

**ADVANCING POPULATION AND PUBLIC HEALTH ETHICS  
REGARDING HIV TESTING AMONG YOUNG MEN**

by

Rodney Eric Knight

MSc, University of British Columbia, 2011  
BA, University of Alberta, 2004

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

The Faculty of Graduate and Postdoctoral Studies

(Interdisciplinary Studies)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

September 2014

© Rodney Eric Knight, 2014

## Abstract

**Background:** Despite the epidemiological and clinical rationale supporting a shift from voluntary approaches to HIV testing (e.g., in which a patient seeks an HIV test) towards the expansion of more routine approaches (e.g., in which a clinician routinely offers patients testing), a set of rather polarized ethical debates has remained somewhat unresolved. And, within these discussions, considerations of young men's experiences and health care needs have remained conspicuously absent. **Objectives:** This dissertation aims to: (1) Systematically investigate the status of ethical debate and discussions within the peer-reviewed literature in the realm of voluntary and routine HIV testing, with a particular emphasis on understanding the structural and agentic factors associated with testing experiences (e.g., HIV-related stigma); (2) Examine and identify the social processes associated with voluntary and routine testing that attenuate or exacerbate HIV-related stigma among young men; and (3) Describe how 'public' values (e.g., solidarity; reciprocity; health equity) may influence the 'autonomous' decisions and/or HIV testing practices of young men. **Results:** The findings highlight a set of social processes that can provide transformative opportunities for young men to reconceptualise expectations pertaining to HIV and HIV-related stigma within routine testing practices. These findings also distil the extent to which young men 'take up' relational values (e.g., solidarity; reciprocity), as well as individual reasons (e.g., obligations to the Self) in their HIV testing practices. **Discussion:** Empirical-normative approaches to advancing population and public health ethics regarding HIV testing may be most usefully pursued as an iterative project (rather than as a linear project), in which the normative informs the empirical questions to be asked *and* new empirical evidence constantly directs conceptualizations of what constitutes morally robust public health practices. This dissertation provides a set of methodological considerations regarding research techniques that may be useful in advancing future empirical-normative inquiry regarding HIV-related population health interventions.

## Preface

This dissertation was conducted under the primary supervision of Dr. Jean Shoveller (PhD, University of British Columbia) and co-supervision of Dr. Thomas Kerr (PhD, University of Victoria) and Dr. John Coggon (PhD, Cardiff University). The research in this thesis was conducted according to the guidelines of the UBC Behavioural Research Ethics Board. Interviews of human subjects and secondary data analyses were approved by UBC BREB (H10-00132). Data is drawn from an ongoing research study, led by Dr. Jean Shoveller and funded by the Canadian Institutes of Health Research called ‘Establishing a new research agenda regarding population health ethics and young people's health’. I serve as a Co-Investigator and as the Project Director for this project.

Each chapter was written by myself, Rod Knight; feedback from committee members was subsequently incorporated into the final draft. A version of Chapter 2 was published in *Critical Public Health* (citation as follows: Knight, R., Shoveller, J., Greyson, D., Kerr, T., Gilbert, M., & Shannon, K. (2014) Advancing population and public health ethics regarding HIV testing: a scoping review. *Critical Public Health*, 24(3):1–13). Contributions from co-authors were consistent with committee or collegial duties. Specifically, co-authors reviewed each iteration of the manuscript prior to publication and offered strategic feedback and critical evaluations. I was, however, responsible for screening articles, data analysis and preparing the initial and final drafts. Finally, highly valued feedback from external reviewers at *Critical Public Health* was also incorporated into the current version of Chapter 2.0. I was responsible for the revisions of this process, following the advice from the journal editor and external reviewers. Pieces of Chapter 4 and 5 draw on an article that has been submitted for publication and constitutes the findings from a component of my doctoral comprehensive exam. Drs Shoveller, Kerr and Coggon offered strategic input for revising and improving this article; however, I was responsible for all revisions.

# Table of Contents

Abstract.....	ii
Preface.....	iii
Table of Contents.....	iv
List of Tables .....	vi
Acknowledgments.....	vii
Dedication.....	viii
<b>Chapter 1 Introduction: Background, Research Justification and Objectives.....</b>	<b>1</b>
<b>1.1 Background.....</b>	<b>1</b>
<b>1.2 HIV testing within the HIV continuum of care.....</b>	<b>2</b>
<b>1.3 Expansion of routine testing.....</b>	<b>3</b>
<b>1.4 HIV testing and young men.....</b>	<b>4</b>
<b>1.5 Ethical discussions pertaining to HIV testing.....</b>	<b>6</b>
<b>1.6 Identifying and filling the empirical ‘gaps’: Advancing population and public health ethics regarding HIV testing .....</b>	<b>9</b>
<b>1.7 Advancing population and public health ethics regarding HIV testing.....</b>	<b>10</b>
<b>1.8 Dissertation objectives .....</b>	<b>13</b>
<b>1.9 Advancing a theory- and evidence-informed population and public health ethics.....</b>	<b>15</b>
<b>1.10 Organization of dissertation.....</b>	<b>16</b>
<b>Chapter 2 Advancing Population and Public Health Ethics Regarding HIV Testing: A Scoping Study .....</b>	<b>18</b>
<b>2.1 Introduction.....</b>	<b>18</b>
2.1.1 Ethics and HIV testing .....	20
<b>2.2 Methods.....</b>	<b>21</b>
2.2.1 Search and inclusion/exclusion strategy .....	22
2.2.2 Analysis.....	26
<b>2.3 Findings.....</b>	<b>26</b>
2.3.1 HIV testing and HIV-related stigma .....	26
2.3.2 Prioritising, targeting and seeking: Addressing individual- and population-level interests .....	29
2.3.3 Structural and agentic factors related to HIV infection and testing experiences .....	32
<b>2.4 Conclusion .....</b>	<b>33</b>
<b>Chapter 3 HIV Stigma and the Experiences of Young Men with Voluntary and Routine HIV Testing: An Empirical-Normative Inquiry .....</b>	<b>36</b>
<b>3.1 Introduction .....</b>	<b>36</b>
3.1.1 Background .....	36
3.1.2 Young men and HIV testing .....	37
3.1.3 HIV testing, HIV-related stigma and young men .....	37
<b>3.2 Methods.....</b>	<b>40</b>
3.2.1 Theoretical framework .....	40
3.2.2 Study setting.....	40
3.2.3 Recruitment of participants and interview procedures .....	42
3.2.4 Interviews.....	42

3.2.5 Data analysis .....	43
3.2.6 Study participants.....	43
<b>3.3 Findings.....</b>	<b>45</b>
3.3.1 Experiences with voluntary testing .....	45
3.3.2 Experiences with routine testing.....	47
3.3.3 Social consequences of HIV and HIV-related stigma .....	51
<b>3.4 Discussion.....</b>	<b>52</b>
3.4.1 Voluntary testing and HIV stigma .....	53
3.4.2 Ethical dimensions of routine testing.....	54
3.4.3 Ethical and empirical implications for the field of population and public health .....	55
3.4.4 Strengths, weaknesses and future research .....	57
<b>Chapter 4 An Empirical-Normative Analysis of Young Men’s Discourse Regarding HIV Testing Practices .....</b>	<b>58</b>
<b>4.1 Introduction .....</b>	<b>58</b>
4.1.1 Young men and HIV testing .....	59
4.1.2 The ethics of HIV testing: Individual and relational perspectives.....	60
<b>4.2 Methods.....</b>	<b>62</b>
4.2.1 Methodological orientation .....	62
4.2.2 Data collection techniques .....	63
4.2.3 Data analysis techniques .....	64
4.2.4 Study setting.....	66
<b>4.3 Findings.....</b>	<b>66</b>
4.3.1 Considering the ‘Other’ in deciding to test: Relational considerations .....	68
4.3.2 Autonomy, relationality and individual motivations to test or not test.....	73
<b>4.4 Discussion.....</b>	<b>75</b>
4.4.1 Relational discourses regarding testing.....	76
4.4.2 Individualistic discourses regarding testing.....	77
4.4.3 ‘Ethics as structure’ .....	77
4.4.4 Implications for the practice of public health and future research.....	79
4.4.5 Strengths and limitations.....	80
<b>Chapter 5 Discussion and Conclusion.....</b>	<b>81</b>
<b>5.1 Overview .....</b>	<b>81</b>
<b>5.2 Summary of findings.....</b>	<b>81</b>
<b>5.3 Implications for population and public health ethics regarding HIV testing and the practice of public health .....</b>	<b>83</b>
<b>5.4 Reflexivity .....</b>	<b>87</b>
<b>5.5 Future research .....</b>	<b>90</b>
<b>5.6 Implications for methods: Advancing empirical approaches within population and public health ethics.....</b>	<b>92</b>
Bibliography .....	94
Appendix A. Socio-demographic questionnaire .....	105
Appendix B. Interview Guide .....	107
Appendix C. Questions for writing a met methodology section in empirical ethics papers as outlined by Molewijk and Widdershove (2012).....	120

## List of Tables

<b>Table 1.</b> List of articles by publication, primary author and approach to HIV testing .....	23
<b>Table 2.</b> Distribution of area of inquiry by global setting .....	24
<b>Table 3.</b> Distribution of articles by population, global setting and approach to HIV testing.....	25
<b>Table 4.</b> Approach to HIV testing by date of publication .....	25
<b>Table 5.</b> Socio-demographic characteristics of study participants .....	44
<b>Table 6.</b> Socio-demographic characteristics of study participants .....	67

## **Acknowledgments**

I would like to thank the young men that took part in this study. I especially thank Drs. Jean Shoveller, Thomas Kerr and John Coggon for their support, wisdom and guidance. I am also appreciative of the support provided by a Canada Graduate Scholarship from CIHR and a Bridge Fellowship from the UBC Bridge Program (funded by CIHR).

## **Dedication**

*To my parents*



# Chapter 1

## Introduction: Background, Research Justification and Objectives

### 1.1 Background

There has recently been a significant change within ethical discourses surrounding public health approaches to HIV testing. Whereas initial HIV testing approaches in the late 1980s and early 1990s emphasized ethical principles and values of patient autonomy and the “three Cs” (voluntary informed consent, confidentiality and pre-test counselling), today, the availability of highly active antiretroviral therapy (HAART) in many global settings has shifted the ethical discourse from ‘*the right not to be tested*’ to ‘*the duty to know one’s status*’ (Oberymeyere, Bott, Bayer et al., 2013; Dawson, 2011). Concurrently, many settings have sought to expand HIV testing efforts, including the scaling up of more routine approaches (e.g., in which a health care provider routinely offers a test to patients) to complement existing voluntary approaches to testing (e.g., in which a patient requests a test). Despite the clinical and epidemiological rationale associated with this trend, some have questioned how this expansion may affect the ethical values and principles associated with individual autonomy (Celada, Merchant, Waxman, & Sherman, 2011; Smith, 2011; Csete & Elliot, 2006). On the other hand, emerging theoretical work has argued that public health interventions such as HIV testing practices ought to be subject to normative inquiry which also considers ‘public’ values, with emerging literature reflecting on how relational concepts such as solidarity, reciprocity and health equity also represent important considerations within public health (e.g., see: Dawson, 2010; Dawson & Jennings, 2012; Dawson & Verweij, 2012; Prainsack & Buyx, 2011; Baylis, Kenny & Sherwin, 2008). Furthermore, as various public health approaches are implemented to enhance testing participation rates, it is often thought that these

approaches are ethically justifiable based on the underlying assumption that these practices will result in the widespread reduction of HIV-related stigma by enhancing public awareness and normalizing HIV (Jurgensen, Sandoy, Michelo & Fylkesnes, 2013; Public Health Agency of Canada, 2013; Wynia, 2006). Nonetheless, a variety of empirical and theoretical gaps remain as to how interventions, such as HIV testing practices, may affect individual autonomy, attenuate or exacerbate HIV stigma, and promote or detract from efforts to enhance health equity (Jurgensen et al., 2013; Sengupta, Banks, Jonas, Miles & Smith 2011; Durojaye, 2011; Mahajan, Sayles, Patel et al., 2009; Earnshaw & Chaudoir, 2009; Parker & Aggleton, 2003). And, while young men represent an important population sub-group in terms of HIV-related health and social outcomes (Knight, Shoveller, Oliffe et al., 2012a; Knight, Shoveller, Oliffe, et al., 2012b), empirical evidence and normative consideration has not tended to emphasize the ethical underpinnings of interventions and their effect on young men's experiences pertaining to HIV testing (Jurgensen et al., 2013; Durojaye, 2011).

## **1.2 HIV testing within the HIV continuum of care**

During the past decade, the use of HAART has transformed HIV from being considered as a terminal illness into a manageable, chronic condition (Public Health Agency of Canada, 2013). Within Canada, for example, the province of British Columbia (BC) has served as a global leader in developing and implementing effective HIV continuum of care strategies, including the antiretroviral 'Treatment as Prevention' (TasP) program that is now widely accepted and implemented as a crucial component of comprehensive HIV prevention efforts worldwide (Montaner, Lima, Barrios, Yip & Wood, et al., 2010). Within this approach, HIV testing is the first critical step to engaging seropositive individuals into a continuum of care toward viral load suppression through the use of HAART, thereby offering opportunities to benefit both individuals (e.g., suppressing viral loads and thus the progression of disease) and the population more broadly (e.g., decreasing the likelihood of onward disease transmission) (Cohen, Van Handel, Branson, et al., 2011; Montaner et al., 2010; Das, Chu, Santos et al., 2010).

Despite advancements in HIV treatment and prevention, individuals unaware of their HIV seropositive status continue to represent a key ‘driver’ of the HIV epidemic within many global contexts (Public Health Agency of Canada, 2013; Lima, Hogg & Montaner, 2010). Within Canada, populations undiagnosed and unaware of their seropositive status represent approximately 25% of the estimated 71,300 people living with HIV in 2011 (Public Health Agency of Canada, 2013). In BC, it is estimated that there are approximately 12,300 HIV seropositive individuals, with up to 2,500 being unaware of their status (Lima, Hogg & Montaner, 2010). As such, there is a strong public health impetus to enhance testing efforts among populations at risk for HIV and/or among those who have not previously or recently tested for HIV (Public Health Agency of Canada, 2013; Gustafson, Montaner & Sibbald, 2012).

### **1.3 Expansion of routine testing**

Given the clinical and epidemiological rationale associated with the benefits of engaging seropositive individuals within the HIV continuum of care, many settings have implemented a set of enhanced efforts to test individuals and populations for HIV. After a large body of evidence indicated that antiretroviral drugs could be used to effectively reduce vertical transmission from mother to child, routine testing was first deployed widely within antenatal care settings. As HAART became more widely available and accessible, routine testing approaches were implemented even more broadly. In 2006, for example, the United States Centres for Disease Control began recommending HIV testing to patients in *all* health care settings (Branson, Handsfield, Lampe et al., 2006). By 2007, the World Health Organisation recommended that all adult patients in high-prevalence settings be tested unless they explicitly ‘opt out’.

On a federal level, Canada has been slower to advance recommendations to implement routine testing practices (Gustafson, Montaner & Sibbald, 2012), with the first set of national guidelines emerging in 2013 (Public Health Agency of Canada, 2013). These guidelines recommend that: ‘the consideration and discussion of HIV testing be made a component of periodic routine medical care’ (Public Health Agency of Canada, 2013, p. ii). Prior to 2013, the province of BC launched routine testing approaches on a more

universal basis. For example, in 2010 the BC provincial government committed to supporting BC's Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV) program which includes scaling up routinized HIV testing and the expansion of HAART (see: British Columbia Centre for Excellence in HIV/AIDS, 2014). In 2011, several of the hospitals within Vancouver (the largest city in BC) began offering routine testing to all patients requiring blood work for other non-HIV related indications, in addition to when a sexually transmitted infection (STI) test or diagnosis occurs (Vancouver Coastal Health, 2011). In 2012, it was recommended that routine testing be offered to all patients upon admission to acute care settings (Gustafson, Montaner & Sibbald, 2012). Based on the success of the pilot stages of routine testing in which 6 positive cases per 1,000 tests were identified,<sup>1</sup> the Medical Health Officer of Vancouver Coastal Health recommended that all primary and acute health care settings routinely offer testing to all adult patients who have not had an HIV test in the last year (Gustafson, Montaner & Sibbald, 2012). Following these recommendations, the family practice testing initiative of STOP HIV provides training opportunities for family physicians to incorporate routine offers of HIV testing into their clinical practice. Finally, in May 2014, the British Columbia Office of the Provincial Health Officer put forward HIV testing guidelines recommending the implementation of routine testing practices province-wide (British Columbia Ministry of Health, 2014).

#### **1.4 HIV testing and young men**

While women and girls are extremely important population subgroups for HIV interventions (and many previous and ongoing policy and programming efforts seek to address their needs), young men (e.g., under 25 years of age) also are a significant population subgroup affected by HIV (Knight et al., 2012a; Shoveller, Knight, Johnson, Oliffe, & Goldenberg, 2010; Gahagan, Fuller, Proctor-Simms, Hatchette & Baxter, 2011). Within Canada, for example, young men represent a group of particular public

---

<sup>1</sup> Routine testing is generally considered cost effective if one positive diagnosis is yielded per 1,000 tests offered (Sanders et al., 2010).

health concern as they continue to bear a disproportionate burden of HIV. In 2012, HIV incidence rates for men between the ages of 20 to 24 and 25-29 in BC were significantly higher than the provincial average at 7.7 and 22.0 per 100,000 cases (compared to the provincial average of 5.2 per 100,000) (British Columbia Centre for Disease Control (BCCDC), 2012). In 2012, men who have sex with men (MSM) represented 63% of all new HIV diagnoses (BCCDC, 2012). Recent data of gay and bisexual men has indicated increases in HIV risk behaviour (e.g., unprotected intercourse) may lead to the potential for a significant increase of HIV spread among this cohort in the near future (Sex Now Survey, 2012). Conversely, men who inject drugs have recently experienced declining rates of HIV (e.g., 43 cases in 2008 compared to 20 cases in 2012 among men), likely reflecting the success of recent expansion and sustained prevention efforts with this population (BCCDC, 2012). As a result, heterosexual contact now represents the risk category with the second greatest number of new HIV diagnoses among men (32 new cases among heterosexual men in 2012, not including heterosexual men who are also ‘captured’ in the categories of MSM or men who inject drugs) (BCCDC, 2012).

