion and design risk communication strategies. Most reported that the workshop had been a valuable learning experience. A significant majority (84%) also stated that they would be “very” or “definitely likely” to attend a workshop like this again in the future. Many treatment B participants were able to recognize complex tradeoffs by reviewing SDM materials. Learning about alternatives through the lens of value objectives at each scale encouraged participants to consider important tradeoffs inherent to each choice. Treatment B participants were therefore better able to articulate tradeoffs that occur between scales for PGD. For example, they understood that pursuing this technological solution could lead to great perceived benefits for families and children while potentially discriminating against people with disabilities and reducing overall diversity for society. Many ultimately viewed this as a justified tradeoff as indicated by the overall support for the technology by the end of the workshop. The ability to identify and cope with tradeoffs is applicable to a range of other problems and is a skill that participants could easily employ during actual decision making opportunities that regularly emerge in their daily lives.

Conclusions

Findings from the risk communication workshops described here contribute empirical evidence to the body of knowledge surrounding public involvement efforts. The results demonstrate that lay participants, especially those who review even the most minimal SDM materials, are able to make well informed, robust, inclusive, and therefore meaningful decisions about a complicated novel technology. Workshop findings also fared well against the National Academy of Sciences, 2008 criteria that judged the quality of the workshops and associated outputs. It was found that SDM materials fostered holistic or “all things considered” judgements (McDonald, 2000). Treatment B participants were more likely to understand and articulate the range of stakeholder hopes and concerns for PGD technology (research question #1). The materials also helped these participants conceptualize complex financial and ethical tradeoffs between families, groups, and society (research question #2). Pre-implantation genetic diagnosis is a technology that is caught up in the culture wars over abortion. Results indicate that participants who received SDM materials are more likely to acknowledge, but get past, the most obvious and politically charged ethical concerns (e.g., PGD is playing God, concerns about killing human embryos, PGD is a slippery slope to eugenics) in order to analyze murky long-term ethical dilemmas that could be easily overlooked without careful analysis as illustrated in the quotation shown below (research question #3).

It's okay that science discover[s] more and more things. But I hope that we are all prepared to use these findings for the benefit of all human kind, not for exclusion of some people or [for] destruction. –Amy

In closing, it seems that including SDM materials in risk communication workshop are in fact worth the extra time they consume and effort from participants (research question #4). The counterfactual experiment described here demonstrates that SDM materials helped participants to make better, more holistic, and ultimately more ethical decisions. In addition, participants did not feel overwhelmed by the inclusion of additional SDM materials. On the contrary, those who did NOT receive SDM materials in treatment A were more likely to rate the workshop as extremely stressful even though participant ratings for extreme difficulty were similar for both treatments.

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Chapter six: Overview, insights, and future research directions

Summary of chapter hypotheses and key insights

The fundamental objective of this thesis was to contribute to the interdisciplinary body of research that seeks to integrate the fields of ethics and risk analysis. It was shown how guidance from bioethics can fortify health risk communication strategies and ultimately foster holistic decision making for a virtually unknown systemic hazard. The chapters included in this thesis have attempted to explain the unique contributions of this study in terms of the topic addressed and the methods used to analyze it. The first introductory chapter explained why systemic health hazards like pre-implantation genetic diagnosis (PGD) are an important area of study for the field of risk communication and how novel methods can be used to elicit risk communication recommendations from lay citizens. Some have argued that democratizing science policy through deliberative efforts may be used as an excuse to persuade citizens or “dilute accountability” of policy makers (Lidskog, 2008). This objection seems particularly persuasive when public engagement efforts fail to show evidence of meaningful outcomes. Research presented here demonstrates that lay citizens can in fact produce thoughtful and well informed recommendations about extremely complex and unfamiliar health topics in line with their own values. The chapters that comprise this thesis introduce novel ways of approaching systemic hazards that include intellectual contributions from the field of bioethics and experiments with deliberative risk communication. Table 6.1 shows the fundamental objectives for each chapter.

Table 6.1 Fundamental objectives by thesis chapter

Chapter	Fundamental objectives
Two: Blending bioethics concepts with risk communication theory and applications	<ul style="list-style-type: none"> to demonstrate how bioethics concepts can help fortify risk communication strategies.
Three: Characterizing expert mental models for systemic hazards: the case of pre-implantation genetic diagnosis	<ul style="list-style-type: none"> to share a novel method of eliciting expert judgment
Four: Learning about systemic hazards through a risk communication experiment: the case of pre-implantation genetic diagnosis	<ul style="list-style-type: none"> to gather empirical evidence that shows lay citizens can in fact learn a great deal about a range of value-oriented and technically-oriented risk/benefit messages
Five: Using structured decision making techniques to help communicate information about controversial technologies: the case of pre-impanation genetic diagnosis	<ul style="list-style-type: none"> to evaluate the quality of lay participant decision processes associated with a series of deliberative risk communication experimental workshops

Chapter two outlined the various ways in which bioethics theory can be used to fortify risk communication strategies for systemic health hazards. It showed how considering substantive and public ethics can help risk communicators identify the moral values that should inform their efforts; build an ethical communication strategy; choose experts that will ultimately inform that strategy as well as the target audience; and evaluate findings. Emerging systemic hazards require more than new theoretical frameworks, they also call for new approaches. The main objective of chapter three was to introduce a novel method of eliciting expert judgment. It demonstrated how the mental models approach (Morgan, 2002), supplemented with bioethics theory discussed in chapter two, can be used to elicit and characterize expert judgments capable of clarifying uncertainties and outcomes for a wide range of heterogeneous stakeholders for PGD technology.

Chapter four discussed the results of mental model interviews and risk communication experimental workshops with lay citizens about PGD. It showed that although most participants were initially unfamiliar with this technology, they could overcome many shared misconceptions and learn a range of technically –oriented and value-oriented risk/benefit messages. Furthermore, these messages did not undermine their own views. Unlike other communication efforts (e.g., propaganda) that attempt to actively manipulate thinking, the messages presented in this study enhanced opinions of PGD thereby respecting the autonomy of participants. For example, although participants became more concerned about the risks that PGD may pose to people with disabilities (or other groups), many anticipated risks of this technology were maintained throughout the workshop (e.g., eugenic concerns and the potential for designer babies). Reported benefits were also more complex by the end of the risk communication workshop although many participants maintained the view that an overall healthier population was a significant benefit of PGD technology.

Chapter five examined the quality of workshop participant decision processes according to criteria presented in the National Academy of Sciences, 2008 report on public participation. Experiment results fared well against the 2008 criteria (National Academy of Sciences, 2008). The workshop included a counterfactual experiment with structured decision making (SDM) components in the form of consequence tables. It was determined that the SDM materials helped participants to arrive at more holistic, inclusive, and therefore ethical decisions by helping them to conceptualize the complex financial and ethical tradeoffs between families, groups, and society (McDonald, 2000).

In summary, this thesis has produced a number of significant insights for existing theory. First, collaboration between applied bioethics and risk analysis is not simply possible, it is productive. I would even argue that such interdisciplinary work is required to effectively cope with systemic hazards in the health domain. There are many interesting overlaps between these two fields of study in terms of shared principles and interests. Ethically informed risk communication efforts, like the experiment described here, help lay participants to deal with complicated tradeoffs and ultimately produce meaningful recommendations in line with their own values. This study also confirmed the value of established risk analysis methods such as the mental models approach and SDM techniques and how these tools can be employed to foster ethical decisions.

Study strengths and weaknesses

The main contribution of this thesis as a collective work is to demonstrate that lay citizens can in fact make holistic and well informed decisions about systemic hazards through deliberative risk communication efforts. Empirical results presented here are generalizable to other kinds of systemic health hazards and can be used to inform standards and methods of risk communication for government bodies and others in the research community. Nevertheless, a perceived weakness of this study could be that the experimental process had no official mandate and therefore no direct influence on public policy making about PGD technology in Canada (as would be the case for federal program evaluations for example). Some may argue that it is both inappropriate and a waste of citizens' valuable time and energy to produce recommendations in a vacuum. However, the study was intended to examine and test a novel approach to deliberative

risk communication, not to statistically represent the views of a particular group for policy guidance. The absence of an official mandate is in fact an overall strength for this study. Official public engagement efforts must produce recommendations in a timely fashion using conservative (and dependable) methods and approaches. The fundamental objective of such efforts is to produce a final product, not to theorize or experiment with novel conceptual frameworks. Academic researchers have the freedom and I would also argue, obligation to pursue research that cannot be conducted elsewhere in private industry or by government officials in order to advance their chosen field of study.

Other weaknesses of this study stem from typical financial constraints placed on any student project that made recruiting lay participants for extended workshops held at expensive facilities impossible. This project used space graciously donated by The W. Maurice Young Centre for Applied Ethics at the University of British Columbia and was only able to provide small honorariums (10\$) for lay participants who could therefore not be expected to donate large amounts of time to this study. Workshop participants had a maximum of one hour to consider the complex issues surrounding PGD during the large group discussion period. Additional deliberation time would likely lead to more substantial and robust recommendations. In the future, with a grant funded research project, it would be preferable to allow participants more discussion time and perhaps even spread the event over an entire weekend (or two) to allow for meaningful reflection and adequate rest periods. Recent deliberative democracy experiments conducted in the topic areas of biobanking and salmon genomics at The W. Maurice Young Centre for Applied Ethics have demonstrated the importance of such considerations (Longstaff and Burgess, forthcoming). It would also be appropriate to experiment with recruitment filters

in order to test the risk communication experiment with different types of lay citizen samples (e.g., family members of people with disabilities, couples, those who have used reproductive technologies).

Future research directions

Communicating the risks and benefits of systemic hazards is a new challenge for risk analysts. However, notable progress has already been made by researchers including Sherwin, Slovic, Renn, and McDaniels et al. Sherwin's *public ethics* probes moral responsibility at multiple scales of impact in relation to systemic hazards (Sherwin, 2008). Her framework examines new *oughts* posed by systemic hazards through employing existing feminist bioethics concepts such as *relational ethics* (Burgess and d'Agincourt-Canning, 2001). Slovic examines the ways in which citizens cope with or make sense of new systemic topics such as genocide. His recent work explains some of the cognitive failures associated, for example, with processing "losses of life as they become larger" (Slovic, 2007). He argues, like Sherwin, that dealing effectively with systemic hazards requires a multi-system, cross-scale approach that includes a commitment to morally responsible actions amongst citizens and institutions but also system changes to international regulatory frameworks, among other things. Both Renn and McDaniels et al propose new risk management frameworks capable of incorporating the value dimensions of systemic hazards into the risk analysis process. Renn's concern assessment complements the conventional risk assessment model produced by technical experts while McDaniels et al introduce decision making frameworks guided by shared

fundamental values of relevant stakeholders (Renn, 2006; McDaniels et al, 2005 & 2006).

Future research studies should continue to experiment with deliberative risk communication experiments that incorporate bioethics theory in the human health domain in order to confirm some of the findings presented here. Additional research is required to determine best practices for communicating value-oriented and technically-oriented risk/benefit information that are effective and trustworthy. Future studies should also test the methods used in this study as well as novel approaches (Cox et al, 2009) with different audiences and experiment with more complex systemic topics such as global climate change, stem cell research, and global poverty (UNICEF, 2008). The findings presented here demonstrate that lay citizens can come to understand and make meaningful recommendations about extremely complicated, unknown technologies like PGD. There is therefore good reason to believe that lay citizens could provide meaningful input for a range of other systemic hazards, which will ultimately help analysts develop more inclusive and ethical risk communication strategies.

Finally, it is important for the dialogue to continue between bioethics and risk researchers as a great deal of work remains to be done in this new interdisciplinary field. The natural next step in this relationship would be to explore the contributions that risk analysis can make to the field of bioethics. It is important for those conducting work in highly complex areas, like systemic hazards, to understand a wide range of perspectives including those of conventional experts and lay citizens. Ethics researchers working in the health domain could benefit from learning more about how to engage the lay public

as well as how to communicate across disciplinary boundaries, topics that have been researched extensively within the field of risk analysis.

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Appendices

Appendix A. UBC Research Ethics Board's Certificates of Approval

Appendix B. Interview questions for experts

Appendix C. Mental model interview questions for lay participants

Appendix D. Expert charts developed after an extensive literature review and then confirm through interviews. Included are charts that discuss the (1) technical risks of PGD to the embryo, fetus, and child; (2) technical risks of PGD to a woman; (3) social risks of PGD, (4) considerations for a Canadian regulatory framework in flux, and (5) and spectrum of conditions screened for by PGD. Charts 4 and 5 were not initially included. They instead were added in response to expert participant feedback.

Appendix E. Example of how expert charts changed over time due to expert participant feedback

Appendix F. Risk communication workshop presentation that was used to guide the workshop (this presentation includes the expert based FAQ's and the consequence matrices)

Appendix G. Risk communication workshop workbook for lay participants

Appendix H. Risk communication workshop scripts for audio recordings (based on Appendix D 1-4 charts)

Appendix I. Risk communication workshop news articles

Appendix J. Risk communication workshop links to videos recommended by experts.

Appendix K. Risk communication workshop database of results

Appendix A. UBC Research Ethics Board's Certificates of Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Michael F. McDonald	INSTITUTION / DEPARTMENT: UBC/College for Interdisciplinary Studies/Applied Ethics	UBC BREB NUMBER: H08-00700
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution UBC		Site Vancouver (excludes UBC Hospital)
Other locations where the research will be conducted: The workshops will take place at locations that are most convenient for my participants. For example, if I am successful in recruiting parents from a dance studio, I will hold the workshops at that location. If I am successful in recruiting a group of office workers to participate in a workshop, then I will hold the workshop at their office. The default location for all workshops will be UBC Vancouver campus. All of the workshops will take place in a private room so that outsiders will not be able to observe.		
CO-INVESTIGATOR(S): N/A		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: Linking Risk Communication and Biomedical Ethics: The Case of Pre-implantation Genetic Diagnosis (PGD)		
REB MEETING DATE: June 26, 2008	CERTIFICATE EXPIRY DATE: June 26, 2009	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: June 27, 2008
Document Name	Version	Date
Protocol:		
A. Research proposal	Final	May 7, 2008
Consent Forms:		
B. Consent form	Final	May 7, 2008
Advertisements:		
C. Recruit poster interview	Final	May 7, 2008
F. Recruit poster workshop	Final	May 7, 2008
Questionnaire, Questionnaire Cover Letter, Tests:		
I. Workshop workbook	Final	May 7, 2008
H. Workshop audio scripts	Final	May 7, 2008
E. Workshop	Final	May 7, 2008
G. Workshop news stories	Final	May 7, 2008
D. Mental model interview questions	Final	May 7, 2008
Other:		
Findings will be posted on this password protected site that currently has no content.		

<http://www.riskcommunication.info/home.html>

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

***Approval is issued on behalf of the Behavioural Research Ethics Board
and signed electronically by one of the following:***

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Daniel Salhani, Associate Chair
Dr. Anita Ho, Associate Chair

Appendix B. Interview questions for experts

Linking Risk Communication and Biomedical Ethics: The Case of Pre-implantation Genetic Diagnosis (PGD)

Questions for experts: running time 1 hour

Introduction

Thank you very much for agreeing to participate in this research study. I have asked you to participate in this project because you have been identified as an expert in some aspect of PGD technology. In this hour long interview, I will ask you to review a series of charts that will eventually be used to create risk communication strategies for lay potential users of PGD technology. These charts represent the findings of a literature review I conducted on the social, technical, ethical, and economic dimensions of PGD technology.

Please do not be concerned if you are unable to comment on particular issues or charts. I will be interviewing a wide range of experts until all aspects of the charts are covered.

The purpose of this interview is to evaluate the accuracy and completeness of these charts and also to identify any phantom risks that may be presented in these charts.

This project is being funded through the Research Allowance portions of my Canadian Institutes for Health Research (CIHR) Ethics of Health Research and Policy Training Project and the CIHR Institute of Genetics Doctoral Research Awards.

Part 1: Social dimensions of PGD

Couples who pursue PGD do so in order to avoid having a child with a specific genetic condition. However, there are many social risks associated with PGD that must also be considered. I would like to start our interview by asking you to comment on the validity of the chart that outlines the social risks of PGD.

Q1) Do you think the chart accurately represents the social risks of PGD? Why/why not?

Q2) Is there anything missing from the chart?

Q3) Is there anything that should be removed from the chart?

Now I would like you to comment on the chart that outlines some of the societal factors that may inform a person's decision to pursue PGD.

Q4) Do you think the chart accurately represents the societal factors that may inform a person's decision to pursue PGD? Why/why not?

Q5) Is there anything missing from the chart?

Q6) Is there anything that should be removed from the chart?

Part 2: Technical dimensions of PGD

Now let's move on to some of the other risks of PGD technology. There are many technical risks associated with PGD that must be considered by potential users. For example, PGD poses certain risks to an embryo, foetus, or child.

Q7) Do you think the chart accurately represents these risks? Why/why not?

Q8) Is there anything missing from the chart?

Q9) Is there anything that should be removed from the chart?

Many of the risks posed to an embryo, foetus, or child also pose some risk to the women who undergo PGD.

Q10) Do you think the chart accurately represents these risks? Why/why not?

Q11) Is there anything missing from the chart?

Q12) Is there anything that should be removed from the chart?

Part 3: Wrap up

Lastly, do you have any additional comments that you would like to make specifically about these charts or generally about this project?

Thank you so much for your time!

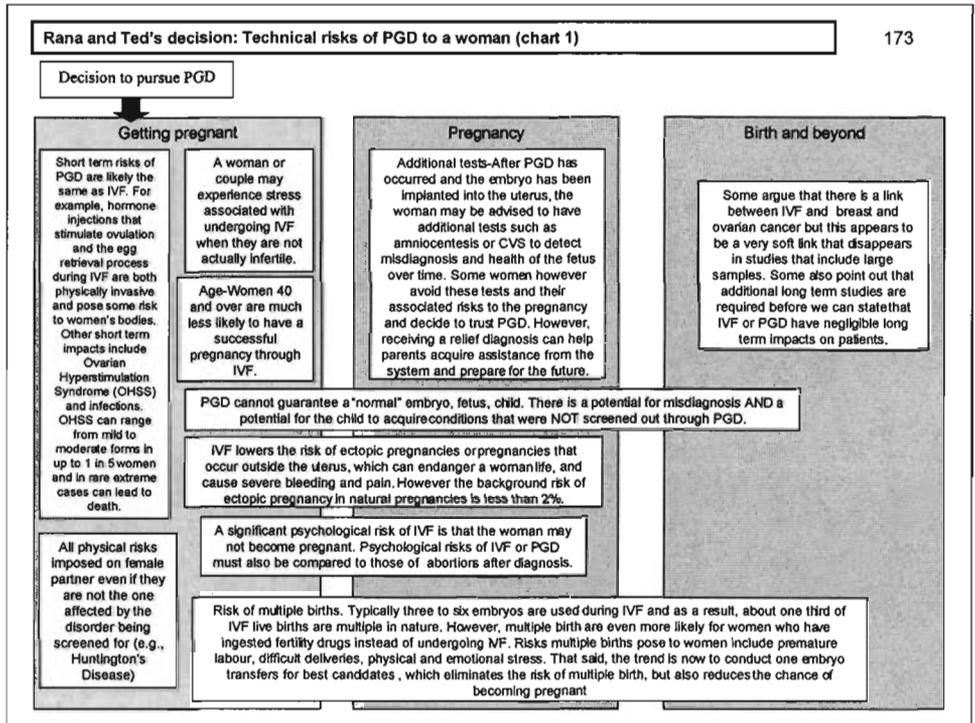
Appendix C. Mental model interview questions for lay participants

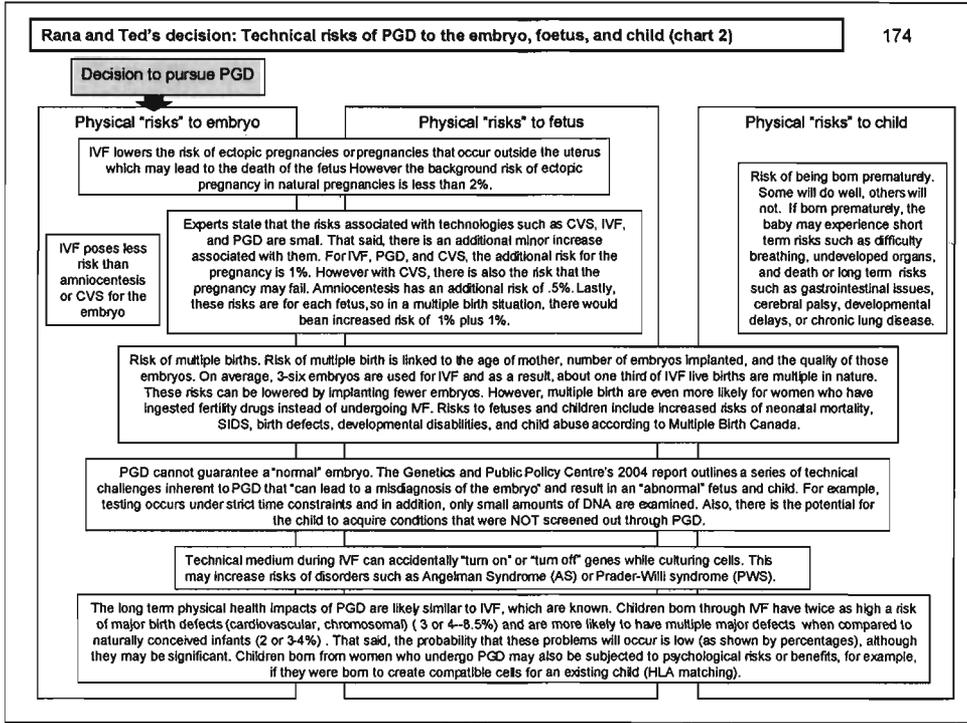
1. Have you ever heard of pre-implantation genetic diagnosis or PGD?
2. Have you ever heard of a saviour sibling?
3. Have you ever heard of genetic testing?
4. Have you every heard of in vitro fertilization or IVF?
5. How about prenatal testing? (e.g., Amniocentesis)
6. What sort of tests can be performed on a woman while she is pregnant? If any.
7. How did you come to learn this (above) information?
8. DEFINITION: IVF is a technology used by people who have difficulties achieving pregnancy. During IVF, egg cells are fertilised by sperm outside of the body.
9. DEFINITION: PGD is used to analyse genetic material from fertilized human embryos during in vitro fertilization. Screened embryos are selected and put back into the uterus of the female patient and hopefully grown to term. There are 3 applications for PGD. One is to screen embryos for abnormalities or identify markers for specific genetic conditions. The second is for sex selection, which is illegal in Canada. The third is to produce a saviour sibling or a sibling that is a tissue match for an existing sick child. Under Canadian law, embryos that are not selected can be destroyed or donated to stem cell research.
10. Who do you think might be concerned about PGD?
11. Who might be excited about PGD?
12. What kind of risks do you think PGD may pose?
13. What kind of benefits do you think PGD may pose?
14. Are there any risks or benefits that PGD may pose specifically to a woman?
15. How about the embryo, foetus, and child?
16. What kind of social risks do you think PGD may pose if any?
17. Where would you go to find info about PGD?