While young men represent a key affected population,<sup>2</sup> voluntary HIV testing participation rates among young men remain disproportionately low (e.g., within many clinical settings in Vancouver, approximately 5-10% of youth clientele ages 15-24 are men) (Shoveller et al., 2010; Shoveller, Johnson, Rosenberg et al., 2009). The low HIV testing participation rates among young men have been attributed to a variety of conditions related to men’s gendered health-related practices (e.g., health-seeking behaviour; HIV-related risk behaviour), as well as the broader social and structural conditions in which their health behaviour occurs. For example, while health care service

---

<sup>2</sup> Despite the ‘utility’ of identifying populations based on a set of socially defined characteristics within population and public health practice and research, I acknowledge that doing so may risk reifying socially contested and potentially dynamic categories of gender and gender identity (as well as other intersecting social identities). For instance, by constituting a population such as “young men”, we risk unintentionally silencing the fluidity and heterogeneity of men’s ‘other’ social positions, gender identities and lived experiences.

delivery systems tend to systematically focus on women's sexual and reproductive health from the onset of puberty (e.g., offering or recommending annual PAP smears), men are not offered similar opportunities (Knight et al., 2012a; Knight et al., 2012b; Shoveller et al., 2010).

Moreover, theories of gender relations, masculinities and men's health suggest that men's sexual health experiences are strongly influenced by the wider set of social relations and expectations that men experience (and contribute to) in their everyday lives (Connell, 2012; Knight et al., 2012a & 2012b; Oliffe, Chabot, Knight et al., 2012). For example, while young men represent a diverse and heterogeneous group (e.g., varying socio-economic statuses, gendered expressions and social identities), in general they are less likely to engage in various health-seeking behaviours, engage in medium- to long-term self-treatment strategies and position 'help-seeking' behaviour as potentially emasculating (Robertson, 2007; Courtenay, 2000; Knight et al., 2012a & 2012b). To date, however, there are limited empirical understandings of how the evolving practices associated with HIV testing are experienced by young men, thereby hampering opportunities to advance socially and ethically robust practices in this area.

### **1.5 Ethical discussions pertaining to HIV testing**

As HIV testing practices have evolved within the broader HIV continuum of care (e.g., expansion of routine testing), a variety of ethical discourses pertaining to these practices has also transpired. Initially, after the first commercial diagnostic test for HIV became available in 1985, public health policy makers were tasked with developing effective – yet ethically appropriate – strategies to test individuals and populations considered 'at risk' for HIV. During the late 1980s, some settings advanced calls for the mandatory testing of specific population sub-groups (e.g., gay and bisexual men; people who inject drugs); however, most feared that mandatory approaches would serve to push the epidemic 'underground' through the use of coercive and paternalistic<sup>3</sup> practices that

---

<sup>3</sup> Coercion and paternalism are distinct concepts: coercion concerns the use of power to ensure an outcome is reached; paternalism relates to an approach (coercive or otherwise)

would serve to stigmatize HIV, rather than benefit those found to be HIV seropositive (e.g., prior to the emergence of promising treatment opportunities) (O'Grady & Schüklenk, 2009; Schüklenk, 1998). As a result, ethical values and principles such as patient autonomy and privacy, as well as clinical practices emphasising informed consent and pre-test counselling, were prioritized in order to ameliorate concerns pertaining to HIV stigma and other forms of HIV-related discrimination (Bayer & Fairchild, 2006). In part, these concerns led many settings to adopt voluntary counselling and testing approaches within health care protocols.

Today, as many settings adopt routine testing approaches, concerns pertaining to health equity, patient autonomy and HIV-related stigma continue to represent important ethical considerations (Dawson, 2011; Bayer & Fairchild, 2006). For example, given the benefits associated with the availability of HAART within many settings, some have argued that voluntary testing represents an overly 'exceptionalistic' approach to testing in that it is treated differently in comparison to other infectious diseases that do not emphasize practices such as informed consent or pre-test counselling practices (e.g., other sexually transmitted infections) (Bayer & Fairchild, 2006). As a result, these arguments have suggested that, rather than operating as a means to protect socially vulnerable and disadvantaged populations by decreasing HIV-related stigma, voluntary approaches may instead be exacerbating these issues by (re)emphasizing HIV as being essentially (e.g., socially and, therefore, morally) different (Bayer & Fairchild, 2006). These arguments suggest that voluntary approaches serve to stigmatize HIV while concurrently representing a significant barrier to care for some individuals (De Cock, Mbori-Ngacha, & Marum, 2002). As an alternative, these arguments have tended to favour routine

---

that aims to protect the interests or welfare (e.g., health outcomes) of an individual. These two ideas have generated much debate within bioethics, and this has continued to do so within the realm of population and public health ethics (e.g., see Coggon, 2012). Although the work of my dissertation examines questions related to both of these concepts, my aim is not to explore the theoretical nuance or relationships between coercion and paternalism.

approaches on the premise that routine approaches will serve to ‘normalize’ HIV because everyone is recommended a test, regardless of their social, behavioural or biological risk profiles (Public Health Agency of Canada, 2013; Celada et al., 2011).

Routine approaches, however, have also been subject to a set of ethical criticisms, including those identifying a variety of potential unintended consequences that may arise. For example, some have suggested that routine HIV testing approaches will unfairly disadvantage population sub-groups already experiencing various social vulnerabilities (e.g., gay and bisexual men; people who inject drugs) (Smith, 2011; Durojaye, 2011). Specifically, some raise concerns that patients may feel pressured into testing, depending on how testing is presented by their clinician; for example, socially vulnerable individuals may be especially likely to feel pressured (e.g., given the influence of clinician-patient power differentials) and failure to opt-out may be the result of disempowerment, rather than an autonomous and informed decision to consent to testing (Pierce, Maman, Groves, King & Wyckoff, 2011; Rennie & Behets, 2006). Others suggest that decontextualized approaches to routine approaches (e.g., approaches that fail to appreciate and consider the social conditions in which individuals live and experience HIV-related issues and risks) may inadvertently increase HIV-related stigma (Durojaye, 2011; Chappel, Wilson, & Dax, 2009; Kippax, 2006).

Historically, these discussions have been interwoven within a set of gendered and sexed considerations, with a set of arguments advancing the merits of routine testing among women – particularly, pregnant women (Ngwena & Cook, 2008; Armstrong, 2008). For example, given the capacity for early initiation of HAART during pregnancy to prevent vertical transmission (i.e., from mother to foetus), consequentialist arguments tend to argue in favour of routine testing among women in antenatal settings. These practices and debates evolved alongside a set of ethical concerns pertaining to women’s autonomy and decision-making capacities within hetero-patriarchal social structures and expectations, including, for example, the concern that routine approaches may involve a degree of coercion for pregnant women based on various societal and familial pressures (e.g., from partners, family and clinicians) (Bennett, 2007; Bayer & Fairchild, 2006; Fields &



Kaplan, 2011). Alternatively, others suggest that accessing voluntary HIV testing requires a degree of agency that may be far beyond some women's social realities (e.g., among conditions of poverty; gender-based violence) (Armstrong, 2008).

While men have not featured as saliently among these discussions, gay and bisexual men represent an important sub-group to consider from an ethical perspective (Wahlert & Fiester, 2011). Considerations of stigma and same-sex behaviour have often resulted in a set of concerted efforts to de-stigmatize HIV and HIV testing among queer and men who have sex with men (MSM) (Wahlert & Fiester, 2011).<sup>4</sup> Nonetheless, considerations of young men's gender-specific health behaviour and experiences have remained somewhat absent – with the exception of some discussion about gendered health-seeking patterns and expectations that are purported to systematically expose more women and girls to the health care system (and thus the routine HIV test offer) than men and boys (April, 2010; Rennie & Behets, 2006). Thus, young men represent a population that has yet to benefit from a careful and contextualized examination of the social and ethical issues associated with the expansion of various HIV testing approaches, including routine testing.

### **1.6 Identifying and filling the empirical 'gaps': Advancing population and public health ethics regarding HIV testing**

While HIV testing practices and the related ethical discussions have shifted during the past 10+ years, several key empirical 'gaps' and theoretical shortcomings remain problematically salient. For example, little empirical work related to young men's experiences with HIV testing has been explored or featured within the ethical discussions in this field. Furthermore, it remains unclear the extent to which theoretical underpinnings (e.g., sociological theories pertaining to: structural and agentic influences

---

<sup>4</sup> For example, given the tendency within popular discourses for HIV to be positioned as a 'gay disease' in many settings, the term *men who have sex with men* (MSM) emerged as an HIV risk category to what Young & Meyer (2005) describe as the convergence of both epidemiological perspectives (e.g., MSM reflects risk behaviour, not social identities), as well as social construction perspectives (e.g., sexual identities cannot be reduced to categorization and are contextual) to 'de-queer' HIV.

on health-related practices/outcomes; HIV-related stigma) and empirical data have been used to support the ethical discussions in this field. Specifically, the extent to which robust understandings of the social processes associated with HIV-related stigma and the ways in which these present or ameliorate barrier/access thresholds remains unspecified. For example, will routine testing practices serve to influence (e.g., attenuate or exacerbate) HIV-related stigma? Moreover, while a growing literature has provided much theoretical guidance on how various relational concepts should inform the practice of public health (e.g., policy and decision-making processes), the extent to which relational normative considerations may actually inform and shape the health-related practices of the ‘public’ (e.g., young men) remains somewhat less clear (Dawson & Jennings, 2012). Given that the normative claims (and thus the development of HIV testing policy) are premised on such issues, additional theoretical work and empirical research is required in order to inform more robust ethical deliberations in this substantive area.

### **1.7 Advancing population and public health ethics regarding HIV testing**

While HIV testing efforts and the associated ethical debates have significantly evolved and transformed over the past 10+ years, efforts to produce a more robust normative inquiry related to public health practices were simultaneously advanced, bringing to light the emergent field of *public health ethics*. Although frequently contested in its origins (Petrini, 2010), Bayer and Fairchild (2004) suggest this field first emerged, in part, from a series of infectious disease outbreaks that exposed the insufficiency of some of the contemporary bioethical frameworks – specifically, those that aimed to provide moral evaluations for various public health actions that can serve to negatively affect an individual in order to ‘protect’ or advance the health of the broader population (e.g., quarantine practices during the SARS outbreaks of those who were asymptomatic in the absence of diagnostic tests).

While a variety of philosophical and normative frameworks have arisen within the public health ethics arena, there is reflective worth in examining and detailing the tenets of what might constitute a ‘good’ and/or ‘robust’ public health ethical theory. Writing at the advent of the recent surge of interest in public health ethics, Jennings (2003)

distinguished four different approaches to developing frameworks in public health ethics. The first works from the values and traditions of the profession of public health itself (i.e., it is contingent on the historically developed, ‘internal’ values of the profession). The second is based on health advocacy; it looks to politically motivated argument directed towards a practical pro-health agenda, rather than any commitment specifically to engaging in philosophical argument. The third is rooted in normative bioethics, but Jennings expresses concern (as have others, e.g., Dawson, 2010) that there is, within bioethics and its dominant analyses, inadequate conceptual and analytical frameworks to accommodate relational ideas such as community (which are indeed central in a population-level ethical analysis). The strengths and weaknesses of these three lead Jennings to advocate for a fourth public health ethics framework that takes what he argues to be ‘best’ from each, while abandoning their ‘bad’ points.

As public health ethics continued to evolve and develop various frameworks and approaches to normative inquiry, some theorists in this domain have also begun to take up many of the issues espoused by social scientists and demographers studying concepts, theories and data related to population health and the social and structural determinants of health (Bayer, Gostin, Jennings & Steinbock, 2007; Powers & Faden, 2006). For example, much theoretical and normative work has been done in this field to advance ethical frameworks that provide opportunities for moral inquiry into the intersections of both proximal (e.g., individual-level experiences) and distal determinants of the distribution of health and illness (e.g., contextual features of the socio-cultural and physical environments), thereby leading some to refer to this emergent field as *population and public health ethics* (Canadian Institutes of Health Research, 2012a & 2012b). According to the Canadian Institutes of Health Research (2012b), population and public health ethics approaches to normative inquiry differ from traditional orientations of bioethics in that these approaches aim to: (1) emphasize moral evaluations related to the population, alongside those of the individual; (2) acknowledge that many “upstream” interventions and influences on health occur outside of the health care system (e.g., from political and legal sectors); and (3) emphasise the prevention of illness and disease.

Given the emphasis on the social determinants of health and illness, population and public health ethics has tended to position individual-level health factors (e.g., biology; behaviour) within the broader social structures and environmental conditions in which the individual is embedded, emphasizing a normative evaluation of the ‘balance’ of individual and collective interests and health outcomes (Bayer, Gostin, Jennings & Steinbock, 2007; Powers & Faden, 2006). In some instances, there is an explicit commitment to the notion that it is possible *and* desirable for everyone to attain health and social health inequalities are portrayed explicitly as being socially unjust (i.e., inequitable) (for example, see: Powers & Faden, 2006). As such, there has been a particular emphasis on the operationalization of the principle of health equity within population and public health ethics, with some arguing that, if social science theories have it ‘right’, socially just societies will seek to minimize social inequities in health (Daniels, 2006).

Much of the theoretical work in the area of population and public health ethics area has also sought to engage in questions related to the (potentially) conflicting values associated with individual autonomy and the values emphasized within public health. For instance, theoretical work in this area has engaged with questions regarding ‘nudge paternalism’ – an area that asks questions about the extent to which public health policy defaults/practices are ethically justifiable (Aggarwal, Davies, & Sullivan, 2014). Within this theoretical work, some have suggested that nudge paternalism may be ethically justifiable if the merits of individual autonomy are sufficiently attained (mainly, that it is easy and economically feasible to ‘opt out’) (Nys, 2008 & 2009). To add to the complexity, however, a set of literature emerging from various feminist perspectives has argued that questions regarding autonomy are far more complex theoretical constructs that may be bound within inherently ‘masculinist’ assumptions or value traits (e.g., assumptions about ‘self-hood’ that may counter the concerns of women and/or subordinate men). As such, feminist perspectives have argued that analyses regarding individual autonomy needs to take into account the *relationality* of an individual’s social relationships, as well as the broader social and structural conditions in which individuals live and make theoretically ‘autonomous’ decisions (McLeod & Sherwin, 2000).

Notably, there has also been a recent set of literature within population and public health ethics that has begun to reflect on how various ‘public’ and ‘relational’ concepts can and should be operationalized within public health decision-making, with an emerging set of literature focusing on how values and principles such as solidarity, reciprocity and health equity can and should be ‘situated’ within the ethical reasoning of public health (e.g., see: Dawson & Jennings, 2012; Dawson & Verweij, 2012; Prainsack & Buyx, 2011). Nonetheless, there remains some disagreement as to how various concepts (e.g., solidarity; reciprocity) should be distinguished from other relational values or dimensions, as well as to how these relational values actually, or empirically, function at the level of the ‘public’. Despite the advances in theoretical work in this domain, the extent to which relational concepts such as solidarity or reciprocity *actually* (empirically) inform the practices of the ‘public’ remain somewhat less clear (Dawson & Jennings, 2012), with little to no empirical and/or theoretical attention focusing on these issues within the substantive area of HIV testing.

### **1.8 Dissertation objectives**

The current dissertation seeks to draw on a reflective and prudent approach to developing a *robust* population and public health ethics (e.g., as outlined by Jennings, 2003). Specifically, owing to the fact that HIV is distributed along a social gradient, and considering the emphasis on health equity within the Canadian setting (e.g., all citizens are legally entitled to the same level of care), the current dissertation draws on normative theory from the realm of population and public health ethics that emphasises the various empirical and normative dimensions of social justice (e.g., Powers and Faden, 2006).<sup>5</sup>

---

<sup>5</sup> It is not my aim to advance an extensive ‘defense’ of the normative superiority of Powers and Faden’s (2006) theory over other theories within population and public health ethics. Instead, I have chosen to draw on Powers and Faden’s theory of social justice, at times, in order to normatively assess and better understand which outcomes (including social and health inequalities) matter most when assessing social institutions and practices (e.g., routine testing policies) – an important aim of Powers and Faden’s theory, and something that I consider an important task within my own research regarding young men and HIV testing.

Therefore, this dissertation seeks to examine (from both empirical and normative analyses) how HIV-related outcomes and experiences (e.g., testing) are distributed (inequitably) within and across populations. In doing so, this approach can analyze both individual-level influences and experiences on/with health (e.g., health-seeking practices; ‘risky’ behaviour), in light of the broader social and structural determinants of health (e.g., men’s gendered expectations and influences pertaining to sexual health) (Baylis et al., 2008), thereby providing opportunities to examine and interrogate the relative merits of various HIV testing practices.

In order to begin to resolve the empirical and theoretical gaps related to the ethical implications of various HIV testing practices among young men, the current dissertation consists of three empirical studies pertaining to HIV testing. The overall aim of the dissertation is to advance empirical-normative knowledge in this area and suggest new lines of inquiry for future studies. Specifically, the objectives are to:

1. Systematically investigate the ethical debate and discussions within the peer-reviewed literature in the realm of voluntary and routine HIV testing, with a particular emphasis on understanding the structural and agentic factors associated with testing experiences (e.g., HIV stigma). (Chapter 2)
2. Examine and identify the social processes associated with voluntary and routine testing that attenuate or exacerbate HIV-related stigma among young men. (Chapter 3)
3. Describe the extent to which ‘public’ values (e.g., solidarity, reciprocity and health equity) may influence the ‘autonomous’ decisions and/or HIV testing practices of young men. (Chapter 4)
4. Synthesize the empirical results by employing philosophical orientations from population and public health ethics. (Chapter 5)

## **1.9 Advancing a theory- and evidence-informed population and public health ethics**

To accomplish these objectives, this dissertation will draw on a variety of disciplines, including methods and theories from the social sciences (e.g., sociology), medicine (e.g., population and public health), as well as philosophy (e.g., normative theory pertaining to population and public health ethics). Thus, the current dissertation will seek to emphasise and draw on the substantial engagement with the generation, application, and re-evaluations of normative approaches given improved empirical understandings. To advance this ‘empirical-normative’ inquiry, this dissertation will draw on the conceptual underpinnings that have recently been advanced within the field of *empirical ethics* – specifically, engaging in the explicit and transparent task of actively integrating empirical data and normative analysis regarding moral issues to reach a normative conclusion (Molewijk & Widdershoven, 2012; McMillan & Hope, 2010).

Frequently characterized as an ‘empirical turn’ in bioethics (e.g., Frith, 2010; Ten Have & Lelie, 1998), the philosophical (e.g., meta-ethical; epistemological) and methodological implications of this transformation have been vigorously debated. For example, critics of empirical ethics have argued that there is a philosophical imperative to delineate between the factual and the normative. These authors have expressed concern that bringing the empirical into the normative risks losing the analytic method and abstraction required in bioethical normative inquiry (Callahan, 1996; Goldenberg, 2005). On the other hand, those in favour suggest that the inclusion of empirical data in normative inquiry is essential (Frith, 2010; Halpern, 2005; Molewijk & Widdershoven, 2012; Petersen, 2013; Solbakk, 2012). To respond to the criticisms of combining empirical and normative approaches, researchers and theorists working in this area have tended to arrive consensus that a transparent and explicit approach should be emphasized, detailing how the interactions between the empirical data, normative reasoning and the moral conclusion are handled (Molewijk & Widdershoven, 2012). The current dissertation will draw on these methods and techniques, seeking an explicit and transparent approach to empirical-normative inquiry, while also engaging in conceptual and theoretical discussions regarding the broader implications for advancing an

empirically oriented population and public health ethics regarding HIV testing among young men.

### **1.10 Organization of dissertation**

This dissertation consists of five chapters, four following the current introductory chapter. Chapter 2 is a scoping study and Chapters 3 and 4 are empirical studies drawing on qualitative methods. Chapter 5 is a synthesis of the study within normative theory flowing from population and public health ethics. Specifically, the aim of each chapter is as follows:

**Chapter 2:** This study provides a systematic and critical evaluation of the peer-reviewed literature to identify how ethical arguments have been put forward and addressed. Specifically, this chapter systematically interrogates the ongoing debate and discussion with specific attention pertaining to HIV-related stigma, as well as how structural and agentic factors of HIV are considered. New areas that require additional empirical and theoretical interrogation are also identified. This chapter also serves to theoretically inform the specific objectives of Chapters 2 and 3 by identifying specific knowledge (e.g., empirical and theoretical) ‘gaps’ in the ethical discussions.

**Chapter 3:** This chapter draws on data gathered during 50 in-depth interviews with young men (ages 18-24) in Vancouver, BC. The aim of this study is to determine how HIV-related stigma is experienced differentially across subgroups of young men within voluntary and routine testing contexts. Specifically, the objective is to describe how voluntary and routine HIV testing serves to attenuate or exacerbate the effects of and experiences with HIV-related stigma among young men. This study also illustrates how HIV-related stigma is experienced differentially across population subgroups of young men (e.g., men experiencing multiple intersecting social vulnerabilities). The empirical results of Chapter 3 will be discussed with regard to the implications for public health and clinical practice.



**Chapter 4:** This study also draws on 50 in-depth interviews with young men (ages 18-24) in Vancouver, BC. The chapter examines how the values and principles pertaining to several tenets of public health – solidarity, health equity and reciprocity – may manifest in everyday discursive practices of individuals. As yet, empirical work describing the extent to which such values influence the ‘autonomous’ decisions and/or health practices of individuals and population sub-groups (e.g., young men) remains largely unarticulated in the population health literature. The aim of this chapter is therefore to examine the normative discourses of young men regarding their decisions and motivations to voluntarily access HIV testing and/or to accept/decline a routine HIV test offer. The empirical results derived through the discourse analysis undertaken in Chapter 4 will be discussed in light of the ongoing theoretical work in this area.

**Chapter 5:** In the final chapter, the findings from Chapters 2-4 are synthesized and theoretical and ethical implications are proposed. The empirical results of each chapter are discussed and integrated within the normative debates in this area in order to determine the extent to which various ethical claims can be empirically and/or theoretically substantiated. As well, recommendations are posed for further research, as well as a discussion that seeks to advance actively integrating empirical approaches within population and public health ethics.

## Chapter 2

### **Advancing Population and Public Health Ethics Regarding HIV Testing: A Scoping Study<sup>6</sup>**

#### **2.1 Introduction**

Globally, approximately 34 million people are living with HIV; and, it is estimated that nearly 30 million people have died from AIDS since the beginning of the pandemic (US Global Health Policy, 2011). HIV rates vary considerably with the burden of disease concentrated among the most vulnerable and marginalized populations within and across low-, medium- and high-income countries. Sub-Saharan Africa accounts for approximately 67% of global HIV infections (United Nations, 2008); combined, low- and middle-income nations account for 97% of global infections (US Global Health Policy, 2011). Within high-income nations, HIV rates are comparatively lower; however, vulnerable populations generally bear the burden of infection.

In the late 1980s, the development of the HIV antibody test presented the opportunity to test individuals considered ‘at risk’ for HIV. During this time, calls for mandatory HIV testing of ‘high risk’ groups (e.g., gay men) were advanced within various contexts (Schüklenk, 1998). However, mandatory approaches were generally considered overly paternalistic and an inefficient means to curtail the spread of disease (O’Grady & Schüklenk, 2009). Moreover, the lack of effective treatment, combined with concerns

---

<sup>6</sup> A version of this manuscript has been published as follows: Knight, R., Shoveller, J., Greyson, D., Kerr, T., Gilbert, M., & Shannon, K. (2014). Advancing population and public health ethics regarding HIV testing: a scoping review. *Critical Public Health*, 24(3), 1–13.

related to HIV stigma, led to the prioritization of informed consent over case finding (April, 2010). As a result, voluntary counselling and testing (VCT) approaches to testing were generally favoured. In the VCT approach (often referred to as client-initiated or ‘opt-in’ HIV testing), the onus is on the individual to access HIV testing services and, in general, clinicians must obtain informed consent and offer pre-test counselling services before commencing blood work.

Recently, treatment and prevention technologies, including antiretroviral therapy (ART), have emerged alongside the adoption of more routine or opt-out approaches to HIV testing in many contexts, marking a departure from the approaches of the prior two decades that emphasised voluntary, opt-in testing approaches (CDC&P, 2010). First deployed within many high-prevalence antenatal settings, this approach was able to effectively reduce vertical transmission from mother to child. Routine testing approaches were soon implemented more broadly; in 2006, for example, HIV testing was “recommended for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines” (Branson et al., 2006) by the United States Centre for Disease Control and Prevention. In 2007, the World Health Organization recommended that all adult patients in high-prevalence settings be tested unless they explicitly ‘opt out’.

Indeed, there is a strong public health impetus to decrease the spread of HIV by identifying those who are infected with the aim of providing treatment and preventing onward transmission (e.g., through behavioural counselling). The provision of HIV testing has been considered as a means to benefit individuals, as well as a mechanism to improve population health by reducing HIV incidence and prevalence. As a result, there has been a proliferation of efforts to test both individuals and populations considered ‘at risk’ for HIV acquisition. Recently, the emergence of empirical evidence supporting the role of ART and ‘treatment as prevention’ (in which viral loads are suppressed, thereby preventing onward transmission) (Montaner et al., 2010) has further altered the landscape within HIV testing. The capacity for ‘treatment as prevention’ to reduce HIV prevalence and incidence at a population level (beyond the known individual-level benefits of ART)

catalyzed the *seek, test and treat approach*, and more recently the *cascade/continuum of care* approach, whereby access to testing is posited as the first step in a pathway leading to suppressed viral loads and reduction of HIV incidence (Cohen et al., 2011).

### **2.1.1 Ethics and HIV testing**

As approaches to HIV testing have shifted over time, so have the ethical debates surrounding and informing these practices. Generally, these perspectives have been informed by either deontological or utilitarian ethical frameworks. Utilitarian approaches often draw on the work of John Stuart Mill to delineate the circumstances in which intervention on an individual (the patient) by a collective (the population or State) is acceptable – namely “that the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others” (1860, p.9). Deontological approaches generally focus on principles that emphasize an individual’s right to autonomy and consent, as well as the duty to minimize harm to others (Darwall, 2003a).

Over the past decade, a number of theorists have called for a more robust population and public health ethics that expands upon traditional orientations of bioethics that focus primarily on the interests of individuals, often in clinical encounters. For example, Bayer and Fairchild (2004) describe how, within several instances of infectious disease outbreaks (e.g., the SARS outbreak in 2002), traditional bioethical frameworks were deemed to be insufficient in providing a moral evaluation of various public health actions thought to be required in order to effectively (and morally) suppress the spread of disease (e.g., quarantining asymptomatic individuals thought to be exposed in the absence of a diagnostic test). Thus, in part, population and public health ethics emerged out of a series of controversies between the central commitments of public health (e.g., with an emphasis on collective well-being) and bioethics (e.g., with an emphasis on individual-level concerns) (Bayer and Fairchild, 2004).

As the field of population and public health ethics developed it also took up ethical issues related to how health is distributed (inequitably) within and across populations (Dawson

& Verweij, 2007; Daniels, 2006). As a result, population and public health ethics seeks to provide a critical evaluation of questions concerning possible, actual and proposed public health measures in order to more fully consider and negotiate a ‘balance’ of individual and collective interests and health outcomes (Coggon, 2012). As Daniels (2006) points out, an inherent challenge within this field is the need to incorporate a variety of theoretical and interdisciplinary approaches in order to situate both the health of a population and individuals within a framework that emphasizes social justice and health equity.

The current paper provides a critical evaluation of the peer-reviewed literature to identify how ethical issues have been addressed since 2001 – recognizing the need to advance population and public health ethics in this area in light of new HIV testing and treatment strategies, as well as evolving testing approaches. This study describes how issues related to the changing context of HIV are connected to practices that target/prioritise testing efforts. I also examine the influences of HIV stigma, as well as the structural and agentic factors that influence HIV-related experiences. Finally, I identify knowledge gaps and areas that require additional theoretical or empirical advancements in order to advance population and public health ethical considerations within the realm of HIV testing.

## **2.2 Methods**

This study draws on scoping review methods outlined by Arksey and O’Malley (2005) in order to acquire a set of peer-reviewed articles discussing the ethics of various HIV testing approaches in order to critically examine each through a population and public health ethics perspective. The aim is to systematically interrogate the ongoing debate and discussion, and describe how this has evolved as the context of HIV also has changed (e.g., treatment opportunities and new knowledge about transmission). As the review was conducted, the following research questions were posed: How have the interests of individuals and populations been considered with respect to what HIV testing approaches ought to be taken? Specifically, how does the literature address: HIV-related stigma; agentic and structural factors of HIV infection; and the targeting or prioritising of specific

populations or population sub-groups? And, finally, what are the strengths, weaknesses and areas that require more attention?

### **2.2.1 Search and inclusion/exclusion strategy**

The MEDLINE database (via the OvidSP interface) was searched for articles on HIV testing and ethics by using subject headings for: HIV and “mass screening”, HIV infection diagnosis, and AIDS serodiagnosis; and subject headings, subheadings and keywords for ethics. The scope of the search was limited to English-language articles about humans that were published from 2001-2012, resulting in a total of 155 articles. In order to be eligible for inclusion, articles had to include normative ethical discussions about the moral justifiability of approaches to HIV testing. Studies that only described a group’s beliefs or preferences about ethical issues were excluded. Upon completion of article-level screening for inclusion, reference lists of included articles were scanned for additional relevant articles (citation snowballing), which resulted in 4 additional articles for inclusion. Finally, one article from a co-author’s personal library collection was included, resulting in a total of 35 articles included in the review. Table 1 presents the distribution of the articles by HIV screening approaches and by global setting. Table 2 presents the distribution of articles by the population of interest, global setting and HIV screening approach. Table 3 presents the distribution of the articles by the year of publication and HIV screening approach. Table 4 presents a list of all articles selected for review by year of publication, primary author and the HIV screening approach on which the article primarily focused.

**Table 1. List of articles reviewed by publication, primary author and approach to HIV testing**

<b>Pub Year</b>	<b>Authors, Primary</b>
2010	April
2008	Armstrong
2007	Aziz
2005	Basu <i>et al.</i>
2010	Bayer
2006	Bayer <i>et al.</i>
2007	Bennett
2011	Brewster
2002	Cameron
2011	Celada <i>et al.</i>
2006	Csete <i>et al.</i>
2011	Dawson
2002	De Cock
2007	Dixon-Mueller
2011	Fields <i>et al.</i>
2006	Gostin
2007	Hanssens
2011	Johansson <i>et al.</i>
2006	Kippax
2001	Leung
2005	Macklin
2007	McQuoid-Mason
2007	Meera <i>et al.</i>
2008	Ngwena <i>et al.</i>
2009	O'Grady <i>et al.</i>
2011	Pierce <i>et al.</i>
2001	Powderly
2006	Rennie <i>et al.</i>
2008	Rennie <i>et al.</i>
2011	Salang Seloilwe
2011	Smith
2011	Vernillo
2012	Vonn
2011	Wahlert <i>et al.</i>
2006	Wynia

**Table 2. Distribution of area of inquiry by global setting**

<b>Approach to HIV Testing</b>	<b>Global Setting</b>			<b>Total</b>
	<b>LMIC*</b>	<b>HIC**</b>	<b>Not specified</b>	
Routine screening (Opt-Out)	9	13	0	22
Mandatory screening	3	6	0	9
Voluntary counseling and screening	1	0	1	2
Seek, test and treat	0	1	1	2
<b>Total:</b>	<b>13</b>	<b>20</b>	<b>2</b>	<b>35</b>

\* LMIC: Low- or Middle-Income Countries

\*\* High-Income Countries



**Table 3. Distribution of articles by population sub-group, global setting and approach to HIV testing**

Population of Interest	Global Setting			Approach to HIV Testing				Total
	LMIC	HIC	N/S	Routine screening (opt-out)	Mandatory screening	Voluntary counseling and testing (VCT)	Seek test and treat	
Health care setting	9	9	1	16	0	2	1	19
Pregnant women	3	5	0	4	4	0	0	8
Pre-marital couples	1	0	0	0	1	0	0	1
Health care providers	0	2	0	0	2	0	0	2
Queer populations	0	1	0	1	0	0	0	1
Dentist office setting	0	1	0	1	0	0	0	1
Entire population	0	1	1	0	1	0	1	2
Correctional institutions	0	1	0	0	1	0	0	1
<b>Total:</b>	<b>13</b>	<b>20</b>	<b>2</b>	<b>22</b>	<b>9</b>	<b>2</b>	<b>2</b>	<b>35</b>

**Table 4. Approach to HIV testing by date of publication**

Approach to HIV Testing	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Routine screening (opt-out)	0	1	0	0	0	6	5	0	0	1	9	0
Mandatory screening	2	1	0	0	1	0	1	3	1	0	0	0
Voluntary counseling and screening	0	0	0	0	1	1	0	0	0	0	0	0
Seek, test and treat	0	0	0	0	0	0	0	0	0	1	0	1
<b>Total</b>	<b>2</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>7</b>	<b>6</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>9</b>	<b>2</b>

### **2.2.2 Analysis**

Each article was reviewed to identify instances in which ethical implications of HIV testing approaches were discussed; the extracted examples were summarized in a Microsoft Excel spreadsheet. Employing thematic analysis techniques, a combination of inductive and deductive approaches was used to identify patterns across the articles and to develop an overall interpretation (Fereday & Muir-Cochrane, 2006) of the literature from a population and public health ethics perspective. First, in order to understand how the literature has dealt with considerations of population and public health ethics and HIV testing, three categories were identified that reflect important influences on HIV infection and testing experiences: (1) HIV-related stigma; (2) prioritising, targeting and seeking testing efforts; and (3) structural and agentic factors pertaining to HIV infection and testing experiences. I drew on the ways in which these three issues have been identified in previous literature to deduce and articulate their conceptual connections with population and public health ethics and HIV testing. I also inductively derived new ideas and interpretations from the analysis of the extracted data in order to further inform my critical interpretation of the overall thematics represented in this sample.

## **2.3 Findings**

### **2.3.1 HIV testing and HIV-related stigma**

Since the beginning of the HIV epidemic, HIV-related stigma has been positioned as a moral dimension of various approaches to HIV testing. For example, there has been a consistent concern that a move towards mandatory approaches could drive the epidemic 'underground' because those who are considered most 'at-risk' for HIV acquisition are those individuals already highly vulnerable to stigmatization (e.g., gay/bisexual/MSM men, drug users and sex workers) (Bayer & Fairchild, 2006). Smith et al. (2011) argue that opt-out frameworks will be especially stigmatising for population sub-groups that are already at increased risk of experiencing hardships as a result of their social position. For example, stigma associated with a positive diagnosis has been described as having particularly harmful effects on women, with potential consequences including abandonment by their partners and community (Kippax, 2006). However, as Csete and

Elliott (2006) acknowledge, there is a need for more empirical research to investigate the stigma-related effects of a positive diagnosis (e.g., rates of depression, suicide, abandonment, violence and other abuses).