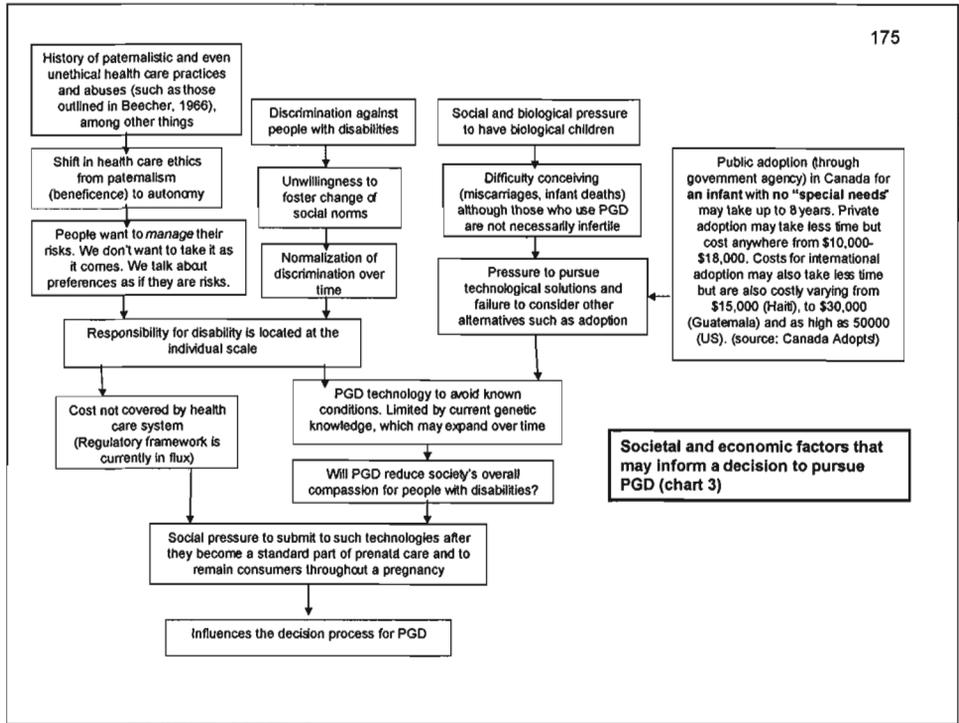
Appendix D. Expert charts (final versions)

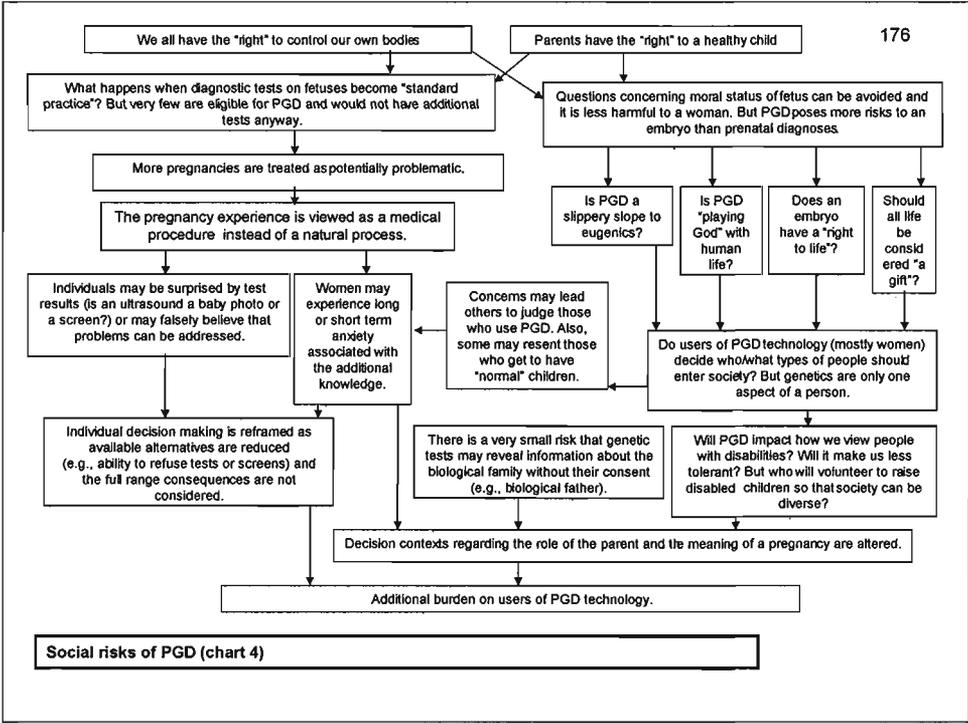
Expert information charts

**(to be disseminated in handout form before
each audio recording is played and collected
before the vote/second questionnaire)**



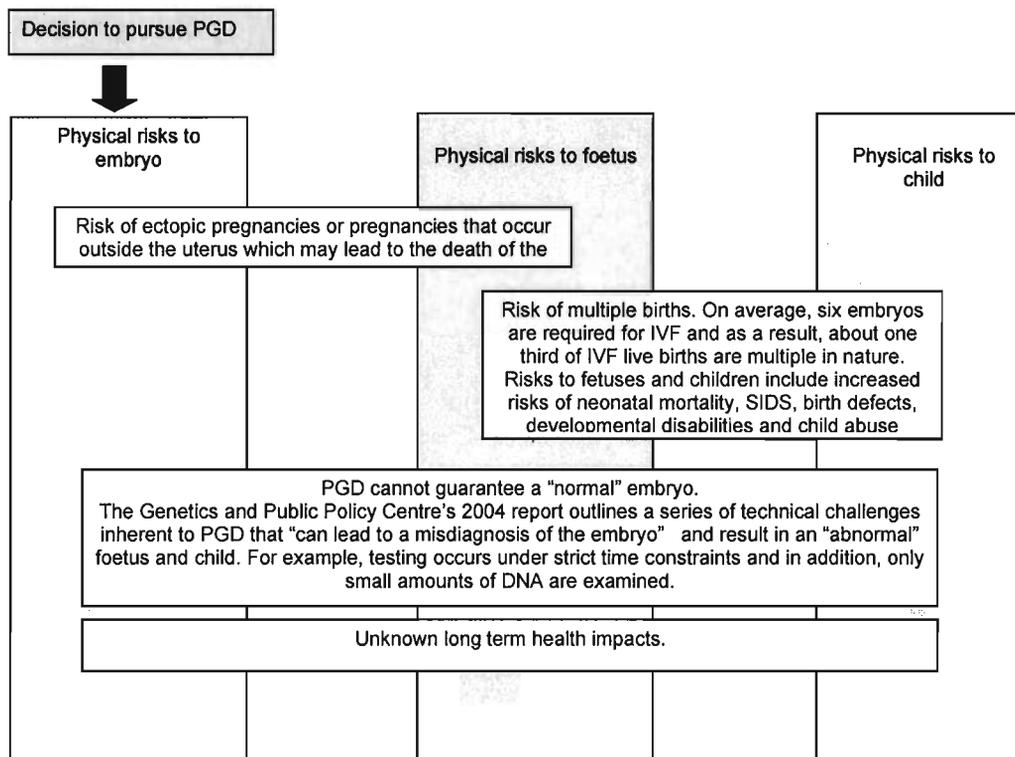




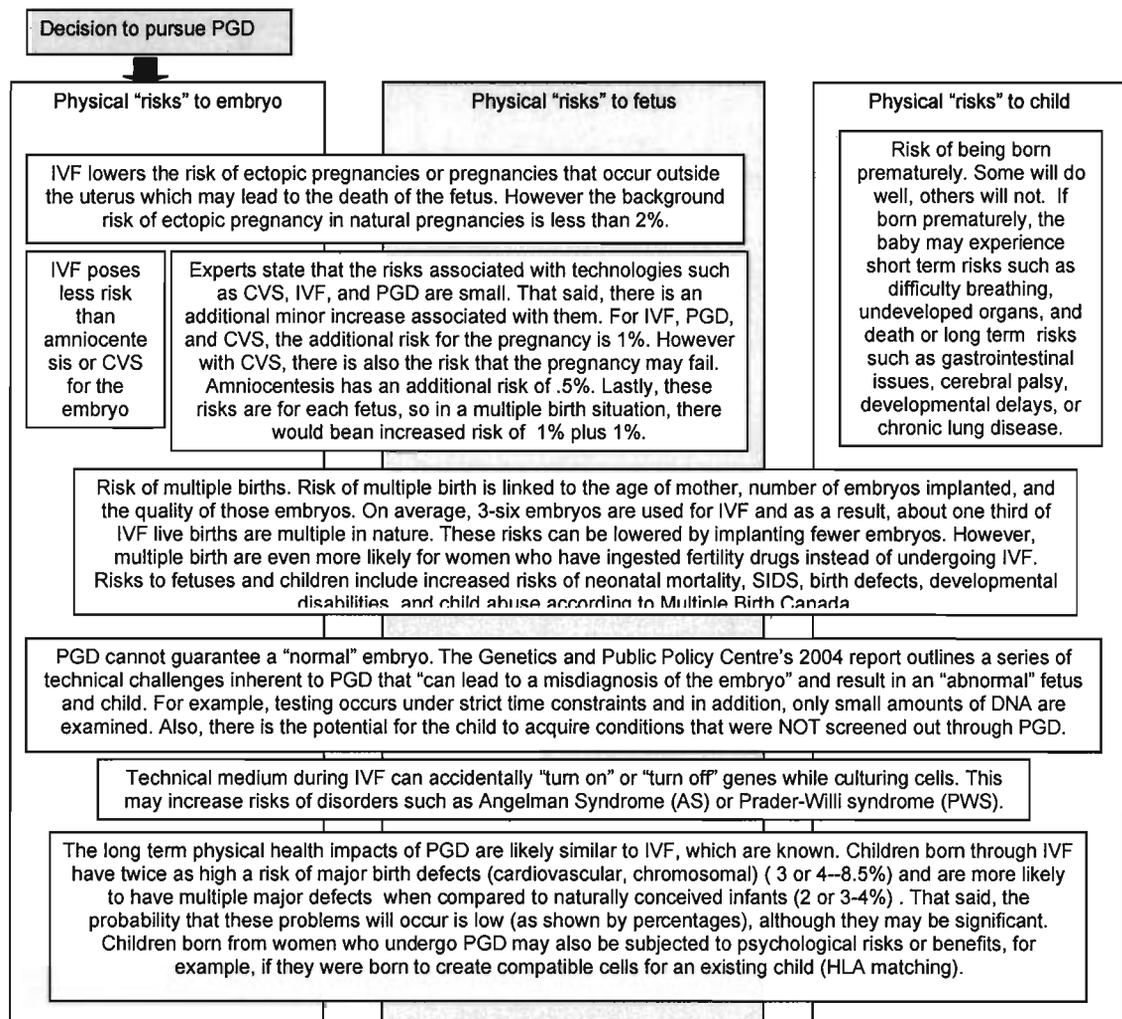


Appendix E. Example of how expert charts changed over time due to expert participant feedback

Technical risks of pre-implantation genetic diagnosis (PGD) to the embryo, foetus, and child
(pre-expert interview status)



Technical risks of pre-implantation genetic diagnosis (PGD) to the embryo, foetus, and child
(post-expert interview status)



Appendix F. Risk communication workshop presentation that was used to guide the workshop (this presentation includes the expert based FAQ's and the consequence matrices)

Medical risk communication workshop

August, 2008

Facilitator: Holly Longstaff

Welcome!!

- A little about me and my PhD project
- Why is this important?
- How will I use this information?
- Introductions-a little about you
 1. What's your name?
 2. Have you ever done a focus group or telephone survey before?
 3. Why did you decide to participate today?

Agenda (2.5 hours in total)

➡ Please hand in your signed consent forms!

Part 1: Pre-deliberation questionnaire (20 min)

Part 2: Presentation of background information (30 min)

Short break for snacks! (10 min)

Part 3: Deliberation and private vote (1 hour)

Part 4: Post-deliberation questionnaire (30 min)

* Please pick up your honorarium before you leave!

Part 1-30 min

- ➔ Please make sure you hand in your signed consent form
- ➔ Then, complete your pre-deliberation questionnaire

Part 2-30 min

Task: Learning as much as we can
about pre-implantation genetic
diagnosis or PGD before we deliberate
about it.

These FAQ's
will help you to answer the
workbook questions.

Pre-implantation genetic diagnosis: background information

What is PGD?

- PGD is used to analyze genetic material from fertilized human embryos during in vitro fertilization or IVF. Screened embryos are selected and put back into the uterus of the female patient and hopefully grown to term.

PGD background

What is in vitro fertilization or IVF?

- IVF is a technology used by people who have difficulties achieving pregnancy. During IVF, egg cells are fertilised by sperm outside of the body.

What is the connection between IVF and PGD?

- PGD is performed on a patient while she is undergoing IVF (extra step). BUT-People who use PGD do not necessarily have problems achieving pregnancy unlike users of IVF.

Now here comes the tricky part!

- Although you must go through IVF to use PGD, you do not have to get PGD if you undergo IVF.

PGD background

Why would someone want to use PGD?

There are 3 applications for PGD

- (1) to screen embryos for abnormalities or identify markers for specific genetic conditions.
 - (2) for sex selection, which is illegal in Canada.
 - (3) to produce a saviour sibling or a sibling that is a tissue match for an existing sick child.
- Under Canadian law, embryos that are not selected can be kept for future use, destroyed, or donated to stem cell research.

What is PGD used for?

- PGD is used to screen for genetic conditions or chromosomal abnormalities. **(TRUE)**
- PGD is used to help infertile couples achieve pregnancy. **(FALSE)**
- PGD is used to determine the sex of an embryo. **(TRUE)**
- PGD is used to diagnose abnormalities during an ultrasound. **(FALSE)**
- PGD is used to match tissue to create compatible cells for an existing child. **(TRUE)**

PGD background

How do people get PGD?

- It is actually quite difficult to qualify for PGD right now in Canada. You can't just walk into a fertility centre and ask for it. You must be at risk for a known serious genetic disorder. If you are eligible, a trained genetic counselor must explain the risks and benefits of PGD to you before you make your decision.

Useful definitions (alphabetical order)

- **Amniocentesis:** a prenatal test that detects chromosomal abnormalities and other genetic conditions while the fetus is in the mother's womb. It tests a sample of amniotic fluid, which is the fluid that surrounds the fetus.
- **Chorionic villus sampling or CVS :** a prenatal test that detects chromosomal abnormalities and other genetic conditions while the fetus is in the mother's womb. It takes cells from the placenta, which surrounds the fetus, and it can be performed earlier on than amniocentesis.
- **Chromosomal abnormalities:** an abnormal number or structure of the chromosome
- **Chromosome:** a chromosome is a bundle of DNA. Every human has 46 chromosomes.
- **Disability types**
 - Medical model of Disability: People disabled by their body-structure related functioning.
 - Social model of disability: People disabled by the attitudinal and environmental barriers they experience due to their non normative body-structure related functioning that hinder their full and effective participation in society on an equal basis with others.
- **DNA:** contains our genetic information.
- **Embryo:** stage in prenatal development from fertilization to the 8th week of a pregnancy.
- **Fetus:** stage in prenatal development from 9th week onward.
- **Gene:** a gene is a distinct section of DNA
- **In vitro fertilization or IVF:** technology used by people who have difficulties achieving pregnancy. During IVF, egg cells are fertilised by sperm outside of the body.
- **Pre-implantation genetic diagnosis or PGD:** technology used to analyze genetic material from fertilized human embryos during IVF.
- **Pre-natal:** before birth.

Recap! The process of PGD (Remember there are 3 main applications)

Application 1: to diagnose genetic conditions or chromosomal abnormalities

1. A couple want to have a biological child.
2. At least one person in a couple is identified as being at risk for a serious genetic disorder.
3. They decide to have PGD to avoid passing on the condition.
4. A trained genetic counselor explains the risks and benefits of PGD to them.
5. The woman undergoes IVF.
6. During IVF, the egg cells are fertilised by sperm outside of the body to make fertilized embryos.
7. The genetic material from those embryos are tested to screen for the specific genetic conditions or chromosomal abnormalities.
8. Embryos that DO NOT carry genetic markers for the specific condition or contain chromosomal abnormalities are selected and put back into the uterus of the woman.

The process of PGD

Application 2: to determine the sex of an embryo.

1. A couple want to have a biological child.
2. At least one person in a couple is identified as being at risk for a serious genetic disorder that is (a) linked to the sex of the child (called X linked) or (b) the couple want to use PGD for "family balancing" (which is illegal in Canada).
3. They decide to have PGD to have a child of a particular sex.
4. A trained genetic counselor explains the risks and benefits of PGD to them.
5. The woman undergoes IVF.
6. During IVF, the egg cells are fertilised by sperm outside of the body to make fertilized embryos.
7. The embryos are screened and only female (in the case of X-linked disorders) or ? in the case of family balancing are selected and put back into the uterus of the woman.

The process of PGD

Application 3: to match tissue to create compatible cells for an existing child

1. A couple have a child that is very sick and needs a special procedure such as a bone marrow transplant.
2. They have searched for a donor but there are no matches.
3. They decide to have PGD to produce a baby that is a tissue match for their sick child.
4. A trained genetic counselor explains the risks and benefits of PGD to them.
5. The woman undergoes IVF.
6. During IVF, the egg cells are fertilised by sperm outside of the body to make fertilized embryos.
7. The genetic material from those embryos are tested to see if any match the sick child.
8. Embryos that match are selected and put back into the uterus of the woman.
9. After birth, stem cells are harvested from the umbilical cord of the new baby and used to help the sick sibling (no guarantee).

PGD used to detect a spectrum of conditions

Some point out that it is important not to trivialize or conflate all genetic conditions. What do you think? In each case, are we selecting for a feature? Are we selecting against pathology? But where does a feature end and pathology begin?

Non-fatal conditions ← → Fatal conditions

From birth: Down's Syndrome

- Caused by an extra chromosome
- Symptoms vary widely
- Likelihood of having a child with Down's increases with age of mother but can occur at any age in any culture
- Children with Down's may face more or less health problems than other children depending on the condition
- [Hyperlink to Video from Down's Syndrome Society](#)

Late/adult onset: Cancer

- BRCA1 is a gene that increases risk of breast and ovarian cancer
- This test detects mutations in BRCA genes
- BBC News story (see handout)

Early onset: Tay-Sachs Disease

- Genetic disorder
- Progressive destruction of central nervous system
- Symptoms begin at around 6 months and may include eventual blindness, mental retardation, inability to swallow, breathing difficulties
- Most die before 5th birthday
- Hyperlink to public service announcement video from National Tay-Sachs & Allied Diseases Association <http://www.ntsad.org/>

Late/adult onset: Huntington's Disease

- Most common type of adult-onset condition
- Do not develop symptoms (motor disturbance, dementia) until later in life.
- It is progressive and degenerative and fatal
- Washington Post story (see handout)

Regulatory framework FAQ's

Who regulates PGD in Canada?

- An agency called Assisted Human Reproduction Canada that reports to the Minister of Health. However, the regulatory framework is currently under development.

Has PGD always been regulated in Canada?

- No. Before 2004, there were no regulations, standards, or professional guidelines for the use of PGD in Canada.

Is PGD covered by the Canadian health care system?

- No, so PGD is quite expensive and can cost up to \$20,000 +. Although some Canadians (such as Ontario citizens) may be partially covered through insurance.

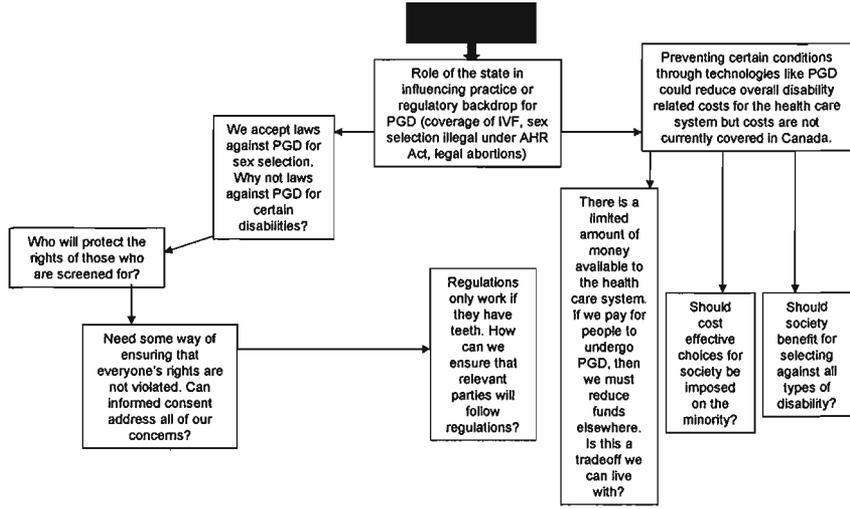
How common is PGD in Canada?

- Fewer than 20 children have been born following PGD in Canada but over 1000 have been in the world.

Can PGD be used for "family balancing" in Canada?

- No, this use of PGD is illegal here.

Considerations for a regulatory system in flux



Risks/benefits of PGD
(Holly will hand out charts that go with
each audio recording)

Rana and Ted's decision

- This decision is about the technical risks/benefits PGD poses to a woman.
- Please listen to this audio story and feel free to examine chart 1 (handout).

Rana and Ted's decision

- This decision is about the technical risks/benefits PGD poses to the embryo, fetus, and child
- Please listen to this audio story and feel free to examine chart 2 (handout).

Social risks of PGD

- We are now moving on to the social risks/benefits of PGD.
- Please listen to this audio story and feel free to examine chart 3 and 4 (handout).