As ART became more widely available, the ‘opt-in’ approach to testing also has been criticised as being overly ‘exceptionalistic’ – that is, it was argued that HIV was being treated differently in comparison with other communicable and sexually transmitted infections (Bayer & Fairchild 2006). In 2002, De Cock *et al* suggested that ‘exceptionalist’ practices may exacerbate HIV stigma rather than prevent it. In this argument, it is instead suggested that routine approaches will reduce stigma because everyone is considered as a target for testing; as a result, specific population sub-groups will no longer be targeted as the ‘risky other’. In general, these arguments rely on the assumptions that individual-level concerns (e.g., an emphasis on a fully informed and voluntary process) may no longer need to be prioritized in light of treatment advances (e.g., ART decreases likelihood of onward transmission and is now more widely available within many global contexts) and social change (e.g., laws that prohibit discrimination based on one’s HIV status) (Gostin, 2006). Other authors remain less convinced, arguing that opt-out approaches do not directly address the underlying issues associated with stigma (Meera and Sreeram, 2007), nor do they adequately take into account the reality that HIV-related stigma is alive and well, even in the most ‘progressive’ societies (Fields & Kaplan, 2011). Relatedly, Kippax (2006) argues that, without understanding or appreciating the cultural and social conditions under which individuals are being tested, opt-out approaches may inadvertently *increase* stigma and discrimination (although Kippax does not describe the pathways through which this effect is likely to be manifested).

Thus, two dominant themes emerged with respect to explaining how HIV testing practices are perceived to be interconnected with HIV-related stigma. First, there is a collection of arguments that position HIV stigma as accumulating through routine testing approaches. Within this way of thinking, increasing the number of HIV positive people tested through routine testing would imply that more HIV positive people will become

aware of their status and therefore exposed to HIV-related stigma. Conversely, another set of arguments exists whereby making HIV testing more routine and normalised, HIV stigma will be reduced. However, both of these streams of arguments related to stigma suffer from empirical and theoretical limitations. Specifically, from a conceptual perspective, stigma is frequently positioned as a binary outcome (e.g., either an individual experiences stigma or does not). In developing a more robust population and public health ethics related to HIV testing, HIV-related stigma should be conceived of as something more than an abstract phenomenon that ‘happens’ to an individual in order to open up new theoretical spaces to conceptualise HIV-related stigma as a question of systemic social and structural inequalities related to the intersections of power, culture and difference (Parker & Aggleton, 2003). Such a conceptualisation of HIV-related stigma emphasizes the relational dimensions of the health and social *effects* of stigma on health, providing opportunities to highlight the social processes that serve to differentially (re)produce social and structural inequalities (e.g., related to: class; gender; race; socio-economic status; culture) within and across global and local contexts (Scambler, 2009). Without conceptualising stigma in more sophisticated ways, the moral dimensions of arguments pertaining to the links between HIV stigma and HIV testing approaches will remain predominantly individualistic, hampering abilities to sufficiently address issues of equity at a population level.

Several of the authors (e.g., Csete & Elliott, 2006; Kippax, 2006) also suggest more empirical evidence is needed to determine how various testing approaches (e.g., opt-out versus opt-in) interact with HIV-related stigma. In part, the lack of empirical population-level data related to the social and health effects of HIV-related stigma and HIV testing approaches stems from relatively limited methodological tools (Parker & Aggleton, 2003). Nonetheless, innovative research methods continue to emerge within this field; for example, a recent study by Jurgensen *et al* (2013) used a pair-matched randomized cluster trial to examine differences in stigma over time among those accessing voluntary testing and counselling versus home-based testing. While new evidence in this field needs to be considered critically and contextually, more evidence should be developed to

inform ethical debates in this field – particularly within consequentialist arguments that rely on potential outcomes to delineate morally justifiable actions (Darwall, 2003).

### **2.3.2 Prioritising, targeting and seeking: Addressing individual- and population-level interests**

Within the review, the prioritisation and targeting of HIV testing to specific population subgroups was discussed in two ways: (1) with respect to the ethics of mandatory testing approaches with health care practitioners, pregnant women and within correctional institutions; (2) with respect to seek, test and treat approaches. Health care practitioners were described within two articles (Leung, 2001; Aziz, 2007) as being a group that may require special consideration related to mandatory HIV testing practices, given that they may engage in medical procedures that elevate the risk of HIV acquisition/transmission. Leung (2001) identifies the deployment of limited resources as an important consideration, acknowledging that while nurses have the duty not to impose risks to their patients, suggesting that they ought to know their status, mandatory testing of nurses cannot be justified, given that the high number of nurses that must be tested in order to prevent one case of nurse-to-patient infection would require too large a resource investment (particularly of concern for low-resource settings). Basu *et al* (2005) suggest that, within the context of correctional institutions, mandatory testing may only be suitable within longer-stay prisons, where there would be more opportunities for sufficient counselling and treatment in the event of a positive diagnosis. Nonetheless, as O’Grady and Schüklenk (2009) point out, there is a dearth of ethical analyses surrounding mandatory HIV testing approaches and future debates and contributions are likely needed in this area.

Pregnant women are a special case within the literature in this area. In general, it was argued that, as perinatal HIV transmission can be reduced through the use of timely treatment, opt-out approaches are warranted when women access gynaecologic/obstetric care. Fields and Kaplan (2011) argue, however, that while there can be significant benefits to both mother and fetus from HIV testing, opt-out approaches may involve a higher degree of coercion for pregnant women (e.g., through subtle/overt pressure from

partners, family and clinicians). Others argue that gendered health-seeking patterns are more likely to expose women and girls to health care service provision and, conversely, exclude men and boys – thereby eliminating the ‘universality’ of opt-out practices and placing a tacit burden of testing on women (Rennie & Behets, 2006; April, 2010).

Most argued that, while it is noble to improve pregnancy outcomes, including the HIV status of foetuses and neonates, it is unethical to construct the rights of the foetus as separate from (or opposed to) the rights of the woman. Salang Seloilwe (2011) accepts that targeting pregnant women may violate arguments regarding bodily sovereignty, but argues that this concern is outweighed by the principle of justice, whereby the distribution of benefits and burdens is particularly concerned with those who cannot protect their own interests (e.g., the foetus). Conversely, Armstrong (2008) argues that mandatory testing may represent a denial of dignity to pregnant women, yet suggests that if mandatory testing for pregnant women is not justifiable in high prevalence settings, then it cannot ever be morally justifiable. Ultimately, these discussions reveal how each of these testing approaches tends to rely on the medicalization of women’s bodies. Indeed, while many testing approaches aim to be ‘universal’, it is clear that women – particularly pregnant women – represent a group that is subject to enhanced HIV surveillance, thereby (re)contributing to a ‘hyper-feminisation’ of HIV testing.

Only two papers in the review discussed the ethics of seek, test and treat approaches. Vonn (2012) worries that, in practice, ‘seeking’ strategies may rely on coercive or incentivizing techniques among economically disadvantaged populations and potentially disregard the “criminal jeopardy” that individuals will be exposed to should they receive a positive diagnosis (e.g., in Canada, it is illegal to withhold one’s HIV status with sex partners) – processes and impacts that have yet to be demonstrated through rigorous empirical investigation. Bayer (2010), on the other hand, argues that ethical analyses that focus exclusively on individual-level concerns are not useful when considering ‘seeking’ strategies, given the severity of the HIV pandemic. Instead, Bayer (2010) calls for analyses that emphasize both collective and individual well-being to determine whether or not various seeking approaches can be justified to increase testing rates.

From more of a consequentialist approach (i.e., the view that the best act is determined by its capacity to promote the greatest amount of good and render the least amount of harm), Dawson (2011) explores how opt-out testing practices are a population health intervention that benefits future populations and are therefore morally justifiable. O’Grady and Schüklenk (2009) argue that, whereas previously mandatory approaches had little benefit to offer individuals, given the advances in ART, early detection is now critical and therefore opt-out approaches to HIV testing are morally justifiable. As a result, mandatory testing has increasingly been positioned within the literature as both a means to help the individual to gain opportunities to improve health, as well as an opportunity to prevent onward transmission and future harm to others. However, April (2010) argues that any justification for opt-out testing must rely on the individual-level benefits, not the population, due to a “lack of evidence” supporting the often promoted population-level benefits. This and other examples do not appear to acknowledge the empirical evidence indicating favourable population-level health benefits (e.g., Montaner et al., 2010), which is somewhat surprising given the high profile of seek, test and treat within contemporary HIV discourses and practices. For example, Vonn’s (2012) ethical assessment of seek, test and treat relies solely on policy documents, excluding empirical assessments of health outcomes or individual experiences. While this may reflect a publication ‘lag’, I also suggest this is a ‘high priority’ area within the field of population and public health ethics and suggest that future debates in these areas will be more informed by available and forthcoming evidence.<sup>7</sup>

In general, there was a lack of discussions of ethical issues related to targeting or prioritising HIV testing programs. Targeting population sub-groups is a hallmark within infectious epidemiology and relates to the distribution of limited resources. Sexual identity and other social characteristics (e.g., ethnicity; social class) are widely used as

---

<sup>7</sup> For a recent example (outside of the field of HIV testing) of a critical interrogation of the population and public health ethical considerations related to available individual- and population-level evidence, see Thompson’s (2013) discussion of an HPV vaccination program in a Canadian-based school.

proxies to target HIV interventions, in part because they are thought to be efficient ways of targeting HIV interventions (including testing programmes), especially to vulnerable, so-called ‘high-risk’ groups. For example, some HIV testing strategies specifically target testing messages at MSM and African-origin immigrants (e.g., National AIDS Trust, 2012), and ethical issues associated with these practices were absent within articles in the current review. However, outside of the current review and within the population health literature more broadly, there is emerging concern that targeted public health intervention approaches in general (e.g., those based solely or primarily on social characteristics) may exacerbate health inequity (Frohlich & Potvin, 2008). A recent paper, for example, suggests that intervening approaches that focus on discrete social differences to address health may (unintentionally) result in positive discrimination or stigmatization (McLaren, McIntyre, & Kirkpatrick, 2009). Targeted interventions also have been criticised for burdening specific population subgroups with an intervention, while aiming to benefit those not explicitly targeted through a dispersion of benefits (e.g., reducing disease in a population will reduce the likelihood of disease acquisition among those not targeted) (O’Neill, 2011). Unfortunately, the literature related to the ethics of HIV testing has yet to unpack the ethical implications of targeted interventions and represents an important area for future empirical and normative inquiry.

### **2.3.3 Structural and agentic factors related to HIV infection and testing experiences**

HIV infection and testing experiences are linked to both agentic practices (e.g., capacity to deploy a range of causal powers with respect to HIV testing) as well as to structural features within and across populations (e.g., socio-economic inequalities). Within the review, the ethical considerations related to structural and agentic influences were frequently implicated in discussions related to paternalism and opt-out testing approaches. Generally, the discussions related to structure, agency and HIV testing tended to emphasize individualistic concerns by positioning the unit of analysis in an HIV test as an individual. In this light, the capacity for HIV testing to operate as a preventative tool was generally conceptualised through counselling individual behaviour change. For example, DeCock *et al* (2002) criticise the limited ability of VCT to function as a preventative tool in high-prevalence settings due to the prioritization of individual-



level considerations of informed consent, counselling and anonymity. Csete and Elliott (2006) argue that, by eliminating (or reducing) the use of pre-test counselling, opt-out HIV testing loses its power as a prevention tool. I suggest that we may require a conceptual ‘shift’ within these moral discussions that position population-level HIV testing practices as both a societal resource (structure), as well as a mechanism that influences the nexus of individual agency (e.g., the ability to deploy a range of causal powers related to sexual health practices) and the (re)production of hierarchal social relations (e.g., norms in which people can engage to promote more socially just health and social outcomes). While I agree with others who have suggested that scaling up individually based interventions does not, in itself, represent a structural intervention (McLaren, McIntyre & Kirkpatrick, 2010), I argue that the various HIV testing approaches can be more meaningfully considered as interventions that have the capacity to be preventative at an individual level (e.g., through pre- and post-test counseling) and structural level. For example, Knight *et al* (2012a) describe how sexual health clinical encounters (including HIV testing) can provide opportunities for young men to engage in social interactions that can begin to deconstruct social structures that (re)produce social injustices (e.g., heteronormativity; hegemonic masculinity; misogyny; HIV-related stigma). While some articles in the current review allude to HIV testing as having a transformative capacity at a structural level (e.g., within arguments suggesting HIV-related stigma can be reduced within opt-out approaches), these arguments neglected to identify the specific pathways in which more equitable outcomes can be advanced (likely due to the lack of empirical investigation and data in this area).

## **2.4 Conclusion**

The issues raised within the current review offer a glimpse into the moral complexities associated with HIV testing approaches. Here, I described how the trend from opt-in to opt-out approaches is being morally justified or criticised and showed how various testing approaches intersect with HIV-related stigma, targeted approaches to testing and structure and agency. While the review does not seek to provide support for or against a specific testing approach, it does illuminate the extent to which the generation of new empirical evidence could advance a more robust set of normative discussions in this area.

Specifically, this scoping study reveals how HIV-related stigma, various prioritising, targeting and seeking strategies and structural and agentic factors have, to date, not received sufficient empirical-normative inquiry in the substantive area of HIV testing. Advancing empirical-normative efforts is integral to robust empirical-normative population and public health ethics, which must carefully engage with normative theory that appreciates (and responds to) empirical evidence that can detail both intended and unintended outcomes from various HIV testing practices. For example, empirical-normative approaches will position the (empirically measurable) *effects* of HIV-related stigma and/or targeted approaches as having moral significance that requires careful normative consideration. In doing so, empirical-normative inquiry in this area will move beyond highly individualistic orientations detailed in the current scoping study, as well as beyond consequentialist approaches that often focus exclusively on health maximization frameworks. Based on this scoping study, I suggest that additional theoretical work and empirical research are required in order to inform more ethically robust debates related to HIV testing practices. Specifically problematic are consequentialist arguments that deem testing approaches as either morally permissible or impermissible without sufficiently robust empirical and/or theoretical underpinnings about how a particular approach would unfold among individuals and populations. A robust population and public health ethics must address issues related to the intersections of individual-level factors (e.g., consent; autonomy), as well as the structural and social inequalities that concentrate illness within the most vulnerable populations. While I agree with others who have cautioned that over-focusing on ‘the empirical’ within ‘the normative’ risks losing sight of the analytic method required in moral evaluation (Goldenberg, 2005), I also argue that the apparent lack of theorising and empiricising deployed in descriptions of HIV-related stigma and structural inequalities reveals the need for a renewed emphasis on interdisciplinary approaches across the humanities (e.g., philosophy; history; law), social sciences (e.g., sociology; political sciences; economics) and health sciences (e.g., medicine; epidemiology).

Arguments that assume a uniformity of agency within and across populations are theoretically problematic, as these arguments tend to be fundamentally threatened by the

reliance on an assumption that each individual has an equal degree of agency and can volunteer for testing as needed (and moreover has the knowledge and motivation to do so). Indeed, from within the realm of public health, this approach relies exclusively on individual-based approaches to give knowledge to the individual in order that they access testing (and therefore disregards social structures and the distribution of agentic privilege). In this capacity, these arguments fail to attend to the philosophical underpinnings of population and public health ethics that emphasize equity, justice and considerations of structural distributions of health and illness.

I acknowledge that many ethical debates related to HIV testing practices take place outside of academic writing/journals (e.g., in the public sphere). However, this review of the current state of normative debates in the peer-reviewed literature related to population and public health ethics and HIV testing offers a distillation of where institutionalized efforts (e.g., within the academy) are being focused, and suggests areas where new efforts could yield potential gains. Philosophical and ethical deliberations are much-needed processes when negotiating a balance of the interests of individuals and populations, particularly in the quickly evolving context of HIV. For example, new HIV-related technologies and evidence continuously emerge in this rapidly changing area, including home-based tests, online testing programs, as well as new pre- and post- exposure prophylaxis (within some settings), bringing forward new challenges with respect to their implications. Whether we can or should attain a state of global consensus or equilibrium about the moral underpinnings of public health actions related to HIV intervention and prevention remains unclear; however, the current review underscores the need to continue to advance evidence in order to articulate and develop a population and public health ethics within this substantive area.

## Chapter 3

### **HIV Stigma and the Experiences of Young Men with Voluntary and Routine HIV Testing: An Empirical-Normative Inquiry**

#### **3.1 Introduction**

##### **3.1.1 Background**

Individuals unaware of their HIV seropositive status continue to represent a key ‘driver’ of the HIV epidemic within many global contexts (Public Health Agency of Canada, 2013; Lima et al., 2010). As a result, there is a strong public health impetus to enhance testing participation rates among those unaware of their HIV status. For example, many settings, including Vancouver, Canada, have implemented routine testing (in which patients presenting at health care facilities are routinely offered an HIV test), thereby representing a departure from the emphasis of approaches that focused on voluntary testing and counselling in which a patient must request a test (predominantly used during the late 1980s to early 2000s). And, as various public health approaches are implemented to enhance participation rates in HIV testing, it is often widely assumed that these approaches are ethically justifiable given the underlying assumption that these practices will result in the widespread reduction of HIV-related stigma by enhancing public awareness and normalizing HIV (Jurgensen et al., 2013). Nonetheless, a variety of empirical and theoretical gaps regarding how interventions such as HIV testing practices may serve to impact HIV stigma remain (Jurgensen et al., 2013; Sengupta et al., 2011; Durojaye, 2011; Mahajan, et al., 2009; Earnshaw & Chaudoir, 2009; Parker & Aggleton, 2003), raising questions about the ethical underpinnings of enhancing HIV testing among various populations (Jurgensen et al., 2013; Durojaye, 2011; Powers & Faden, 2006; Bayer & Fairchild, 2006).