- **NOTE: the following section was only viewed by treatment B participants**

Consequence Matrix for PGD at the **individual** scale: objectives by alternatives

Alternatives	Fundamental objectives of families		
	1) To avoid condition X	2) To select sex of child	3) To create saviour sibling
Natural : status quo	Chance of avoiding an undesirable condition depends on the condition type (e.g., chance of chromosomal abnormalities increase with age of mother, with autosomal dominant disorders, there is typically one affected parent, with autosomal recessive conditions if both parents are unaffected but both carriers, they have a 25% chance of having an affected child)	50-50 chance of having the desired sex	Naturally creating a child that is a perfect match for existing sick child is unlikely but theoretically possible.
PGD: testing fertilized embryos before they are implanted in the female patient	Embryos can be screened to avoid certain conditions	Illegal in Canada	Embryos can be screened for a perfect match
Prenatal diagnosis: includes a variety of tests used to determine the health and status of an unborn fetus (e.g., ultrasound Amniocentesis, chorionic villus sampling)	One cannot avoid an undesirable condition, but can determine if the fetus is affected before birth. Some may choose to abort an affected fetus (a difficult option both physically and psychologically). However, others may view this as an unacceptable option for a variety of reasons.	Illegal in Canada	Naturally creating a child that is a perfect match for existing sick child is unlikely but theoretically possible.
Adoption: private, public, or international	Can avoid conditions but it takes a long time, it is expensive, and the couple cannot have a biological child.	Can select the sex of the child	Highly unlikely

Consequence Matrix for PGD at the group scale: objectives by alternatives

Alternatives	Fundamental objectives of groups (people with disabilities example)	
	1) To encourage better lives for those affected by disability	2) To reduce discrimination against people with disabilities
Natural : status quo	More people having natural pregnancies will lead to more people born with disabilities and increased diversity for society. If there are more people born with disabilities, society may be more willing to support them (e.g., modifying infrastructures, assistance and support from government programs, wider social networks)	More people having natural pregnancies will lead to more people born with disabilities and increased diversity for society. If there are more people born with disabilities, our society may begin to show more tolerance for these folks.
PGD: testing fertilized embryos before they are implanted in the female patient	PGD is used to avoid people with disabilities, which will reduce the overall number of people with disabilities in our society. This may reduce our overall compassion and available resources for people with disabilities and their families.	PGD is used to avoid people with disabilities, which will reduce the overall number of people with disabilities in our society. This may lead some to believe that discriminating against them is acceptable since we are trying to reduce their overall numbers.
Prenatal diagnosis: a variety of tests that are used to determine the health and status of an unborn fetus (e.g.,ultrasound, amniocentesis, chorionic villus sampling)	These techniques may help families prepare for life with a child affected by disability. However, it may also encourage some to abort affected fetuses.	These techniques may help families prepare for life with a child affected by disability. However, it may also encourage some to abort affected fetuses. This may lead some to believe that discriminating against people with disabilities is acceptable since we are trying to reduce their overall numbers.
Adoption: private, public, or international	Adoption may increase the likeness of placing children who have "special needs" who would otherwise grow up without a family.	If adoption becomes socially desirable and popular, it may become more acceptable to adopt children with special needs and less acceptable to discriminate against them. 202

Consequence Matrix for PGD at the societal scale: objectives by alternatives

Alternatives	Fundamental objectives of society		
	1) To foster overall health & wellbeing of Canadians	2) To foster overall diversity of Canadian society	3) To treat all Canadians equally
Natural : status quo	Some natural pregnancies will result in children with disabilities who may or may not experience short lived or painful lives.	Some natural pregnancies will result in children with disabilities who contribute to the diversity of our society.	Supporting natural pregnancies and therefore not supporting techniques that assist in reproduction means that some Canadians will not be able to have their own biological "normal" children.
PGD: testing fertilized embryos before they are implanted in the female patient	PGD will reduce the overall number of those born with specific conditions and will therefore increase the overall number of healthy babies.	Reducing the overall number of people with disabilities will reduce the genetic and cultural diversity of our Canadian society.	Part of treating Canadians equally means that there should be equitable access to government services. However PGD is expensive and currently only available to some. If PGD is made available to all, other services will have to be reduced.
Prenatal diagnosis: a variety of tests that are used to determine the health and condition of an unborn fetus (e.g., ultrasound, amniocentesis, chorionic villus sampling)	Prenatal diagnosis can help families prepare for life with children affected by disabilities or avoid affected fetuses who would experience short lived or painful lives.	Prenatal diagnosis can help families prepare for life with children affected by disabilities. However, it may also lead some to abort affected fetuses, which may reduce the overall genetic and cultural diversity of our Canadian society.	Part of treating Canadians equally means that there should be equitable access to government services. However, prenatal diagnosis techniques are expensive. If they are made available to all, other services will have to be reduced.
Adoption: private, public, or international	All types of adoption should be encouraged so that all of us have the opportunity to be raised by loving families.	If adoption becomes socially desirable and popular, it may become more acceptable to adopt children with "special needs", which will increase the overall genetic and cultural diversity of our Canadian society.	All types of adoption should be encouraged so that all of us have the opportunity to be raised by loving families.

- **SDM section complete**

Short group discussion

- A lot of information has been presented in the last 30 minutes, do you have any comments or questions at this point that you would like to share with the group?

Break time!!

- Please take **10 minutes** to grab a snack or take a bathroom break.



Part 3-1 hour

Small group discussion

(Feel free to refer to handouts and ask questions!)

**Question: how should we communicate
the risks/benefits of PGD?**

Rules of discussion

- There are no right or wrong opinions here
- Its okay to disagree!
- Always remember to be respectful
 - Let others have their say
 - Try not to judge
 - Don't cut people off while speaking
 - No side discussions please
 - Really listen to what is being said

Role of the facilitator

- Each question will be discussed in turn by the group with guidance from the facilitator (Holly)
- Holly will ...
 - Go back to FAQ's or definitions upon request
 - Keep the discussion on track and respectful
- Sonja will...
 - Keep track of key ideas
 - Record points of consensus and persistent disagreements

Risk communication background

- What is risk communication?
- Who are risk communicators?
- Why do we communicate risk/benefit information?
 - What role do experts play?
- How do we communicate risk?

When picking a risk communication strategy....

Consider ...

- Is this the kind of risk information you need to/can only communicate once? Or will the information change over time? (think tsunami warning vs. heart health information)
- Should the method be interactive or one way? (think focus groups vs. public service announcements)
- How much can we spend on this method? (think \$\$-who is funding it?)
- How quickly does this information need to get out there? (think food recalls vs. health risks of fatty foods)
- Do we have all the information we need or do we need to talk to others? (think exposure to toxins vs. public policy about risks of salmon farming)

A few popular risk communication strategies

Public service announcement (PSA)

- To provide a lot of one way information to people quickly. This is a one shot, expensive format.

Pamphlets

- To provide one way information to people in a format they can use over time. This is a one shot, cheap format.

Website

- To provide information to people that can modified over time and can be interactive. This method is only good for those comfortable with and able to access the net.

Face to face discussion with medical expert

- To provide information from one expert. This may or may not be a one shot format and will most likely be interactive depending on the medical expert.

Telephone survey

- To find out what people think and give them information. This is a one shot format that is both quick and cheap.

Interviews or discussion groups

- To learn about how people think about a topic, determine misconceptions, gather advice, give people new information, and develop risk communication strategies. This is an expensive, time consuming, and interactive format.

Something else???????

Discussion questions

Questions to consider:

1. How can our risk communication strategies help to achieve the fundamental objectives of families, group, and society?
2. What are the pros and cons of each strategy?
3. What tradeoffs are we willing to live with?

- The following slide was only shown to treatment B participants

Recall the relevant fundamental (or most important) objectives of families, groups, and society for PGD

Families

1. To avoid condition X
2. To select sex of child
3. To create saviour sibling

Groups (For example: people with disabilities)

1. To encourage better lives for those affected by disability
2. To reduce discrimination against people with disabilities

Society

1. To foster overall health & wellbeing of Canadians
2. To foster overall diversity of Canadian society
3. To treat all Canadians equally

Discussion questions continued

Potential risk communicator

- **Who should communicate this information?**
(For example: physicians, genetic counselors, Health Canada, academics, someone else?)

Target audience

- **Who should we targeting with these strategies?**
(For example: all Canadians, people considering PGD, people considering IVF, all women who are pregnant, someone else?)

Discussion questions continued

Developing a risk communication strategy

- What are the best strategies to use for PGD? Public service announcement (PSA), pamphlets, website, face to face discussion with medical expert, telephone survey, interviews or discussion groups, something else?
- What types of information should we consider for our strategies? Think about the information provided to you today, is it all relevant?
- Should all applications of PGD be treated in a similar manner? In other words, do we use all types of information for all uses of PGD?
- Should certain types of information be optional at times?
- Who should have a say when developing these materials? In other words, who should comprise our expert panel?
- When should our target audience receive risk information about PGD?

Please hand in all background
materials and receive voting
cards/second questionnaire

Private workbook vote

Recommended risk communication strategies

Feel free to use the strategies developed by the group or develop your own.

1. **Who should communicate information about PGD?** (For example, physicians, genetic counselors, Health Canada, academics, someone else?)
2. **Who is the target audience?** (For example, all Canadians, people considering PGD, people considering IVF, all women who are pregnant, someone else?)
3. Check off the **types of information** that you include in your strategy. Think about the range of information that was presented today.
4. Check off the **strategies you like best** from the list. Notice there is a space to add a new strategy.
5. Please **describe how your strategy** would work.

Part 4-30 min

Post-deliberation questionnaire

* Remember to pick up your honorarium before you leave!

* Do you want to know what I do with all this information? All combined and anonymized results and votes will be posted on a password protected website.

Complete

Appendix G. Risk communication workshop workbook for lay participants**Pre-deliberation questionnaire**

Hi, and thank you for participating in this workshop. Before we begin, I would like to take a moment to explain a few things.

First, THIS IS NOT A TEST!!!! You will have the opportunity to revise each of the following questions at the end of the workshop. I know some of these questions may be difficult to answer but please do your best to answer each one. It is perfectly okay to guess! But if you don't want to, you can just write in "don't know". I don't expect you to know all the answers. I am using this questionnaire to determine how much you learn and how your opinions change over the course of the workshop.

Please fill in the following information before you begin

Name: _____

Date: _____, 2008

²²² Please take your time to respond to the following questions.

- 2) Have you ever heard the term pre-implantation genetic diagnosis otherwise known as PGD?

(Please circle one)

YES

NO

- 3) Please provide a description of PGD. Remember, it's okay to guess! You will have the opportunity to revise all your responses at the end of the workshop.

- 4) Where have you heard about PGD?

(Feel free to circle more than one response)

- a) The television news
- b) The newspaper
- c) The Internet
- d) In a magazine
- e) In a classroom from a teacher/professor
- f) From a physician/nurse/genetic counsellor
- g) From my friends/family
- h) I have never heard of PGD before today
- i) Other (please describe)

5) As far as you know, what are the applications of PGD?

(Feel free to circle more than one response)

- a) PGD is used to diagnose genetic conditions or chromosomal abnormalities.
- b) PGD is used to help **infertile** couples achieve pregnancy.
- c) PGD is used to determine the sex of an embryo.
- d) PGD is used to diagnose abnormalities **during** pregnancy.
- e) PGD is used to match tissue to create compatible cells for an existing child.
- f) Don't know

6) Who regulates PGD in Canada?

(Feel free to circle more than one response)

- a) An agency called Assisted Human Reproduction Canada that reports to the Minister of Health.
- b) No agency takes responsibility for PGD in Canada.
- c) Each province is responsible for creating its own agency that must report to the Minister of Health.
- d) Before 2004, there were no regulations, standards, or professional guidelines for the use of PGD in Canada.
- e) There have been regulations, standards, & professional guidelines for the use of PGD in Canada since the birth of the first test-tube baby, Louise Brown in 1978.
- f) Don't know

7) Is PGD covered by the Canadian health care system?

(Please circle one)

YES NO Don't know

8) Have you ever heard the term in vitro fertilization otherwise known as IVF?

(Please circle one)

YES NO

- 9) Please provide a description of IVF. Remember, it's okay to guess! You will have the opportunity to revise all your responses at the end of the workshop.

- 10) Where have you heard about IVF?

(Feel free to circle more than one response)

- a) The television news
- b) The newspaper
- c) The Internet
- d) In a magazine
- e) In a classroom from a teacher/professor
- f) From a physician/nurse/genetic counsellor
- g) From my friends/family
- h) I have never heard of IVF before today
- i) Other (please describe)

- 11) Is there a relationship between PGD and IVF?

(Please circle one)

YES NO Don't know

- 12) If a woman wants to use PGD, must she also undergo IVF?

(Please circle one)

YES NO Don't know

13) If a woman undergoes IVF, must she also undergo PGD?

(Please circle one)

YES

NO

Don't know

14) What risks and benefits might PGD pose to **a woman**? Please list as many as you can. Point form is okay.

Risks	Benefits

15) What risks and benefits might PGD pose to **an embryo, foetus, or child**? Please list as many as you can. Point form is okay.

Risks	Benefits

16) What social risks and benefits might PGD pose? In other words, what risks and benefits might PGD pose to **society, groups, or individuals or those other than families, doctors, etc**? Please list as many as you can. Point form is okay.

Risks	Benefits

17) What are some of the reasons for why people may use PGD?

(Feel free to circle more than one response)

- a) To help **infertile** people achieve pregnancy.
- b) To have a baby that could provide tissue for a pre-existing sick child.
- c) To have a baby of a particular sex.
- d) To have a baby that is **NOT** affected by a particular condition/disability.
- e) To avoid aborting an “abnormal” fetus.
- f) To have their own biological child.
- g) Adopting a child is too expensive or takes too long.
- h) To detect abnormalities **during** pregnancy.

18) In Canada, is it legal to use PGD to select a baby of a particular sex for “family balancing”?

(Please circle one)

YES NO Don't know

19) In Canada, can anyone get PGD?

(Please circle one)

YES NO Don't know

20) Is PGD common in Canada?

(Please circle one)

YES NO Don't know

21) Who (what individuals or groups) might be concerned about the use of PGD?

(Please list below)

22) Why might the individuals or groups you mentioned in question 19 be concerned about PGD?

23) How confident are you in your knowledge of the risks and benefits of PGD?

(Please circle one)

1	2	3	4	
Not at all	A little	Somewhat	Very	

24) At this time, what would you say are your biggest **hopes** for PGD (if any)?

For example, I hope that PGD will

25) At this time, what would you say are your biggest **concerns** regarding PGD (if any)?

For example, I fear that PGD will

26) Please circle the response that best describes your opinion about PGD at this time.

(Please circle one)

- a) I am strongly supportive of PGD
- b) I am somewhat supportive of PGD
- c) I am somewhat opposed to PGD
- d) I am strongly opposed to PGD
- e) I have no opinion about PGD
- f) I don't care about PGD

Please use the space below to explain your above response.

27) Who would likely be the most impacted by the use of PGD?

(Feel free to circle more than one response)

- a) Families
- b) Women
- c) Children
- d) People with disabilities
- e) Disability activists
- f) Families affected by disability
- g) Religious groups
- h) All Canadians
- i) Others (please name) _____
- j) Don't know

*******END**

Private vote and post-deliberation questionnaire

Please fill in the following information before you begin

Name: _____

Date: _____, 2008

Private vote: Post-deliberation

A number of risk communication strategies for PGD were considered during your small group discussion. Please use this space to explain your preferred strategy.

1) Who should communicate information about PGD?

(For example, physicians, genetic counselors, Health Canada, academics, someone else?)

2) Who is the target audience?

(For example, all Canadians, people considering PGD, people considering IVF, all women who are pregnant, someone else?)

3) What types of information would you include in your strategy? Think about the range of information that was presented today and check off the topics you would include.

Information type	Check off <input type="checkbox"/>
1. General background about PGD (that I presented in FAQ's at the beginning)	<input type="checkbox"/>
2. Information about the PGD regulations in Canada (that I presented in FAQ's at the beginning)	<input type="checkbox"/>
3. Information on the spectrum of conditions that PGD can test for (I showed this in video and news article formats)	<input type="checkbox"/>
4. Technical information on the risks PGD poses to a woman (shown today in an audio recording and a chart-Rana and Ted's decision)	<input type="checkbox"/>
5. Technical information on the risks PGD poses to the embryo, fetus, and child (shown today in an audio recording and a chart- Rana and Ted's decision)	<input type="checkbox"/>
6. Information on the social risks of PGD (shown today in an audio recording and in charts)	<input type="checkbox"/>
7. Other information (please describe) _____	<input type="checkbox"/>
8. * only for B groups* Charts showing objectives by alternatives for individuals, groups and society (Decision Matrixes)	<input type="checkbox"/>

4) Please check off the strategies you like best for communicating the risks of PGD
 Notice that there is space to add in a new strategy.

Strategy	Check off \checkmark
1. Public service announcement (PSA)	
2. Pamphlet	
3. Website	
4. Face to face discussion with medical expert	
5. Telephone survey	
6. Interviews or discussion groups	
7. Other? _____	

5) Please describe how your strategy would work. Feel free to include drawings, diagrams, anything you want!

*****END

You are almost done!
Please move on to the post deliberation questionnaire.

Post-deliberation questionnaire

Hi, and thank you for participating in this workshop. Before you leave for the day, I would like you to answer a few final questions.

Remember, like the first questionnaire, **THIS IS NOT A TEST!!!!** This is your opportunity to revise each of your responses from the beginning of the workshop. I know some of these questions may still be difficult to answer but please do your best to answer each one. Once again, it is perfectly okay to guess! I don't expect you to know all the answers. I am using this questionnaire to determine how much you have learned and how your opinions have changed over the course of the workshop.

Please take your time to respond to the following questions. These are the same questions that I asked before the workshop.

- 1) Have you ever heard the term pre-implantation genetic diagnosis otherwise known as PGD?

(Please circle one)

YES

NO

- 2) Please provide a description of PGD. Remember, it's okay to guess! You will have the opportunity to revise all your responses at the end of the workshop.

- 3) Where have you heard about PGD?

(Feel free to circle more than one response)

- a) The television news
- b) The newspaper
- c) The Internet
- d) In a magazine
- e) In a classroom from a teacher/professor
- f) From a physician/nurse/genetic counsellor
- g) From my friends/family
- h) I have never heard of PGD before today
- i) Other (please describe)

4) As far as you know, what are the applications of PGD?

(Feel free to circle more than one response)

- a) PGD is used to diagnose genetic conditions or chromosomal abnormalities.
- b) PGD is used to help **infertile** couples achieve pregnancy.
- c) PGD is used to determine the sex of an embryo.
- d) PGD is used to diagnose abnormalities **during** pregnancy.
- e) PGD is used to match tissue to create compatible cells for an existing child.
- f) Don't know

5) Who regulates PGD in Canada?

(Feel free to circle more than one response)

- a) An agency called Assisted Human Reproduction Canada that reports to the Minister of Health.
- b) No agency takes responsibility for PGD in Canada.
- c) Each province is responsible for creating its own agency that must report to the Minister of Health.
- d) Before 2004, there were no regulations, standards, or professional guidelines for the use of PGD in Canada.
- e) There have been regulations, standards, & professional guidelines for the use of PGD in Canada since the birth of the first test-tube baby, Louise Brown in 1978.
- f) Don't know

6) Is PGD covered by the Canadian health care system?

(Please circle one)

YES NO Don't know

7) Have you ever heard the term in vitro fertilization otherwise known as IVF?

(Please circle one)

YES NO

- 8) Please provide a description of IVF. Remember, it's okay to guess! You will have the opportunity to revise all your responses at the end of the workshop.

- 9) Where have you heard about IVF?

(Feel free to circle more than one response)

- a) The television news
- b) The newspaper
- c) The Internet
- d) In a magazine
- e) In a classroom from a teacher/professor
- f) From a physician/nurse/genetic counsellor
- g) From my friends/family
- h) I have never heard of IVF before today
- i) Other (please describe)

- 10) Is there a relationship between PGD and IVF?

(Please circle one)

YES NO Don't know

- 11) If a woman wants to use PGD, must she also undergo IVF?

(Please circle one)

YES NO Don't know

12) If a woman undergoes IVF, must she also undergo PGD?

(Please circle one)

YES

NO

Don't know

13) What risks and benefits might PGD pose to **a woman**? Please list as many as you can. Point form is okay.

Risks	Benefits

14) What risks and benefits might PGD pose to **an embryo, foetus, or child**? Please list as many as you can. Point form is okay.

Risks	Benefits

15) What social risks and benefits might PGD pose? In other words, what risks and benefits might PGD pose to **society, groups, or individuals or those other than families, doctors, etc?** Please list as many as you can. Point form is okay.

Risks	Benefits

16) What are some of the reasons for why people may use PGD?

(Feel free to circle more than one response)

- a) To help **infertile** people achieve pregnancy.
- b) To have a baby that could provide tissue for a pre-existing sick child.
- c) To have a baby of a particular sex.
- d) To have a baby that is NOT affected by a particular condition/disability.
- e) To avoid aborting an “abnormal” fetus.
- f) To have their own biological child.
- g) Adopting a child is too expensive or takes too long.
- h) To detect abnormalities **during** pregnancy.

17) In Canada, is it legal to use PGD to select a baby of a particular sex for “family balancing”?

(Please circle one)

YES NO Don't know

18) In Canada, can anyone get PGD?

(Please circle one)

YES NO Don't know

19) Is PGD common in Canada?

(Please circle one)

YES NO Don't know

20) Who (what individuals or groups) might be concerned about the use of PGD?

(Please list below)

21) Why might the individuals or groups you mentioned in question 19 be concerned about PGD?

22) How confident are you in your knowledge of the risks and benefits of PGD?

(Please circle one)

1	2	3	4	
Not at all	A little	Somewhat	Very	

23) At this time, what would you say are your biggest **hopes** for PGD (if any)?

For example, I hope that PGD will

24) At this time, what would you say are your biggest **concerns** regarding PGD (if any)?

For example, I fear that PGD will

Now I would like to ask you a few general questions about the risk communication strategies I used during this workshop.

For the following questions, please check off only one response.

Parts of the workshop	1) What was your favourite part of the workshop?	2) What was your least favourite part of the workshop
a. The questionnaires.		
b. The private voting.		
c. The presentation of FAQ's about PGD at the beginning.		
d. The audio recordings and charts that discussed the technical risks of PGD to a woman and to the embryo, fetus, and child.		
e. The audio recording and charts that discussed the social risks of PGD.		
f. The videos and news articles that talked about different types of conditions.		
g. The group discussion.		

For the following questions, please check off \checkmark only one response

Of all the information provided to you today, which was the...