### **3.1.2 Young men and HIV testing**

Young men represent a unique population in terms of sexual health needs broadly and HIV-related interventions specifically (Knight et al., 2012a; Shoveller et al., 2010; Gahagan et al., 2011). While HIV testing participation rates vary globally, within many settings *young* men represent a group with disproportionately low testing rates (Shoveller et al., 2010). These low rates of HIV testing among young men have been attributed to structural conditions within health care service delivery systems (e.g., the focus on women's sexual and reproductive health from the onset of puberty), as well as men's gendered (sexual) health-seeking behaviour (Knight et al., 2012a & 2012b; Shoveller et al., 2010). Theory regarding gender relations, masculinities and men's health suggests that men's sexual health experiences are strongly influenced by the wider set of social relations and expectations that men experience (and contribute to) in their everyday lives (Doull, Oliffe, Knight & Shoveller, 2013; Connell, 2012; Knight et al., 2012a & 2012b; Oliffe et al., 2012; Robertson, 2007; Courtenay, 2000). Young men's experiences with HIV testing has been particularly linked to broader (stigmatized) societal expectations regarding their sexual health-related practices. For example, sexual health clinical encounters frequently represent a unique anxiety-inducing experience in which men's (hetero)sexuality is explicitly 'interrogated' (Knight et al., 2012a), as well as a process in which young men experience multiple vulnerabilities associated with seeking 'help' (Shoveller et al., 2010). Recent research exploring men's experiences with HIV testing has also revealed how broader societal expectations pertaining to young men's sexual health practices and self-assessed risk lead some men to feel 'expected' to test (e.g., queer men), thereby (re)stigmatizing queer identities, while alleviating notions of risk among heterosexual men (Knight et al., 2012a & 2012b). Nonetheless, little is known about how the expansion of routine testing approaches may influence young men's experiences with HIV-related stigma in clinical encounters or beyond, opening a space for new empirical investigation and normative consideration.

### **3.1.3 HIV testing, HIV-related stigma and young men**

While much empirical work positions HIV stigma as a key barrier to HIV testing, treatment and care, efforts to attenuate HIV-related stigma through various interventions

have had limited impact. A recent systematic review (Stangl, Lloyd, Brady, Holland & Baral, 2014) of HIV-related interventions found that most HIV stigma reduction interventions remain somewhat individually focused (e.g., information provision within staff training initiatives) and, while they frequently reported reductions in stigma, the capacity for these interventions to influence long-term change is unlikely given the “downstream” orientations. Given these findings, these studies advance calls for more evaluations of structural-level interventions (e.g., policy changes) that can have a larger reach within and across various populations.

From various theoretical perspectives, the shortcomings of HIV-related stigma reduction interventions are frequently attributed to the cross-cultural complexity and specificity of the dynamic social processes and mechanisms associated with HIV stigma (Mhajan et al., 2009; Parker & Aggleton, 2003). For example, many theories from the 1990s through to the early 2000s pertaining to HIV-related stigma have been criticised for their exclusive focus on individual-level attitudes and beliefs without sufficient consideration of the socio-cultural contexts which frame social and cultural norms (Scambler, 2009; Parker & Aggleton, 2003), thereby highlighting a disregard for the causal ‘inputs’ of social and structural conditions (e.g., gender, socioeconomic status) (Scambler, 2009). In other sociological and anthropological contributions to the theorization and empiricisation of HIV-related stigma, scholars have argued that stigmatization is equally contingent upon broader socio-cultural influences (e.g., gender; culture; place) in addition to individual-level phenomena (e.g., cognitive or behavioural responses) (Parker & Aggleton, 2003). Within these socio-ecologic frameworks, individual-level social processes pertaining to HIV-stigma (e.g., enactments of prejudice, discrimination and stereotyping; internalization of shame and guilt) are thought to be shaped by the broader social and structural contexts, including features of power, culture, privilege and social difference (Parker & Aggleton, 2003; Scambler, 2009). Thus, the relational dimensions of the social effects of stigma on health are emphasized, thereby offering empirical opportunities to highlight both the social processes that (re)produce social inequalities (e.g., class; gender; race) (Scambler 2009), as well as highlight the *effects* of HIV-related stigma on individuals (e.g., social consequences; agentic capacities) (Knight, Shoveller, Greyson et

al., 2014a). Empirical work in this area could thus provide important opportunities to identify ethically robust public health practices that might serve to attenuate the effects of HIV-related stigma.

To date, few empirical studies have explored how various HIV testing approaches (e.g., voluntary versus routine) affect experiences associated with HIV stigma (Jurgenson, 2013). Some research has been conducted in high-prevalence and low-income settings and examined the association of stigma and voluntary testing and counselling (Kalichman & Simbayi, 2003; Koku, 2011; Pettifor, MacPhail, Suchindran, & Delany-Moretlwe, 2010; Sambisa, Curtis, & Mishra, 2010; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009; Young, Hlavka, Modiba et al., 2010). Within these studies, cross-sectional study designs have limited the capacity to identify causal relations (Jurgensen et al., 2011) or social processes over time (e.g., the influence of socio-cultural norms pertaining to expectations to test). This work has tended to draw on individualistic theoretical frameworks and methods (e.g., measuring individual-level beliefs and attitudes) (Stang et al., 2013). And, while findings from some studies provide important, provisional insights within high-prevalence and low-income settings (e.g., the challenges of stigma-reduction initiatives among men who have sex with men within homophobic societies) (Obermeyer et al., 2013), to date, no research has investigated the social and structural influences potentially contributing to stigma within a context of expanding routine HIV testing efforts in settings such as Vancouver, Canada (e.g., high-resource settings with a concentrated epidemic). Furthermore, studies pertaining specifically to men, HIV testing and HIV-related stigma have tended to focus exclusively on men who have sex with men (for example, see: Flowers, Knussen, Li & McDaid, 2012), revealing the importance of gendered analyses. Nonetheless, empirical and theoretical work focusing on and appreciating *young* men's gendered practices in this realm remains conspicuously absent.

Because HIV is distributed inequitably among young men (e.g., along a social gradient), and owing to the fact that HIV-related stigma differentially (re)produces social and structural inequalities (e.g., related to: class; gender; race; socio-economic status; culture), there are important ethical questions that arise within the context of evolving

and expanding HIV testing practices (Knight et al., 2014a). Specifically, concerns related to whether routine testing serves to attenuate or exacerbate HIV-related stigma among young men in the context of existing voluntary testing approaches requires additional empirical evidence and ethical interrogation. The aim of this study is therefore to determine how HIV-related stigma is experienced differentially across subgroups of young men within voluntary and routine testing contexts. The results of the current study may be useful to informing normative deliberation in this area.

## **3.2 Methods**

### **3.2.1 Theoretical framework**

This study is informed theoretically by the exploratory hypothesis that public health practices related to testing for HIV are concomitantly linked with social and structural phenomena pertaining to the spread of HIV and the proliferation or attenuation of HIV-related stigma. To address empirical-normative gaps in knowledge pertaining to HIV testing, the current study draws on methods from the social sciences, as well as theoretical orientations from the field of population and public health ethics. While there exist a variety of frameworks within population and public health ethics, a general aim is to consider, negotiate and balance the interests of both populations and individuals (Daniels, 2006). Normative analyses within population and public health ethics also emphasizes how health and illness are distributed (in)equitably within and across populations (Daniels, 2006), with a particular emphasis on the integrations of individual-level influences on health (e.g., ‘risky’ behaviour) with broader social and economic determinants of health (Baylis et al., 2008).

### **3.2.2 Study setting**

Vancouver, British Columbia (BC) provides a context within which to explore these questions, presenting an opportunity to gather and analyze data generated via an ongoing ‘natural experiment’. In Vancouver, the norm until recently has been voluntary testing. Since 2011, there has been a policy and practice shift towards institutionalizing routine testing approaches on a more universal basis within Vancouver. For example, in 2010 the



provincial government committed to supporting BC's Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV) program which includes scaling up routinized HIV testing and the expansion of highly-active antiretroviral therapy (HAART). In 2011, several of the larger hospitals within Vancouver began offering routine testing to all patients, including those requiring blood work for other non-HIV related indications. In 2012, it was recommended that routine testing be offered to all patients upon admission to acute care settings (Gustafson, Montaner & Sibbald, 2012). More recently (May 2014), the Provincial Health Officer put forward a revised set of HIV testing guidelines, thereby "scaling up" the implementation of routine testing practices province-wide (British Columbia Ministry of Health, 2014).

To further characterize the setting for the study (particularly for the international reader), it is helpful to describe the local, epidemiological context of HIV. In BC, there are approximately 12,300 HIV seropositive individuals, with up to 2,500 unaware of their status (Lima et al., 2010). In 2012, men accounted for 88% of all new HIV diagnoses in BC. While many other risk groups have begun to experience reductions in HIV incidence, young men have not experienced such a trend. In 2012, HIV incidence rates for men between the ages of 20-24 years and 25-29 years were significantly higher than the provincial average at 7.7 and 22.0 per 100,000 cases (compared to the provincial average of 5.2 per 100,000) (British Columbia Centre for Disease Control (BCCDC), 2012). And, men who have sex with men (MSM) continue to bear a disproportionate burden of the disease. For example, MSM represent 63% of all new HIV diagnoses in 2012 (BCCDC, 2012). Men who inject drugs also have recently experienced declining rates of HIV (e.g., 43 cases in 2008 compared to 20 cases in 2012 among men), likely reflecting the success of sustained prevention efforts with this population (BCCDC, 2012). Heterosexual contact now represents the risk category with the second greatest number of new HIV diagnoses among men (32 new cases among heterosexual men in 2012) (BCCDC, 2012).

### **3.2.3 Recruitment of participants and interview procedures**

Men ages 18-24 years were recruited between June and November 2013 to participate in in-depth, semi-structured interviews using a range of recruitment strategies, including online approaches (e.g., Facebook advertisements) and posters and pamphlets at both clinical (e.g., within sexual health clinics) and non-clinical (e.g., bus stops; community bulletin boards) locations, as well as at the At-Risk Youth Study (ARYS), a prospective cohort study of street-involved youth (for details on the ARYS cohort, see: Wood, Stoltz, Montaner & Kerr, 2006). Interviews took place in private locations (e.g., research offices; clinical spaces), lasting between 1-1.5 hours each. Interviewers explained the purpose of the study and obtained informed consent before commencing the interview. Participants were also asked to complete a brief socio-demographic questionnaire (see Appendix A), and all participants received a CDN\$25 honorarium.

### **3.2.4 Interviews**

Semi-structured, in-depth interview guides were used (See appendix B) to elicit participants' perceptions of and experiences with voluntary and routine HIV testing practices. Participants were asked about their experiences with voluntary and/or routine testing, as well as their perceptions about how various HIV testing practices would influence their comfort levels and considerations of privacy. Men who had been tested with a specific approach were asked to reflect on interactions in clinic spaces, including discussions and comfort levels. Men who had never voluntarily and/or routinely tested were asked about their perceptions pertaining to each approach, including how these interactions could influence their future considerations to test, how the approach might influence their comfort levels, and whether they would prefer various approaches and/or practices associated with each testing approach. Men also shared perceptions about broader features of the social and structural contexts (e.g., ideals and norms related to young men's health and HIV), as well as the effects these influences might have on their testing experiences.

### **3.2.5 Data analysis**

Interviews were audio-recorded and transcribed with identifying details removed. A research assistant checked each transcript for accuracy. *QSR NVivo 10™* was used to manage the data. To code the data and compare themes across interviews, a constant comparative technique was used to develop a set of codes (Dey, 1999) after an initial set of codes featured participants' negative and positive experiences with each approach, avoiding, where possible, preconceived theoretical constructs (e.g., theories related to masculinities; ethical theory). Coding occurred iteratively to test emergent ideas about the connections between concepts and to identify new themes; as additional interviews were completed, coding was organised into 'trees' to group the open codes into more abstract conceptual categories pertaining to the objectives of this manuscript, with a particular emphasis on the various ethical issues that have been identified previously in the literature. Thus, both inductive and deductive approaches were used to identify and interrogate each thematic outlined within the findings below. Finally, to bridge the empirical within normative discussion, the current study also draws on techniques used within reflective equilibrium (Daniels, 1996), which facilitates combining empirical data with normative reasoning and theory. In this approach, moral theories, moral intuition, as well as social theories that emphasize the theoretical interactions between structural- and individual-level determinants of health, are combined to seek a temporal equilibrium (Daniels, 1996).

### **3.2.6 Study participants**

In total, 50 young men completed interviews. Participants were purposefully recruited to reflect varying social positions and lived experiences, including men from a range of socio-economic statuses and sexual identities. Participants were also recruited who could provide a variety of perspectives regarding their experiences with either, both or neither voluntary and routine approaches to HIV testing. Participants either selected or were assigned a pseudonym, for the purposes of reporting. Table 3.1 provides details on the socio-demographic characteristics of the study sample.

**Table 5. Socio-demographic characteristics of study participants**

<b>Ethnicity</b>	<i>(n)</i>	<i>(%)</i>
Aboriginal	6	12
African-Canadian	1	2
Euro-Canadian	26	52
Latin	2	4
South Asian	0	0
South East Asian	7	14
Middle Eastern	1	2
Other	7	14
<b>Living arrangement</b>		
With parents	9	18
With friends or partner	22	44
Alone	7	14
In a shelter or on the street	11	22
In a recovery house	1	2
<b>Previously tested</b>		
Never	5	10
One or more	45	90
<b>Testing approach experienced</b>		
Voluntary testing	32	66
Routine testing	5	10
Both Voluntary and Routine	8	14
None	5	10
<b>Sexual Orientation</b>		
Bisexual	8	16
Gay	7	14
Heterosexual/straight	34	68
Two-Spirit	1	2
<b>Gender Identity</b>		
Transgender man	1	2
Cisgender man <sup>8</sup>	49	98

---

<sup>8</sup> Cisgender refers to individuals who have a gender identity that aligns with the biological sex they were born with (e.g., a biological male who identifies as a man).

<b>Recruitment medium</b>	<b>(n)</b>	<b>(%)</b>
Online advertising	23	46
Posters	2	4
ARYS	24	48
Other	1	2

### 3.3 Findings

The findings begin with a description of men’s experiences with voluntary testing and then their experiences with routine testing. These sections are followed by descriptions of the young men’s perceptions about HIV and HIV-related stigma. Details regarding participants’ self-identified ethnicity, sexual identity, previous experiences with voluntary and/or routine testing approaches and the number of times tested<sup>9</sup> are provided in brackets following each illustrative quote.

#### 3.3.1 Experiences with voluntary testing

Interviews began with a discussion of men’s experiences with voluntary testing. Some participants described the act of voluntarily seeking out testing as an anxiety-inducing experience, stemming from a tacit acknowledgement of one’s ‘regretful’ or ‘shameful’ behaviour associated with the need to test. For example, Frank described:

If I do get tested, then it means I *should* get tested, and if I *should* get tested, it means I might have HIV. [...] With the voluntary approach, it’s more like I have to kind of come to the decision that I should be tested and so there might be more stigma attached with that. Like, do I have a *reason* to be tested? (Frank, 24, Euro-Canadian, straight, voluntary, *n*=1)

Some men also said that young men would be most likely to voluntarily seek testing if they had engaged in same-sex sexual behaviour, had sex under the influence of drugs or

---

<sup>9</sup> Men who indicated they had tested more than five times are reported as “≥5”.

alcohol, or used drugs (e.g., shared needles), actions they frequently associated with societal disapproval. Participants described how societal-level ‘moral expectations’ regarding how men *should* behave with respect to sexuality and sexual health could influence their views of ‘themselves’. For example, Herbert described:

It’s sort of like that morality police – people disapprove. There’s a stigma around HIV because people think that people who have HIV are people who engage in morally incorrect behaviour. I think a lot of people probably think that ‘Well if you’re getting tested for HIV, you probably think that you might have HIV which means that you probably took part in some sort of behaviour that I don’t condone. And as a result I’m judging you for getting tested because that tells me that you probably did some sort of activity that I disapprove of’. (Herbert, 23, Euro-Canadian, straight, voluntary,  $n=2$ )

Narratives like Frank’s and Herbert’s reveal how socio-cultural expectations regarding young men’s sexual health behaviour (particularly in relation to the ‘act’ of seeking HIV testing) have the capacity to become internalized and influence men’s conceptions of self-identity, as well as their health-related practices. Some men also described how the effects of HIV-related stigma affect their experiences within clinical encounters. For example, some described that in order to ‘convince’ their clinician that they needed to be tested, they had to reveal the (stigmatized) risk behaviour that prompted their request for a test. For example, Kaiser described a clinical encounter in which he asked to be tested for HIV:

So I was like, ‘Okay, so I was having sex and the condom broke.’ And she [the nurse] was like, ‘Well, you’re not at risk’. And I was like, ‘Well-ll-ll, I might be. I just wanna get tested.’ And, she was like, ‘Oh, who were you with?’ And, I was just like ‘This guy.’ And she had this look on her face, like ‘*Oh, you’re gay.*’ And then it was like very awkward in the room ’cause I could like tell she was judging me kind of. [...] And I was uncomfortable, because I just wanted her to give me the requisition form so I could go to get test, and like *end* this questioning. (Kaiser, 22, gay, Euro-Canadian, voluntary,  $n\geq 5$ )

Among the men in this study who had previously accessed voluntary testing, many also described how their previous life experiences influenced the extent to which notions of HIV-related stigma affected their internalization of stigma. For example, Robert explained:

When I was going to get STI testing for instance and then eventually got the HIV testing, when you're in the room of the clinic, are you smiling at everyone around you and going, 'Hey, I'm Robert, nice to meet you...Robert. No, you're keeping to yourself, you're very quiet and you're probably looking at the ground, embarrassed that you're there, not proud of what you're doing.' Why that is so? I feel like there is a bit of maybe some guilt, some blame. 'Well, I'm here because this is my fault I did things that have led me into this situation.' But, I know that now that I'm older, now that I'm no longer a teenager, I know that it's a normal thing that any responsible person should do. [...] The first time you go is completely different from the second time. (Robert, 22, Euro-Canadian, bisexual, voluntary,  $n=2$ )

Robert's narrative reveals how both becoming more mature (e.g., gaining access to cultural capital associated with being an adult) and having previous experiences with testing attenuated his experiences with experiencing and internalizing feelings of shame and guilt.