Information types	3) most important when considering your private vote?	4) least important when considering your private vote?
m. The presentation of FAQ's about PGD		
n. The audio recordings that discussed the technical risks of PGD to a woman-Rana and Ted's decision.		
o. The charts that discussed the technical risks of PGD to a woman-Rana and Ted's decision.		
p. The audio recording that discussed the technical risks of PGD to the embryo, fetus, and child-Rana and Ted's decision.		
q. The charts that discussed the technical risks of PGD to the embryo, fetus, and child-Rana and Ted's decision.		
r. The audio recording that discussed the social risks of PGD.		
s. The charts that discussed the social risks of PGD.		
t. The videos that talked about different types of conditions.		
u. The news articles that talked about different types of conditions		
v. The small group discussion		
w. The opinions that I held before the workshop.		
x. Other _____ _____		

5) How confidence do you feel about your private vote today?

(Please circle one)

1 2 3 4

Not at all A little Somewhat Very

For the following questions, please check off \surd only one response.

4) Of all the risk communication strategies I used today, which was ...

Strategy	6) your favourite?	7) your least favourite?	8) the most trustworthy?	9) the least trustworthy?
a. The presentation of FAQ's about PGD				
b. The audio recordings that discussed the technical risks of PGD to a woman or the embryo, fetus, and child -Rana and Ted's decision				
c. The charts that discussed the technical risks of PGD to a woman or the embryo, fetus, and child -Rana and Ted's decision.				
d. The audio recording that discussed the social risks of PGD				
e. The charts that discussed the social risks of PGD.				
f. The videos that talked about different types of conditions.				
g. The news articles that talked about different types of conditions.				

Please answer the following questions on a scale of 1-4, where 4 is very and 1 is not at all.

Check off only one response.

Questions	1 not at all	2 a little	3 somewhat	4 very
10) How stressful would you say that the workshop was to you?				
11) How enjoyable would you say that the workshop was to you?				
12) How difficult would you say that the workshop was for you?				
13) How worthwhile was the workshop?				
14) How interesting was the workshop?				

15) On a scale of 1-4 where 4 is definitely likely and 1 is not at all likely, **how likely** is it that you would attend a workshop like this again in the future?

(Please circle one)

1 2 3 4
Not at all Somewhat Very Definitely

16) In your opinion, is it sensible for risk communicators to rely on a process like this one when determining risk communication strategies for PGD?

(Please circle one)

YES NO Don't know

17) Please use the space below to describe any suggestions you may have for ways to improve this workshop or any final thoughts you may have about this workshop.

Last but not least, please take a few moments to answer the following questions. Your responses will be used for statistical purposes only.

Age (Please circle one)

19-21 22-30 31-40 41-50 51-60 61-70 71-80

Cultural background (please describe) _____

Gender _____

Occupation _____

Marital status (please circle one)

Married In a relationship Single Divorced Widow

Highest level of education (Please circle one)

1. Some high school
2. High school
3. On the job training
4. College or some college
5. Trade school/apprenticing or some
6. University degree or some university
7. Graduate school or some

Do you have children? (Please circle one)

YES NO If YES, how many? _____

You average household income (Please circle one)

1. Under \$20,000
2. \$21-30,000
3. \$31-40,000
4. \$41-50,000
5. \$51-60,000
6. \$61-70,000
7. \$71-80,000

8. Over \$80,000

*******END**

Appendix H. Risk communication workshop scripts for audio recordings (based on Appendix I charts)

1) Audio recording of Rana and Ted's decision: Technical risks of pre-implantation genetic diagnosis (PGD) to a woman (compliment to chart 1)

Rana and Ted are a couple who really want to have their own biological child. Although they could have a baby naturally they really want to use PGD. You see, Ted is at risk for Huntington's Disease. Ted was profoundly affected by watching his father suffer with the condition and they do not want to pass this disorder on to their child. They have just found out that they are eligible for PGD and have been referred to a fertility centre to receive information about the risks and benefits of PGD from a genetic counsellor.

Judy, the counsellor, tells them that PGD poses a number of risks to a woman's body while she is trying to get pregnant. She explains that they can only use PGD if they also undergo IVF. She notes that Rana and/or Ted may experience stress associated with undergoing IVF when they are not actually infertile. She explains that the short term risks of PGD are likely the same as IVF. For example, hormone injections that stimulate ovulation and the egg retrieval process during IVF are both physically invasive and will pose some risk to Rana's body. There are also other short term risks that Rana and Ted must consider such as Ovarian Hyperstimulation Syndrome (OHSS) and infections. OHSS can range from mild to moderate forms in up to 1 in 5 women and in rare extreme cases can lead to death. Judy points out that Rana is over 40 and she is therefore much less likely to have a successful pregnancy through IVF. Judy also notes that all of these risks are to Rana's body even though she is not the one affected by Huntington's Disease. She asks if this will lead to problems for Rana or Ted relationship if Rana feels resentful or Ted feels guilty. Judy says that it is something they must think about before they make their decision.

She also states that some of the risks and benefits of PGD are psychological in nature. A significant psychological risk of IVF for some is that the woman may not become pregnant. Psychological risks of PGD must also be compared to those of abortions after diagnosis. Judy explains that some couples choose PGD because affected embryos can be avoided **before** pregnancy occurs. For religious or other reasons, they do not want to have a baby naturally, find out that it is affected, and then have an abortion before it is born. Judy says that, she understands that Rana and Ted want to use PGD to avoid passing on Huntington's Disease to their child. However, she also adds that PGD cannot **guarantee** a "normal" embryo, fetus, or child. There is a potential for misdiagnosis AND a potential for the child to acquire conditions that were NOT screened out through PGD.

Judy can see that Rana and Ted are looking a little discouraged so she says that there are also some benefits associated with PGD and IVF. She explains that IVF lowers the risk of ectopic pregnancies or pregnancies that occur outside the uterus, which can endanger a woman life, and cause severe bleeding and pain. However the risk of ectopic pregnancy in natural pregnancies is really not a significant risk and is less than 2%.

Judy now moves on to risks that may occur during a pregnancy. Judy explains that one significant risk of PGD and IVF is multiple births. Typically three to six embryos are used during IVF and as a result, about one third of IVF live births are multiple in nature. However, she is quick to point out that multiple birth are even more likely for women who have ingested fertility drugs instead of undergoing IVF. Risks that multiple births pose to women include premature labour, difficult deliveries, physical and emotional stress. However Judy says the trend is now to conduct one embryo transfers during IVF for best candidates. Although this eliminates the risk of multiple births it also reduces the chance of becoming pregnant because fewer embryos are implanted.

Judy states that if they do in fact achieve pregnancy, Rana and Ted will also have to consider if they want to have additional tests throughout that pregnancy. She explains that after PGD has occurred and the embryo has been implanted into the uterus, they may be advised to have additional tests such as amniocentesis or CVS to detect misdiagnosis and health of the fetus over time. Judy explains that some couples avoid these tests and their associated risks to the pregnancy that come with them and decide to trust PGD. However, she adds that receiving a relief diagnosis could help them acquire assistance from the system and prepare for the future.

Lastly, Judy explains that PGD may pose some long term risks to Rana's body. Some argue that there is a link between IVF and breast and ovarian cancer but Judy assures the couple that this appears to be a very soft link that disappears in studies that include large samples. Some researchers also point out that additional long term studies are required before we can state that IVF or PGD have a small long term impact on patients.

Rana and Ted tell Judy that they understand that there are many risks to consider. Although they are still pretty sure that they would like to use PGD at this clinic, they will definitely need some more time to think about it.

2) Audio recording of Rana and Ted's decision: Technical risks of pre-implantation genetic diagnosis (PGD) to PGD poses to the embryo, foetus, and child (compliment to chart 2)

After discussing the risks that PGD poses to a woman, Judy states that Rana and Ted should also consider the risks that PGD may pose to an **embryo, foetus, and child**. Judy begins by mentioning again that IVF lowers the risk of ectopic pregnancies or pregnancies that occur outside the uterus. She explains that avoiding an ectopic pregnancy is good for Rana but it is also good for the fetus because ectopic pregnancies can lead to the death of the fetus. However she notes again that the background risk of ectopic pregnancy in natural pregnancies is less than 2%.

Judy goes on to say that IVF poses less risk to an embryo than prenatal tests like amniocentesis or CVS because those prenatal tests can lead to miscarriages. She adds that experts in her field state that the risks associated with technologies such as CVS, IVF, and PGD are all quite small. That said, there is an additional minor increase associated with them. For IVF, PGD, and CVS, the additional risk for the pregnancy is 1%. However with CVS remember there is also the risk that the pregnancy may fail. Amniocentesis has an additional risk of .5%. Lastly, Judy explains that these risks are for each fetus, so in a multiple birth situation, there would be an increased risk of 1% plus 1% or 1% for each fetus.

At this point Judy returns to the subject of risk associated with multiple births. She tells them that the risk of multiple births during IVF is linked to the age of mother, the number of embryos implanted, and the quality of those embryos. However, multiple births are even more likely for

women who have ingested fertility drugs instead of undergoing IVF. She goes on to say that on average, 3–six embryos are used for IVF and as a result, about one third of IVF live births are multiple in nature. Judy notes that these risks can be lowered by implanting fewer embryos. Risks to fetuses and children who are twins, triplets, etc. include increased risks of neonatal mortality, SIDS, birth defects, developmental disabilities, and child abuse. Judy also says that children of multiple births are at risk of being born prematurely. Some will do well, others will not. If born prematurely, the baby may experience short term risks such as difficulty breathing, undeveloped organs, and death or long term risks such as gastrointestinal issues, cerebral palsy, developmental delays, or chronic lung disease.

Judy explains once again that PGD cannot guarantee a “normal” embryo. There are a series of technical challenges inherent to PGD that “can lead to a misdiagnosis of the embryo” and result in an “abnormal” fetus and child. For example, testing occurs under strict time constraints and in addition, only small amounts of DNA are examined. Also, there is the potential for the child to acquire conditions that were NOT screened out through PGD. In addition, the techniques used during IVF can accidentally “turn on” or “turn off” genes while culturing cells. Judy explains that this may increase risks of disorders such as Angelman Syndrome (AS) or Prader-Willi syndrome (PWS).

Judy says that the long term physical health impacts of PGD are likely similar to IVF, which are known. Children born through IVF have twice as high a risk of major birth defects (cardiovascular, chromosomal ranging from 3 or 4--8.5%) and are more likely to have multiple major defects when compared to naturally conceived infants (ranging from 2 or 3-4%). That said, the probability that these problems will occur is low (as shown by percentages), although they may be significant. Children born from women who undergo PGD may also be subjected to psychological risks or benefits, for example, if they were born as a savior sibling to create compatible cells for an existing child.

Rana and Ted tell Judy that they understand that there are many risks to consider. Although they are still pretty sure that they would like to use PGD at this clinic, they will definitely need some more time to think about it.

3) Audio recording of societal and economic factors that may inform a decision to pursue pre-implantation genetic diagnosis (PGD) (compliment to charts 3 and 4)

Sadly, there have been many documented instances of unethical health care practices and abuses throughout the world. It is quite easy to locate cases that discuss experiments performed on incarcerated or institutionalized adults and even children without their consent. For example, during World War II Jewish people and others were subjected to horrible experiments against their will. But these cases also occur right here in North America. In the 1930’s, Black men included in the “Tuskegee Study” were left to suffer with untreated Syphilis for decades.