These narratives distil a set of social processes by which external (societal) notions of stigma become internalized through acts associated with voluntary testing (e.g., deciding to seek a test; experiences within clinical encounters). These data also reveal how previous experiences with voluntary testing can serve to lessen the degree to which stigma is internalized (e.g., within subsequent testing experiences).

### **3.3.2 Experiences with routine testing**

For many of the participants, routine testing offered an opportunity to alleviate barriers associated with HIV-related stigma that prevents them from regularly accessing voluntary testing. For example, Nicholas compared the barrier/facilitator thresholds associated with seeking voluntary testing versus being offered a routine test as follows:

I feel like stigma keeps a lot of people from going out and doing a voluntary [test], and I feel like for the routine test [...] like, if someone offered me an HIV test while I was at the doctor anyway, I'd definitely take it. (Nicholas, 22, Aboriginal, bisexual, voluntary,  $n=2$ )

Many of the young men also described how routine testing practices serve to de-stigmatize HIV testing and HIV. For example, Kaiser, explained how a routine offer might influence his perceptions of HIV-related stigma:

I feel like it eliminates the stigma if someone is offering it to you, and you don't have to go out of your way to ask for it, you know what I mean? It's very sheepish, I feel, to have to raise your hand and ask for extra medical attention that maybe isn't necessary. I think if they offer it across the spectrum, it makes people more aware that this is something they should be doing regardless of who they're sleeping with. (Kaiser, 22, Euro-Canadian, gay, voluntary,  $n \geq 5$ )

Kaiser's narrative reveals how the universal dimension of a routine offer can serve to alleviate stigma associated with voluntary testing. These data also reveal the complex packaging of gay masculinities as they relate to sexual health practices; for example, Kaiser's narratives reveal how he is both 'expected' to regularly test (i.e., as a gay man), while concurrently deferring to a set of normative masculine dispositions that often prescribe stoicism and avoidance of help-seeking behaviour (e.g., positioning help-seeking practices as 'sheepish').

Other participants expressed concern that some men are incorrectly assessing their own levels of risk for acquiring HIV (e.g., based on heterosexual sexual identities) and therefore may be unlikely to voluntarily seek testing. As a result, routine testing was described as a practice that could particularly benefit these men. For example, Nicholas, described how routine testing could concurrently 'reach' his straight friends, as well as serve to normalize (e.g., de-queer) HIV among them:

It would just make it accessible to people who might not otherwise think of testing. Especially with a lot of my heterosexual friends, they don't consider it something they have to do or it's something that they don't feel concerned about. [...] It would probably normalize it and make it less of a life event that it is. (Nicholas, 22, Aboriginal, bisexual, voluntary,  $n=2$ )

Similarly, some men described that routine testing could benefit them because, due to a set of expectations within their community surrounding young men and sexual health, they had not been afforded opportunities to seek testing (though testing was frequently



positioned as an important health practice in which they would like to engage in more frequently). For example, Charles explained that within his family and friends networks (whom he identified as ‘Chinese’), routine testing might normalize the notion that anyone could benefit from knowing their HIV status. As Charles described:

Like it should be part of something we see regularly. Like if you go to a health care professional, get tested, you know. I mean, the more you say ‘Oh, young, gay men should go for testing’ the more there’s a stigma surrounding it then that becomes a problem, you know? When you go to the doctor you’re like ‘oh I’m not young, I’m not gay. I don’t want to get tested.’ If you can make it more like a regular thing. ‘Just do it, it’s part of your health check-up. (Charles, 22, Chinese, straight, never tested)

Charles’ narrative highlights how HIV and HIV testing can be positioned as ‘queer’ issues for straight men and therefore potentially ‘dangerous’ activities for ‘non-queer’ identities to engage in (e.g., represents a potentially emasculating/feminising/queering experience). His narrative also reveals how a routine offer has the capacity to alleviate the barriers stemming from the broader stigmatizing cultural and familial perceptions of HIV.

While many were in favour of routine testing, some expressed serious reservations that some men could feel ‘targeted’ within a clinical encounter in which a test is offered because they would perceive the offer as a form of stereotyping or profiling (e.g., based on their affiliation with queer identities). For example, Jeremy described how these experiences could be perceived as being based on a set of assumptions or stereotypes about social identities:

People don’t want to be told that they need HIV testing... The person [clinician] who’s targeting them assumes certain things and it comes across as being, “You think I’m high risk because I have, you know, whatever it is, drug use, you think I’m sleeping around a lot. You’re targeting me because I’m gay.” Being targeted is not positive. (Jeremy, 22, Euro-Canadian, transgender, bisexual, voluntary & routine,  $n=2$ )

Among the straight-identified men in the study, none said that they would feel ‘targeted’ as being potentially ‘queer’, although some worried they were being offered an HIV test

because they were perceived to be ‘poor’ or ‘someone who uses drugs’. For example, John Smith, a man with a history of drug use and street-entrenched experiences, described how one’s social identity influenced his perceptions of a routine offer of HIV testing:

HIV is associated with poor people, gay people, drug users. So those are the demographics that are going to feel really discriminated against. Because if they’re already part of that demographic and they know that demographic is susceptible, then if a doctor comes up to them and is like, “Well, do you want HIV testing?” It’s like, “Are you asking me that question because I’m poor?” (John Smith, 23, Euro-Canadian, straight, voluntary,  $n=4$ )

John Smith’s concerns pertaining to targeted practices underscore the extent to which one’s social positioning can serve to influence their experiences and perceptions in clinical encounters. His narrative also reveals how men experiencing multiple intersecting social vulnerabilities may experience or perceive a routine offer differentially (e.g., based on perceptions of profiling or stereotyping), thereby illuminating the importance of the social-relational features within clinical interactions (e.g., asymmetrical clinician-patient power relations).

All of the men who expressed concern about being the ‘subject’ of targeted practices also indicated that in the cases where a health care practitioner had explained clearly: ‘It is now recommended that we offer *everyone* an HIV test’, their anxieties or concerns about being ‘targeted’ had been either eliminated or dampened. For example, while Nikolai initially said he would feel targeted in a routine offer, he later explained how understanding that the test was offered universally would:

...remove any sort of doubts about any sort of behaviour of mine that might have caused it and it would remove a lot of the social stigma from it because [...] if everybody’s getting tested anyway then it just removes any sort of negativity. (Nikolai, 22, Euro-Canadian, bisexual, routine,  $n=1$ )

Men’s descriptions of their experiences with and perceptions of routine testing highlight how a routine offer can serve to reduce experiences of HIV-related stigma and voluntary testing, as well as potentially serve as a mechanism to reduce barriers associated with

HIV stigma to testing. However, these data also reveal how the degree to which stigma may be alleviated, mitigated or exacerbated is contingent upon equitable social-relational features within clinical encounters (e.g., men's intersecting social identities; practices to ensure men understand the universal dimension of the routine offer).

### **3.3.3 Social consequences of HIV and HIV-related stigma**

In order to more fully elucidate young men's perceptions about HIV and HIV-related stigma, participants were asked to describe their perceptions of both the social- and health-related effects of HIV. Within these discussions, some men described how HIV is no longer the terminal condition it once was. For example, George described how, in the context of effective treatment opportunities, he considers voluntarily testing as more of a regular health check-up, no different than seeking help for a common cold:

I moved to the thought that, you know, HIV and AIDS is just like the common cold and they're just something else you can have. Whereas, I used to think it was like 'This is the end of the world' versus, you know, 'It's just out there with anything else you can even have.' [...] I think it's just like the common cold! [...] HIV does not equal AIDS. (George, 23, Euro-Canadian, gay, voluntary,  $n \geq 5$ )

Here, George's narrative reveals how, while he had previously considered HIV to be a terminal illness (i.e., a condition that leads to AIDS), he now considers HIV as a more of a manageable chronic condition – much like treating symptoms for a common cold. As George's interview progressed, he described how the effects of HIV stigma would present far more detrimental consequences in the event of an HIV positive diagnosis. He explained how friends and family might treat him differently if he were HIV positive:

I think everyone around you would treat you differently. Naturally, some positive, some negative, in the sense that, I guess, I think there would be a lot of pity. For the majority of the other people who understand like, it's not the end of the world, but the general public who doesn't get it. And again, coming back to the majority of the heterosexual population [...] you know, worried for you or stigmatizing you. (George, 23, Euro-Canadian, gay, voluntary,  $n \geq 5$ )

Thus, while many participants described how HIV can be managed through the use of treatment (e.g., HAART) and that one can lead a healthy life, participants underscored

the effect to which the effects of HIV-related stigma (e.g., changing social interactions) would negatively impact their lives. For example, almost all of the men in the study – including those that described HIV as being manageable in the context of treatment – said that testing HIV positive would significantly affect their sexual and romantic experiences. For example, Sam described how he would perceive his sex life changing:

I would be infinitely more cautious and perhaps even abstinent to some extent 'cause I don't think I could deal with the guilt of potentially passing it on to someone. So that would really affect that aspect of my life. Yeah, it'd just, to some degree, eliminate that aspect of my life. (Sam, 22, Chinese, straight, never tested)

As a result, while men had a general knowledge that HIV can be managed in the context of advanced treatment opportunities, generally, men also suggested that there would be a profound changes to their social lives in the event of an HIV positive diagnosis, thereby highlighting the highly socialized underpinnings of HIV and HIV stigmatization.

### **3.4 Discussion**

Despite decades of efforts to reduce HIV-related stigma, these data reveal the extent to which young men continue to be influenced by (and contribute to) the social and structural conditions that influence various individual-level social processes and practices associated with HIV testing. These data also underline the key levels at which societal norms can influence attitudes and behaviours (Heijnders & van der Meij, 2006); namely: at the individual level (knowledge, behaviour); interpersonal (e.g., within clinical interactions); organizational (e.g., institutional policies, such as the expansion of routine testing); and community (e.g., cultural values). As such, these findings corroborate previous empirical work highlighting the complexity of addressing individual-level issues in clinical encounters, while concurrently considering (and adapting services to) the broader socio-cultural and structural conditions that shape young people's lives (Knight, Shoveller, Carson & Contreras-Whitney, 2014b). Importantly, these data also provide opportunities to explore how young men experience HIV-related stigma within voluntary and routine testing in order to determine the extent to which these practices attenuate or ameliorate the effects of HIV stigma.

### **3.4.1 Voluntary testing and HIV stigma**

Given the benefits associated with the availability of HAART within many settings (including Vancouver), some scholars previously argued that voluntary testing represents an overly ‘exceptionalistic’ approach, leading to HIV being treated differently in comparison to other infectious diseases that do not emphasize informed consent or pre-test counselling practices (April, 2010; Bayer & Fairchild, 2006). As a result, these arguments have suggested that, rather than operating as a means to decrease HIV-related stigma, voluntary approaches may unintentionally position HIV as being socially and, therefore, morally different from other infectious diseases, representing a potential barrier to care (De Cock, Mbori-Ngacha & Marum, 2002) – particularly among socially vulnerable and disadvantaged populations.

While a majority of the men in this study report having ‘taken up’ messaging regarding the importance of regular HIV testing, many men also have ‘taken up’ so-called ‘exceptionalistic’ perspectives on HIV testing that might differentiate HIV from men’s other health-related practices and experiences. The data from the current study also reveal that many men either avoid testing or experience the effects of HIV-related stigma when they engage in testing, highlighting how the internalization of HIV-related stigma influences men’s capacity to voluntarily access testing services. However, stigmatization did not appear to be concentrated exclusively within the most ‘vulnerable’ or ‘disadvantaged’ groups of men (e.g., men experiencing vulnerabilities, such as queer-identified and/or street-entrenched men). For example, many men from ‘privileged’ heterosexual identities (e.g., middle or upper class) described how societal expectations related to their sexual health negatively influenced their experience with HIV testing. These findings underline the extent to which heterosexual, masculine ‘privilege’ is continuously ‘at stake’ and, ultimately, how HIV testing ‘disrupts’ dominant masculine ideals that tend to prescribe stoicism, independence and lack of care in (sexual) health-seeking practices (Connell, 1995; Courtenay, 2000a & 2000b). These findings also underscore how voluntary testing continues to be positioned as a ‘non-heterosexual’ or risk-based concern (e.g., drug use) that does not include heterosexual sexual activity, thereby corroborating previous theoretical and empirical work (Knight et al., 2012a)

indicating that heteronormative masculine expectations may remain entrenched in normative discourse regarding HIV testing, thereby also serving to negatively impact the health and social practices of straight-identified men.

### **3.4.2 Ethical dimensions of routine testing**

Routine approaches to HIV testing have also been criticized in the previous literature, with some worrying HIV-related stigma could be (unintentionally) exacerbated within these approaches – particularly among already vulnerable populations. For example, some have suggested that routine HIV testing approaches will unfairly disadvantage population sub-groups (e.g., gay and bisexual men; people who inject drugs; Black people) (Smith, 2011; Powers & Faden, 2006). Others suggest that decontextualized approaches to routine testing approaches fail to appreciate and consider the social conditions in which individuals live and experience HIV-related issues and risks – and that this may inadvertently increase HIV-related stigma (Durojaye, 2011; Kippax, 2006).

While theoretical work in this area has traditionally conceptualized clinical interventions as having little transformative capacity beyond the individual level (McLaren, McIntyre, & Kirkpatrick, 2010), these data corroborate some arguments (Knight et al., 2014a; Knight et al., 2014b; Knight et al., 2012a) suggesting social processes associated within clinical encounters have the potential to transform social structures related to HIV and stigma. These data, for instance, highlight that, under the right conditions, a routine offer may provide transformative opportunities for individuals to reconceptualise expectations pertaining to HIV and HIV-related stigma. For example, many men in the current study indicated that the routine testing approach could be helpful in both reducing barriers perceived to be associated with HIV stigma, as well as serve to diminish some of the external (stigmatizing) conceptions that HIV testing is a so-called ‘exceptional’ experience.

The findings from the current study highlight how (mis)interpretations of universal, routine practices may serve to (unintentionally) burden already disadvantaged population subgroups. Men’s interpretations of routine testing practices as being ‘targeted’ have

important consequence for ethical practices associated with a routine offer. For example, from a social justice perspective, stereotyping is morally problematic and socially unjust (Powers & Faden, 2006). For instance, within Powers & Faden's (2006) theory of social justice, dimensions of respect positions all individuals as requiring equal moral concern. Given this premise, discrimination based on stereotyping (e.g., related to: gender, sexual identity, physical appearance) is morally problematic and socially unjust. In the context of the current study, these data highlight the potential for routine testing to be perceived as conferring respect to everyone in that it aims to be universal and avoids 'othering'. These data also provide evidence substantiating arguments that some ethical concerns related to routine testing can be alleviated or pre-empted by implementing succinct and robust consent processes within clinical protocols (Wahlert & Fiester, 2011; Meera & Sreeram, 2007). For example, while men's narratives positioned the routine offer as having the capacity to be interpreted as a form of stereotyping, when sufficiently explicated, the universal dimension of a routine offer diminished these concerns; as a result, by sufficiently explicating the universal dimension of a routine offer, offers of routine testing can represent socially just practices.

### **3.4.3 Ethical and empirical implications for the field of population and public health**

While these findings underline the extent to which HIV is acknowledged by men to be a manageable health condition (e.g., in the context of HAART), the data also reveals that HIV remains a highly stigmatized social condition. These empirical findings present important issues to consider when analyzing the relative merits of both voluntary and routine approaches to HIV testing. For instance, these findings (re)emphasize the "upstream" influences of unjust social and structural hegemonies (e.g., dominant masculine expectations about sexual health; societal 'norms' that stigmatize HIV). From a normative perspective, the advancement of routine testing practices cannot be justified exclusively based on economic cost-benefits analyses or the capacity to increase effective HIV case finding efforts. Instead, for example, from a population and public health ethics perspective, concerns pertaining to the rights and values associated with individuals should be addressed in light of the interests of the broader public and collective (e.g., an

infectious disease should be seen as something that affects the whole group, not just an individual) (Dawson, 2011). While a broad consensus in articulating the specific framework in population and public health ethics has yet to be reached, a key aim is (generally) the advancement of social justice and health equity. For example, as HIV is distributed on a social gradient, efforts to remediate (e.g., “level up”) are ethically justifiable (Dawson, 2011). As such, in the interest of health equity and social justice, ongoing efforts (within and beyond the health sector) should also continue to attend to the social structures influencing HIV-related stigma (e.g., Powers and Faden, 2006).

The current study therefore offers empirical-normative techniques to advance normative theorization in this substantive area. The generation of evidence in population and public health ethics has a distinct set of implications for various potential biases, generalizability issues, as well as the normative assessments of various “kinds” of evidence. Moreover, empirical approaches to population and public health ethics face an important task of identifying what types of empirical evidence needs to be developed, and how that data should be assessed to provide philosophically and empirically robust moral conclusions.

In paralleling some of the discussions pertaining to the field of empirical bioethics, I argue that an empirical PPHE will be most helpful at advancing normative-empirical inquiry by actively engaging in the generation of new data (e.g., as demonstrated by the current study). Those working within the field of population and public health ethics have already been at least *considering* evidence; therefore, those wishing to advance empirical approaches to population and public health ethics could benefit by actively integrate empirical research and normative analysis. As implied by the current study, this research agenda suggests a process in the generation, and constant re-evaluation, of ethical imperatives in population and public health: the normative informs the empirical questions to be asked; the answers to those questions demand critical reflection on the validity of the original norm; and so on. In doing so, empirical approaches to population and public health ethics can meaningfully engage with normative theory that ‘moves beyond’ highly individualistic bioethics, as well as consequentialist approaches that prioritize population-level health outcomes over other lived and human experiences.



#### **3.4.4 Strengths, weaknesses and future research**

The current study has several strengths and limitations. For example, the composition of the study sample is not ‘representative’ of all young men in Vancouver and as such is not generalizable to all young men’s experiences. The heterogeneity of the sample, however, provides opportunities to explore a diverse set of experiences pertaining to HIV stigma and HIV testing experiences. Future research should seek to expand understandings of how heterogeneous and diverse social identities (including intersecting vulnerabilities, such as low-income, racialized and queer-identified men) have the capacity to deploy agentic practices within clinical encounters, as well as how experiences with testing (including HIV stigmatization) are contextually contingent (e.g., related to technological features of the test, such as rapid testing; social-relational power dynamics within clinical encounters). For example, important ethical criticisms of routine testing have suggested that patients may feel pressured into testing (e.g., depending on how testing is presented by their clinician) and that socially vulnerable individuals may be especially likely to feel pressured (e.g., given the influence of clinician-patient power differentials) (Rennie & Behets, 2006). Moreover, as various public health practices are advanced based on ‘public’ values (e.g., solidarity), future research should seek to determine the various normative relational (e.g., based on notions of reciprocity or solidarity) and/or individual (e.g., obligations they feel they have to themselves) reasons that serve to influence men’s ‘autonomous’ decisions to voluntarily seek a test and/or accept/decline and routine offer. While the current study is limited in its capacity to illuminate these complex issues, future empirical-normative research could address these concerns.

## Chapter 4

### **An Empirical-Normative Analysis of Young Men's Discourse Regarding HIV Testing Practices**

#### **4.1 Introduction**

Within and across many global settings, voluntary HIV testing participation rates among young men remain disproportionately low compared to other population subgroups (Shoveller et al., 2010; Knight et al., 2012a). Given the public health imperative to enhance HIV testing rates among those unaware of their seropositive status, young men represent a population of particular importance as expanded HIV testing initiatives unfold (e.g., scaling up of routine HIV testing practices). Despite the clinical and epidemiological rationale for expanding testing among population subgroups, such as young men,<sup>10</sup> some scholars have expressed concern that practices to enhance HIV testing uptake may not sufficiently align with values and principles associated with applied medical ethics that emphasize individual freedoms (e.g., patient autonomy) and the limits of State action (e.g., paternalistic or coercive public health practices and policies) (e.g., see: Vonn, 2012; Smith, 2011; Csete & Elliot, 2006; Gostin, 2006). Alternatively, emerging theoretical work has argued that public health interventions, including HIV testing initiatives, ought to be subject to normative inquiry that considers 'public' values. This emerging body of literature reflects on how relational concepts (e.g., solidarity; reciprocity; health equity) also represent important considerations within

---

<sup>10</sup> HIV testing provides opportunities to link individuals to treatment regimes using highly active anti-retroviral therapy that can effectively prevent disease progression among seropositive individuals *and* decrease the likelihood of onward disease transmission to uninfected partners through the suppression of viral loads (Montaner et al., 2010).

public health (e.g., see: Dawson, 2010; Dawson & Jennings 2012; Dawson & Verweij, 2012; Prainsack & Buyx, 2011; Baylis, Kenny & Sherwin, 2008). Nonetheless, while this growing body of literature has provided much theoretical guidance on how these concepts should inform the practice of public health, including policy and decision-making processes, the extent to which relational normative considerations may (or ought to) inform and shape the health-related practices of the ‘public’ remains less clear (Dawson & Jennings, 2012).

#### **4.1.1 Young men and HIV testing**

Traditionally, low HIV testing participation rates among young men (as compared with the practices of older men or of women) has been linked to various social and structural influences, including masculine expectations related to sexual health that differentially limit their engagement with health-promoting practices (Knight et al., 2012a, 2012b; Oliffe et al., 2012; Shoveller et al., 2009 & 2010; Duck, 2009). For example, getting tested for sexually transmitted infections (STI) or HIV can be perceived as potentially emasculating experiences for young men (Knight et al., 2012a & 2012b; Duck, 2009), exposing them to clinical encounters in which their sexuality, sexual identity and sexual behaviour may be ‘interrogated’ and, in some situations, their bodies ‘inspected’ (e.g., genital exams) (Knight et al., 2012b; Shoveller et al., 2010). While some research has also identified factors that may ‘motivate’ men to seek testing (e.g., a sexual experience they consider to be ‘high risk’; the beginning or end of a sexual relationship; experiencing symptoms) (Katz, Swanson & Steckler, 2013; Shoveller et al., 2010), there has been very little empirical research regarding the extent to which young men’s HIV testing practices may be influenced by normative considerations, including out of notions of responsibility/obligation to Self, as well as various relational considerations to Others.<sup>11</sup>

---

<sup>11</sup> The term ‘Other’ has been widely used in the humanities and social sciences scholarship – as well as in the field of population and public health – to acknowledge and explain perceived differences (and similarities) between the Self and the Other. For

#### 4.1.2 The ethics of HIV testing: Individual and relational perspectives

Within the scholarship of bioethics, ethical discussions regarding HIV testing have concentrated on individual-level considerations, with a particular emphasis on the ethical treatment of the patient within clinical encounters (Knight et al., 2014a; Dawson, 2011). For example, within ethical discussions related to the recent expansion of routine testing practices, a dominant set of ethical concerns assert that individuals may feel pressured to accept a test when it is offered (e.g., given the influence of clinician-patient power differentials), and that failure to opt out may be the result of disempowerment and a lack of individual autonomy (e.g., within potentially coercive clinical interactions). This characterization is usually juxtaposed to an autonomous and informed decision to consent to testing (Smith, 2011; Rennie & Behets, 2006). With respect to voluntary testing, the act of *choosing* to voluntarily access HIV testing has been characterized as something that may require a degree of agency beyond the reach of some individuals (Armstrong, 2008).

To date, there appears to have been less philosophical interrogation of how individual ‘acts’ associated with HIV testing may also have normative implications, with the exception of some arguments that assert that individuals have a ‘sexual responsibility’ to know their serostatus so that they can exercise their responsibility to protect their sexual partners (Dixon-Mueller, 2007). These arguments, however, do not appear to fully afford consideration to how various ethical dimensions (e.g., reciprocal obligations; enactments of solidarity) are empirically instantiated and serve to shape the HIV testing practices of the ‘public’ in the everyday world (Knight et al., 2014a).

---

example, it is in reference to the Other that the Self (including actions of the Self) can be identified and understood.

Some theorists have suggested that the majority of the work in the area of HIV prevention and treatment specifically and the field of bioethics more broadly disregards how individuals are influenced by relational normative motivations, such as a shared awareness of mutual interdependences – particularly within the context of infectious diseases (Baylis et al., 2008). In part, this has led to a growing body of theoretical work arguing that relational (as opposed to predominantly *individualistic*) lines of normative inquiry are needed in order to better ‘situate’ individual interests (e.g., autonomy) among features of the broader contextual conditions (e.g., among various social, relational and structural ‘forces’) (Baylis et al., 2008). For example, whereas ‘conventional’ approaches to bioethical inquiry tend to focus on the ability for individual actors to make autonomous decisions, relational conceptualizations of autonomy highlight the role of social and political structures (McLeod & Sherwin, 2000). As such, these theoretical approaches (largely informed from feminist perspectives) argue that normative inquiry within this area needs to evaluate society (rather than the individual) when determining the extent to which an individual can make a theoretically ‘autonomous’ decision.

More recently, some theorists have argued that public health interventions should be considered in light of relational normative ‘dimensions’ that seek to promote health equity through enactments of solidarity or obligations to Others, including those within one’s ‘close’ interpersonal networks, in addition to so-called ‘distant’ Others (e.g., those that are socially or geographically distant). These more recent works present arguments that, in (re)conceptualizing HIV testing as an intervention that seeks to benefit both individuals and populations, various relational and public values ought to be more strongly invoked (Dawson, 2011; Bayer, 2010). This chapter examines how the values and principles pertaining to several tenets of public health (solidarity; health equity; reciprocity) manifest in everyday discursive practices of individuals. As yet, the extent to which values, such as solidarity, reciprocity and health equity, influence the ‘autonomous’ decisions or health practices of individuals and population sub-groups (e.g., young men) remains largely unknown. The aim of this chapter is therefore to examine the normative discourses of young men regarding their decisions and motivations to voluntarily access HIV testing and to accept/decline a routine HIV test

offer. This study seeks to explore the ways in which various values influence men's experiences with HIV testing, rather than to assess the 'validity' of their HIV testing beliefs and/or attitudes. Finally, the empirical results of this discourse analysis will be discussed in light of the ongoing theoretical work in this area.

## **4.2 Methods**

### **4.2.1 Methodological orientation**

The methods and techniques used in this study are informed by a critical discourse analysis (CDA) (Fairclough, 2003 & 1995) of a qualitative data set (in-depth, semi-structured interviews) collected with young men, which posits that discourse (in this case, the discourses of young men pertaining to their HIV testing practices) reflects *population-level, social* phenomena and transcend individual-level relational interactions and decision-making processes (Fairclough, 2003). By employing a CDA approach, it becomes possible to examine how empirical data gathered through in-depth interviews with young men regarding their HIV testing *experiences* might be influenced by broader systems of knowledge and various structural features of power relations (e.g., those stemming from the expectations of heterosexual patriarchy), rather than solely 'describing' their attitudes, preferences and beliefs (including moral preferences) regarding various testing practices.

Drawing on methods and techniques from CDA, the aim of this study is to distil contextualized and normative representations of solidarity, health equity and reciprocity in young men's discourses (Fairclough, 1995), and how these meanings may influence young men's health-related practices (e.g., HIV testing practices). Specifically, I employ a Faircloughian (1995) method of CDA that focuses on: various features of the text, such as grammar and word choice; the context in which the discourse is produced and practiced, such as the audience in which the discourses are produced and deployed; and the broader societal influences, such as various historical, socio-political, economic and institutional contexts from which various discourses emerge. By employing CDA, I seek to identify how various normative considerations are identified and operationalized (e.g., as young men's health practices are discursively justified as 'ethical') (Chouliaraki &

Fairclough, 1995), as well as how various normative discourses may influence the HIV testing practices of young men more broadly, as a social phenomenon.

#### **4.2.2 Data collection techniques**

Ethics approval was obtained from the University of British Columbia to recruit and interview young men ages 18-24 according to the following recruitment and interview procedures. Participants were recruited through the use of posters in clinical (e.g., youth sexual health clinics) and non-clinical (e.g., bus stops; youth centres) settings frequented by young people, as well as through online advertising (e.g., Facebook Adverts; Craigslist volunteers' webpage). A purposive sampling strategy was employed in order to maximize an array of perspectives among socially diverse population sub-groups of young men, including across various sexual identities, ethnicities, ages, and testing experiences. Men from the At-Risk Youth Study (ARYS) (see: Wood et al., 2006), a study that consists of a prospective cohort of street-involved young people who have previously indicated they used illicit drugs, were also invited to participate. Prospective participants contacted the research office via telephone, email or in-person to screen for eligibility and to schedule an interview. Eligibility criteria included: being or having previously been sexually active with another person; being between the ages of 18-24; identifying as a man (including both cisgender<sup>12</sup> and transgender men); having previously tested or considered HIV testing; and having the ability to speak and understand English.

Audio-recorded interviews took place in research offices between June and November 2013. Before starting the interview, interviewers explained the purpose of the study and reviewed with participants a written informed consent form. Interview guides (see Appendix A) were semi-structured and in-depth in order to elucidate a variety of young men's experiences with voluntary and routine testing. Specifically, interview questions

---

<sup>12</sup> Cisgender refers to those individuals whose biological sex aligns with their gender identity; for example, a biological male who identifies as a man is referred to as being cisgender.

addressed various topics related to HIV voluntary and routine testing (e.g., experiences with deciding to test), as well as their reasons for not testing under either voluntary or routine testing regimens. Participants were also asked to describe the social contexts in which their decisions to test (or not) took place (e.g., location; comfort levels; topics; tone of conversations and reactions of their health care providers), as well as the various responsibilities or obligations they feel they have to themselves, as well as other young men may have to others (e.g., to their sex partners). Participants also were asked to describe how they perceived various socio-cultural and structural conditions (e.g., gender norms; community expectations regarding young men's sexual health-related practices) might influence their ability to make an autonomous decision regarding HIV testing. All participants received a CDN\$25 honorarium. Participants also completed a socio-demographic questionnaire (see Appendix B).

#### **4.2.3 Data analysis techniques**

Before describing the analytic approach I employed, it is important to explicate how the techniques used in this analysis reflect a set of assumptions and that this analysis cannot fully suspend the subjective biases espoused by myself as the researcher and data analyst. Acknowledging this limitation is particularly important within the context of a CDA in which efforts are explicitly advanced to interrogate how discursive strategies are employed to legitimate various oppressive structural and social inequalities. Indeed, a CDA is in itself "...primarily interested and motivated by pressing social issues..." in which the researcher has a set of vested interests (van Dijk, 1993, p. 252). Nonetheless, efforts were advanced to reflect on how my presentation of evidence can offer partial glimpses into so-called 'facts', but that these facts are indeed value-laden. In order to provide a starting point and to reflexively engage with my own biases (e.g., values or beliefs) on the production of data and how normative assumptions are drawn on the interactions with the empirical, see Appendix C for a set of issues regarding the broader meta-methodological issues that seek to advance a transparent and explicit discussion (as outlined by Molewijk & Widdershoven, 2012).



To begin my analytic work, interviews were transcribed, accuracy checked and uploaded to NVivo 10<sup>TM</sup> to manage the data analysis. The texts (i.e., interview transcripts) were analysed to explore various discourses (e.g., subverting and/or contesting discourses) (Fairclough, 2003) by asking two key analytical questions: (a) What dominant discourses do men employ to morally justify their HIV testing practices?; and (b) How do men's discourses elicit individual-level considerations (e.g., concerns about Self) or relational considerations (e.g., considerations for Other(s)) with regards to their testing practices?

The interview transcripts were read and re-read using these two analytical questions as a rubric, employing constant comparative techniques (Strauss & Corbin, 1998) to develop an initial set of codes, and to identify broad themes across interviews, paying special attention to the discourses that illuminated men's various ethical 'motivations' for testing (e.g., voluntarily seeking a test and/or accepting a routine offer). Codes were then iteratively developed by using an open coding approach within the interview transcripts and avoiding, where possible, preconceived theoretical constructs. As data collection and analysis progressed, constant comparative techniques were used to test emergent ideas about the connections between existing theoretical concepts (e.g., relational considerations about testing) and to identify new themes. An axial coding schematic was then organised into 'trees' to group the open codes into abstract conceptual categories. In doing so, this analysis is based on both an inductive approach to develop an initial coding schema (e.g., 'tree' and 'child' nodes) (Thomas, 2006), as well as a deductive approach in which the findings were compared and contrasted to the existing theoretical and empirical literature base (e.g., masculinities theory; ethical discussions pertaining to voluntary and routine testing; theoretical work related to relational autonomy and solidarity).

The axial codes that I settled upon from this process consisted of the various relational and individually oriented 'reasons' that emerged within an analysis of men's discourses regarding their motivations and decisions to test. Specifically, this consisted of the following codes: (i) *Individual dimensions*: This code includes discourses by participants that incorporate considerations of both the benefits and risks of HIV testing as they relate

directly to the *individual who is considering testing*; (ii) *Interpersonal dimensions*: This code includes discourses that incorporate considerations of the benefits and risks of HIV testing as they relate to *another person or persons* (e.g., sex partners); (iii) *Public dimensions*: This code includes discourses that incorporate the perceived benefits and risks as they relate to the *broader public's interests* (e.g., the interests of the community; public health). After several iterations of the analysis, two conceptual categories emerged: (i) *Considering the Other in deciding to test: Relational considerations*; and (ii) *Autonomy, relationality and individual motivations to test or not test*. Each of those conceptual categories is presented in the findings section of this chapter; quotations from the interview transcripts are used to illustrate specific features of the discourses that featured within each of these two conceptual categories.

#### **4.2.4 Study setting**

The study took place in Vancouver, the largest city located on Canada's Pacific Coast. Vancouver is home to a large and long-standing queer community; the city also has a large population of street-entrenched youth. Within Vancouver, voluntary HIV testing services are available at most specialized and general health care facilities, including: youth and/or sexual health clinics, general medical clinics, as well as through family doctors and emergency rooms. Recently, in 2012, the Medical Health Officer of Vancouver Coastal Health recommended that all primary and acute health care settings routinely offer HIV testing to all adult patients who have not had an HIV test in the last year (Gustafson et al., 2012). While health services in Canada are publicly funded, a monthly premium to the Provincial Medical Services Plan is required of between \$0 and \$66.50 per month (depending on income) in order to access many services (British Columbia Ministry of Health, 2013); however, youth clinics and emergency facilities do not require proof of enrolment in the MSP for services.