These, and other similar events, have lead to a shift in how people are treated within the health care system. Policies such as the Nuremberg Code (established after the Nazi atrocities) have been created to protect and inform research subjects. Where we once trusted our doctors to make medical decisions on our behalf, we now demand to be involved in these decisions. Most of us are interested in managing our risks and are not prepared to “take it as it comes”. We may even sometimes think of preferences as if they are risks.

We also live in a country that sometimes discriminates against people with disabilities. Although we make our world more liveable for people with disabilities by modifying infrastructures (for example, building ramps), or by opening up employment opportunities, we could do more. We could even criminalize discrimination if we wanted to. Some argue that our relaxed attitude towards this type of discrimination has led us to view discrimination as a normal everyday thing.

Perhaps our desire to control health related decisions coupled with our decision to ignore certain types of discrimination is what has led us to place the responsibility for disability mostly on families instead of the community or society. **But what does this have to do with PGD?**

Most of us would likely agree that there can be great social and biological pressure to have babies. But not all of us can have our own biological healthy children. Some of us may be infertile, have difficulty conceiving, experience miscarriages, or even infant deaths. And some of us who **are** fertile, may have a genetic condition running in our family that makes it almost impossible to have our own biological healthy children. People in this situation may feel pressure to use technological solutions like PGD to solve their fertility dilemmas and may fail to consider other alternatives such as adoption. But is adoption really a practical alternative for Canadians? Public adoption, or adoption through a government agency, for **an infant with no “special needs”** may take up to 8 years. Private adoption may take less time but can cost anywhere from \$10,000-\$18,000. Costs for international adoption may also take less time but are also costly varying from \$15,000 in Haiti, to \$30,000 in Guatemala, and as high as \$50,000 in the US.

So families who are at risk for certain conditions and want to have a biological child may decide to use PGD. However PGD technology can only be used to avoid **known** conditions. Our ability to detect conditions is limited by our current genetic knowledge, although this is likely to expand over time. In addition, costs for PGD are not covered by the Canadian health care system. In fact, the regulatory system for PGD in Canada is currently in flux so we don't really know what it is going to look like in the future.

Yet some will argue that despite all these complications, each of us is entitled to control our own reproduction because we are entitled to control our own bodies. In addition, some also believe that parents have the “right” to a healthy child.

However, there are other issues to consider. Risks associated with PGD don't just affect the mother, father, and child, they can also affect others citizens. Some insist that as new technologies that screen and perform diagnostic tests on fetuses are made widely available and used with increased frequency, these procedures may become “**standard practice**” and therefore difficult for families to refuse. Couples may not understand that they have the option of refusing tests or screens and may not understand the range of consequences associated with having these procedures. However, others are quick to point out that currently, most people are not eligible for PGD (as it has a high barrier for entry) and additional tests are not an option for those who oppose abortion. In other words, the reason some couples choose PGD in the first place is because it happens before pregnancy occurs. They do not want to use prenatal tests like CVS or amniocentesis and then abort affected fetuses.

But let's suppose for a moment that technologies like PGD were to become a part of standard medical care. When medical technologies become a standard part of care, we sometimes forget what their real purpose is and the consequences of the procedures can be masked. Ask yourself, is an ultrasound a baby photo or a genetic screen? Why do people hang them on the walls of their office? Individuals who have ultrasounds and forget that they are actually genetic screens may be

surprised by positive test results or may falsely believe that problems discovered about their fetus can be addressed.

In addition, if PGD becomes a standard part of care during pregnancy, will this mean that more pregnancies will be treated as potentially problematic? That the pregnancy experience will be viewed as a **medical procedure** instead of as a **natural process**? And would this be a bad thing or not? Also, what happens to the people who receive all this additional information about their embryos and fetus? Some women may experience long or short term anxiety associated with the additional knowledge and choices that screens and tests provide.

On the other hand, some people are excited about PGD because with it, unlike abortions, one does not have to be concerned about the moral status of the fetus. PGD occurs before a woman is pregnant so it pre-empts moral dilemmas associated with having an abortion after a positive prenatal diagnosis. Also, when compared to abortion, some view it as less harmful to the woman's body, and less psychologically and emotionally stressful. When compared to prenatal diagnosis however, the risks to the embryo are greater because with PGD, affected embryos are destroyed or donated to stem cell research. In other words, embryos are more likely to live after a prenatal test than during PGD. Others are concerned about PGD because they believe it is a form of eugenics, which is defined as selectively breeding humans or getting rid of types of people like the Nazi's did during World War II. Some are concerned that PGD is "playing God" with human life. Some are asking about the moral status of embryo. Does an embryo have a "right to life"? Should all life be considered "a gift" no matter what? Ethical and other concerns surrounding PGD may lead others to judge those who use this technology. Also, those affected by a condition may resent others who get to have "normal" children.

Some argue that users of PGD technology (mostly women) may have too much power because they are deciding who and what types of people should enter society. However, others are quick to point out that genetics are only one aspect of a person. In other words, defining types of people purely by their genetics is misleading. But we should be careful to note that genetic tests are unlike other types of medical procedures. Genetic tests are unique in that they will sometimes reveal information about the biological family, potentially without their consent (such as a biological father). However, there is a very small risk that this will occur with PGD.

Right now PGD is rarely used in Canada but suppose it were to become a standard part of prenatal care and used frequently. Will Canadians experience social pressure to submit to such technologies and remain consumers of genetic tests throughout their pregnancies? Will PGD reduce our society's overall compassion for people with disabilities? Will PGD impact how we view people with disabilities? Will we become less tolerant or try less for adults with disabilities who are already here? That said, who will volunteer to raise children with disabilities so that society can be diverse? In any case, PGD is likely going to alter a couples' decision context regarding the role of the parent and the meaning of a pregnancy and may place additional burdens on users of PGD technology.

Appendix I. Risk communication workshop news articles**The Vow (this is only a portion of the article)**

When Dave Kendall promised to love Diana 'in sickness and in health,' he meant it

The Washington Post

By Liza Mundy, Sunday, March 9, 2008; W10

SHE MIGHT HAVE SEEN A SHIMMER ON THE WATER, OR SOMETHING ELSE COULD HAVE TRIGGERED HER REACTION. All Dave Kendall knew was that one minute he was sitting in the stern of his fishing boat, steering, during an excursion on the Occoquan Reservoir about a decade ago. The next minute Diana, his wife of more than 20 years, had fallen from her seat near the bow. She was on the floor of the boat, limbs flailing in what looked like a violent seizure.

Diana had had fainting spells before, but doctors had not determined the cause. They didn't this time, either. Yet there were other things that now seemed wrong with Diana: She was having bizarre reactions to music, which made her head hurt so acutely that she would sometimes bolt out of church. One day, she came home from work at Fort Belvoir saying she no longer remembered how to use Excel. Dave, giving her a refresher session, saw that she was losing her focus.

And she was gaining weight. Diana, who had always been trim and active, began eating junk food and sitting for days, crying. Dave took her to more doctors, including a neurologist who said he wanted to run a test for something called Huntington's disease. He didn't tell them much about it -- just that they had better hope the test came back negative.

Dave felt reasonably optimistic while they were waiting for the results. Doing some Internet research, he learned that Huntington's is a hereditary disorder, and they didn't know of anyone in Diana's family who had it. The life the Kendalls had built together -- decades of hard work that had allowed them to leave behind impoverished childhoods in rural Virginia for the middle-class comforts of suburban Washington -- felt secure.

But when they returned to the neurologist on August 6, 2000, they learned that the future wasn't secure at all. The test had come back positive. "This is really bad news, isn't it?" asked Diana, turning to Dave. She was strikingly calm and dry-eyed. It was the beginning of a transformation in her; deterioration, yes, but also acceptance and what can only be described as grace. It was also the moment -- Dave realizes in retrospect -- when she entrusted herself to his care. It was the end of married life as they had known it, the beginning of marriage in an entirely new form. Same contract, radically altered circumstances. "She put her life in my hands," he says.

Diana was 48; Dave was 51. By then, they had been living with a fatal neurodegenerative disease for several years. Parts of Diana's brain were dying, an inexorable process caused

by a single abnormal gene, a glitch that affects everything: thought, mood, movement. After the diagnosis, Dave began keeping a journal to record Diana's rapid decline.

"She was unable to walk in grocery store to complete shopping -- sat on bench," he wrote in December 2001, adding, "I start peeling apples, potatoes, etc., to avoid accidents with knives."

In February 2002: "Walks like a drunk -- falls against wall."

In August 2002: "Cannot find hymn number in book. Leans while sitting."

In October 2003: "Cannot put her shoes on" and "could not get out of chair."

In April 2005: "Could not subtract 6 from 1977."

In November 2005: "This is the first Thanksgiving in which I had to spoon feed her."

In May 2007: "Di has no ability to read anything or create a thought. I do it and ask her if she likes the thought."

More than seven years after Dave began keeping his journal, Diana has lost her balance and her ability to stand unaided. She can count forward from one to 10, but not backward from 10 to one. She is immune to boredom and has no sense of the passage of time. Yet she is still capable of teasing Dave, as well as expressing a deep appreciation of what her disease has cost her husband. Three years ago, he asked her what her New Year's resolutions were. "To read my Bible more," she said, "and to be less of a burden to you."

BBC News Story

'I wouldn't have to fear for my child'

A report from the Human Fertilisation and Embryology Authority is to recommend extending embryo checks to look for cancer genes, which make people highly susceptible to certain forms of the disease.

Karin Cohn, from Middlesex, found out last year that she carries the BRCA1 gene - which greatly increases her risk of developing breast or ovarian cancer. Both her sister and mother have had breast cancer, and there is a long family history of both conditions.

“It gives people an option not to have to go through the stress and the anxiety that I've been through.”

-Karin Cohn

Karin, who is in her 30s, has already undergone a preventative double mastectomy to remove her breasts, and she also plans to have her ovaries removed to take away her risk of cancer. She said she fully supported the proposal to use pre-implantation genetic diagnosis to select embryos which did not carry the cancer gene.

Karin told the BBC: "It's fantastic. It gives people an option not to have to go through the stress and the anxiety that I've been through, making my decision.

"If I had had the option, I would have done it. And I would continue to do it until I got a clear embryo.

"It would mean I wouldn't have to worry about my child in the future." 'I feel guilty'

She said she worried for her four-year-old daughter, Sophie, who has a 50/50 chance of also carrying the BRCA1 gene.

"We've been advised to wait until later to have her tested. But it is a worry."

Karin's mother Pat Gibor said she feels responsible for passing the BRCA1 gene on to her daughters.

"I feel guilty. Rationally I know I shouldn't, but emotionally I do."

And she said she too backed the idea of using PGD to select embryos which did not have the cancer susceptibility gene.

"They do step in in other instances, so if it can be done if embryos can be tested for cystic fibrosis or Huntington's disease, I don't see why they can't be tested for the BRCA1 gene."

Appendix J. Risk communication workshop links to videos recommended by experts

1) Hyperlink to “Belong” Video from Down’s Syndrome Society

http://www.onetruemedia.com/otm_site/view_shared?p=50a08d8c72399d9fd791c7&skin_id=601&utm_source=otm&utm_medium=email

2) Hyperlink to public service announcement video from National Tay-Sachs & Allied Diseases Association <http://www.ntsad.org/>

Appendix K. Risk communication workshop database of results