#### **4.3 Findings**

In total, 50 young men between the ages of 18-24 years were interviewed (mean age: 21.7). See Table 4 for the socio-demographic characteristics of the sample.

**Table 6. Socio-demographic characteristics of study participants**

<b>Ethnicity</b>	<b>(n)</b>	<b>(%)</b>
Aboriginal	6	12
African-Canadian	1	2
Euro-Canadian	26	52
Latin	2	4
South Asian	0	0
South East Asian	7	14
Middle Eastern	1	2
Other	7	14

  

<b>Living arrangement</b>		
With parents	9	18
With friends or partner	22	44
Alone	7	14
In a shelter or on the street	11	22
In a recovery house	1	2

  

<b>Previously tested</b>		
Never	5	10
One or more	45	90

  

<b>Testing approach experienced</b>		
Voluntary testing	32	66
Routine testing	5	10
Both Voluntary and Routine	8	14
None	5	10

  

<b>Sexual Orientation</b>		
Bisexual	8	16
Gay	7	14
Heterosexual/straight	34	68
Two-Spirit	1	2

  

<b>Gender Identity</b>		
Transgender man	1	2
Cisgender man	49	98

  

<b>Recruitment medium</b>		
Online advertising	23	46
Posters	2	4
ARYS	24	48
Other	1	2

The quotations from participants' discourses are identified by a pseudonym (selected by each participant), supplemented by a brief description of the participant's profile (age; ethnicity; sexual orientation; voluntary and/or routine testing experiences; and number of times tested).

#### 4.3.1 Considering the 'Other' in deciding to test: Relational considerations

In order to understand how young men consider HIV testing practices as constituting and being influenced by various relational normative dimensions, participants were asked to describe the motivations that lead them to seek out testing or accept/decline a routine test offer. Within the "Considering the Other" discourses, a *quid pro quo* 'transactional' discourse emerged across many interviews in which the act of testing was positioned as relational between patient and clinician. Within this discourse, young men described varying levels of autonomy as well as moral or social obligations towards their clinicians, which might influence their decision to get tested for HIV. For example, one young man who was living on the streets at the time of the interview described how he had previously gone to the emergency room to seek treatment for a broken nose. While he had not been offered a routine HIV test at the emergency room, he hypothesized that he would have felt that he 'owed' the health care practitioner a test, as a *quid pro quo* for having treated his broken nose<sup>13</sup>:

Interviewer: And would it change the situation for you at all if the doctor or nurse said, you know, they dealt with your broken nose and they're moving on and they said, 'We now recommend everyone get an HIV test. Do you want to participate today?'

Cocolish: I'd feel very good because they just fixed my nose so I might as well get tested for them. It'd kinda be, like, a balance sorta thing. You fix my nose I'll give you an HIV test. After they did me a favour and fixed up my shattered nose.

Interviewer: Would you feel obliged to do the HIV test?

---

<sup>13</sup> When the interviewer asked Cocolish to describe how he might feel, if he was offered an HIV test *before* being treated for his broken nose, he said he would have been offended and felt angry and probably would have refused the offer to test.

Cocolish: Yeah. I'd feel like I should do it just because they did something for me. So it sorta evens it out I guess. [...] Because I know they probably want me to get it and I know they fixed my nose so I might as well help them out. (22, white, straight, voluntary & routine,  $n=3$ )

Within these transactional discourses, participants also recognized a 'mutuality' within the clinical interactions in which both parties could benefit. For example, Cocolish described how an interaction around HIV testing could provide an opportunity to 'help' his clinician. By agreeing to be tested for HIV, Cocolish situates his decision to be tested as helping his clinician do the job well. He also situates his receipt of medical care ("I know they fixed my nose") within his broader understanding of what is expected of a clinician ("I know they probably want me to get [tested]"). Evident within these 'transactional' discourses is the extent to which men's decision to test turn at least in part on the reciprocal and symmetrical arrangements of 'giving and receiving' (e.g., "You fix my nose; I'll let you test me for HIV"), rather than exclusively for their own self-interest or moral concern for their sex partners. Furthermore, the way this discourse is presented in the interviews reveals a degree of agentic capacity afforded to the 'patient' within this type of transactional discourse that may even exceed the agentic capacity said to be afforded to the clinician – the clinician is positioned as having to fix Cocolish's nose as well as having to ask the question about HIV testing, while Cocolish presents himself as deciding whether to accept the offer of an HIV test (albeit a choice that is viewed in light of his receipt of medical treatment).

Narratives that drew on descriptions of interpersonal social connections tended to position the act of testing as a reciprocal act that is based on a 'reasonable expectation' that others will get tested "if I do". In this discourse, participants described how notions of reciprocity within sexual and romantic relations influenced their decisions to voluntarily seek a test or accept a routine offer. For example, Ion and Robert both described how they expect themselves *and* their sex partners to test based on considerations for their mutual well-being:

It [HIV testing] would – it's the responsible thing to do. There's an expectation that you will care enough about yourself that you will be able to pass that care onto others. So it's a reasonable expectation to have of someone. They would wanna know. [...] To keep us safe. (Ion, 22, Aboriginal, Two-Spirit, routine,  $n=1$ )

After we'd [Robert and his girlfriend] been dating for a couple of months, we kind of had a conversation just about past sexual experiences. And it's always good to go over that and we realized that we kind of hadn't, because neither of us had been sexually active for a little while, like a few months, so it had never really been too much of a concern. And my girlfriend told me at the time, she said that I should go get tested and I fully agreed. And I went to the clinic on [address]. [...] And [the nurse] just said, 'Oh, you're just here for a check-up?' And I said, 'Yeah, I'm just here for the safety of my partner *and*, you know, for myself'. (Robert, 22, Latin American and white, bisexual, voluntary,  $n=1$ )

Thus, within narratives such as Ion's and Robert's, a discourse emerged in which the value of (and for) one's interpersonal social connections positions the act of testing as reciprocal. Testing is aligned with 'reasonable expectations' within social relations. Within these discourses, enactments of 'self-care' were discursively linked with notions of 'mutual care'. For example, Ion's use of the pronoun 'us' underscores how testing practices are implicated within notions of responsibility and care for both partners, where each partner is poised to (mutually) benefit from their own as well as their partners' testing practices. In this discourse, the act of testing was featured as an act that is 'responsible' and 'caring' and something they should do in order to keep *both* themselves and their partners 'safe'. As a result, this sub-set of discourses tended to elicit many of the various theoretical features of social capital, including both the reciprocal and beneficial dimensions that can be derived from caring for Self and Other(s) (i.e., both parties benefit from these social arrangements).

Underscoring the reciprocal features of these discourses, some participants described how interpersonal relations (e.g., shared interests and trust with peers or sex partners) shaped their perceptions about the normative dimensions of HIV testing behaviour. For example, participants who said that they regularly get tested also described how their practices were strongly affiliated with the norms espoused in their social networks that explicitly supported or encouraged regular HIV testing. For example, Kaiser described how he had

previously been involved in a relationship with a man who had stressed the importance of regularly accessing testing among gay men:

I was like seeing this guy for a couple years, and he probably like, he was 29 and I was 21, and I remember one of the first times we hung out he gave me like the talk, of like, listen, you're young, but you need to go do this because so and so's a nurse, and he sees all these young men get AIDS because they don't get tested and they aren't safe, and he was just reaffirming that it was something that he cared about and went and did, and now it's just like a habit for me after that. (Kaiser, 22, white, gay, voluntary,  $n \geq 5$ )

Here, Kaiser reveals the processes that lead him to 'take up' voluntary testing on a regular basis, stemming largely from another man's representations of the socio-historical and epidemiological features of HIV and the positioning of a 'responsible' gay masculinity as one who pro-actively takes care of sexual health (e.g., by regularly HIV testing). Thus, within this subset of discourses, influences of social capital on young men's HIV testing practices were discursively emphasised by the role of social relations and mutual benefits (i.e., to both individuals and collectives). This discourse does not feature the various qualities of relational solidarity (seen in other discourses) in which reciprocal or symmetric power relations are potentially unimportant and not necessarily required (Dawson & Jennings, 2012a; Prainsack & Buyx, 2011).

In other discourse, the act of testing was not portrayed as transactional or reciprocal; rather, some participants positioned HIV testing as a social practice that is embedded in notions of justice and the broader public 'good'. For example, Sam, a young man who felt he was at relatively low risk and thus had never actually been tested (although he had considered it), described how he would respond to and deliberate about a routine offer:

- Sam: If it's recommended, I'd force myself to do it because this is – because I think highly about the recommendations that people give me. And I think about them like – 'Is this for good or is it for bad?' And, and in this case it's for good, so I'll force myself into it. Like, I should do it right away – yeah.
- Interviewer: And tell us a little bit more about why you would think that's for good. Is it good for yourself or is it good for... [interviewer is interrupted by Sam].

Sam: It's good for society as well – not just for me. (Sam, 21, Arab, straight, never tested)

Sam's discourse begins to position his decision to test as an act that will also benefit society. For Sam, his decision to test in the context of a routine offer is driven by both his concern and respect for a clinician's recommendation as well his understanding of his own mutual interdependence with broader society. In doing so, Sam's discourse associates the individual 'act' of testing as also having 'public' meaning and purpose: if he "forces" himself to test – an act that he ultimately constructs as "...good for society as well – not just me" – then Sam's acceptance of a routine offer is one that emphasizes a moral concern for the Other (including the 'distant' Other) without obvious reference to transaction or reciprocity, *per se*. This type of discourse was usually surfaced by participants in explicit ways (i.e., with little ambiguity regarding testing as a practice that *should* be done to benefit the broader community) and often was devoid of descriptions about individual-level benefits. For example, Prometheus described:

I think it's important like, for the population as a whole, all the community, everybody in general is interconnected with, you know, the whole. It's weird, it's like a sexual network. Everybody is connected with each other, right? And the only way for us to eliminate HIV, really, is to have... like, a *collective* effort where *everybody* is tested and *everybody's* in. (Prometheus, 20, Taiwanese, gay, voluntary,  $n=3$ )

As Prometheus' quote illustrates, this discourse linguistically links testing with sympathy and understanding the needs of Others ("everybody") stemming from an awareness of mutual interdependence between Self and Others – both among romantic and sexual partners as well as more broadly with 'distant' Others. This discourse reveals how collective agentic practices (e.g., enactments of solidarity) can have the potential to position HIV testing practices as a social phenomenon with implicit public health benefits. In discourses where solidarity is featured as a normative consideration related to testing practices, individual-level acts are assigned 'public' value and are positioned as being integral to the broader collective's commitment to advancing justice (e.g., the individual-level act of testing is positioned as an important part of the collective's efforts to "eliminate HIV").



### 4.3.2 Autonomy, relationality and individual motivations to test or not test

Within a subset of interviews, participants used discourse to relationally position themselves as dominant males. For instance, a discourse distinct from the previously described relational considerations (e.g., in which obligations or responsibilities to Others were either explicitly or implicitly espoused) emerged across a subset of interviews where participants described how they engage in HIV testing to derive personal benefits, as the following excerpt illustrates:

I've had situations in the past where I've gone in and I've just been for something else and they said, 'Well do you want to do it [HIV test] since you're here?' And I'm like, 'Yeah sure, why not?' [...] But I would say if you're going in to the hospital anyways and you're getting something checked out anyways and they offer it to you, there's no reason not to accept it...short of, really... an *ego* thing. (Smith, 23, white, straight, voluntary & routine,  $n=4$ )

Smith's description underlines how a set of individualistic motivations may be linked with stereotypical representations of male "ego" (e.g., not engaging in testing in order to avoid being perceived of as weak or self-indulgent). Conceptions of hegemonic masculinity that denigrate self-care (operationalized as testing in this case) were often ridiculed overtly in participants' discourses, with (masculine) autonomy and individual choice being positioned as important drivers that motivate individuals to engage in HIV testing. Discourses that primarily featured descriptions of individuality and autonomy were unlikely to invoke descriptions of solidarity, but they did sometimes feature strong portrayals rooted in normative concerns. For example, Billy-Bob described how normative concerns – in his case, a highly masculinized portrayal of competition – 'trump' other concerns (e.g., dominant masculine expectations portraying help-seeking behaviour as weak or feminine):

I just feel like, if you engage in risky business, then you pay the 'troll toll'. I mean, might as well 'buck up', you know, just like go and do it. Just have a clear mind. Whatever it is, it is and there's no going back. [...] If you find out you're clean that's like the best feeling in the world. You do that multiple times you feel like, 'Fuck yeah! Fuck of all of you! I'm cleaner than you fuckers!' And you just love it. (Billy Bob, 20, white, straight, voluntary,  $n\geq 5$ )

As this example illustrates, these discourses can position the act of testing (and being declared ‘clean’) as a highly masculinized virtue. For example, by “bucking up” and “paying the troll toll”, Billy Bob deploys a discourse in which HIV testing practices are positioned as a masculine-affirming practice. Taken in the context of “engaging in risky business” – another (hyper-)masculine virtue – this example positions the act of testing as a ‘manly’ action (e.g., imbued with masculine power references) that he, as a powerful individual, has the autonomy to undertake. The (self) affirmation of his ‘moral superiority’ over others demonstrates a set of relational considerations that appear to be more oriented towards deploying (masculine) power over others than the previously described discourses that emphasized notions of shared interdependence (e.g., ‘self-care’ as ‘mutual-care’).

In light of the very low testing rates among young men, it was not surprising to identify a discourse that featured autonomy and individual motivations to *not* engage in testing. While everyone in our sample indicated that they had *considered* testing (often based on a set of relational considerations, such as beginning a new sexual relationship), a dominant discourse emerged to assert the claim of not needing to get tested because they perceive themselves as being at low risk for HIV (and/or STIs), as the following excerpt from Herbert’s interview illustrates:

Part of me thinks that maybe I need, you know – maybe I should be more rigorous about doing the testing. But part of me also, I’m not sure. Maybe it’s just laziness, I don’t know. [...] If I get tested semi-regularly, that’s not the worst thing in the world. Better than doing nothing. But at the same time, the part of me that, you know, wishes that I was just, you know, a “model” sort of HIV-tester person. I haven’t brought myself to do it for some reason or another. [...] I mean, I wanna say that I would go get tested every time I change partners. [...] And so that’s what I would like to do but like so many things in life, like flossing, I don’t do it every day. Part of me thinks it’s risky but then part of me also thinks that, sort of, taken in context on the whole ‘My sexual behaviour isn’t risky’, and so I don’t know what the appropriate thing is but at least in my mind, that’s kind of what I think of as being the ‘right’ thing to do. (Herbert, 23, white, straight, voluntary, *n*=2)

Herbert’s quote reveals a discourse that resounds with dissonance between being a responsible young man (e.g., “a ‘model’ HIV tester”) against a contextual backdrop in

which dominant masculine norms do not prioritize regular (sexual) health care-seeking behaviour among young men. Within this discourse, a “model HIV tester” is positioned as one who takes up and enacts responsible behaviour *and* is the kind of man who can contest dominant masculine norms that de-emphasize sexual health-seeking practices. A thread of this discourse moves beyond dissonance, to more fully reflect a disregard for Others, in favour of preserving one’s autonomy. For example, John explained why he decided *not* to get testing, despite being asked by his girlfriend to seek testing before beginning a sexual relationship together:

When I started that relationship she [my girlfriend] was a virgin and she wanted me to do the test. So, I kind of felt like I had to do it. I was just going to do it because she wanted me to do it. But then, ...I didn’t do the test. [...] I am sure that I don’t have HIV.... (John, 23, Latin American, straight, never tested)

As this example illustrates, in this discourse, it is possible to acknowledge a level of obligation to Others, but that this relational concern can be neutralized – so that an ‘autonomous’ decision based on one’s own self-interest can be realized. John’s story underlines how conceptualizing HIV testing as ‘non-relational’ (i.e., of no normative consequence to Others) can erase from the discourse notions of obligations to Others – thereby potentially erasing concerns (and actions) regarding broader social injustices (e.g., unequal gender power relations within the heterosexual patriarchy).

#### **4.4 Discussion**

These findings provide a rich opportunity to explore the various influences on men’s decisions to voluntarily seek testing or accept/decline a routine offer. Specifically, these data highlight the various normative discourses related to men’s decisions to test, including those that feature relational considerations (e.g., reciprocity; social capital; solidarity), as well as those featuring more individually based imperatives (e.g., notions of responsibility; obligations towards Self).

#### **4.4.1 Relational discourses regarding testing**

Within the relational discourses pertaining to men's HIV testing practices, several different types of discourses emerged. First, a transactional discourse emerged among a sub-set of interviews in which the decision to test featured an arrangement of 'giving and receiving' – between men and their clinicians or between men and their sex partner(s). The act of testing was positioned as 'self-care', while concurrently constituting qualities of 'mutual care' (e.g., concern for their sex partners' well-being and/or their clinicians recommendations). Within the reciprocal discourses, features of young men's social capital (e.g., their social networks) also emerged as an important influence on their normative motivations/reasons for testing. In this discourse, men recognized (even lauded) their membership within a broader collective, positioning their decision to get tested as a moral consideration, thereby revealing how individual and collective agentic practices relate to recent conceptualization(s) of the normative concept of solidarity (Dawson & Jennings, 2012). As Dawson and Jennings (2012) describe, individuals acting on the basis of solidarity do so not for individual benefit (necessarily), but rather for moral concerns for Others. Thus, these discourses were differentiated from the reciprocal discourses, which featured the influences of mutual (and reciprocal) benefits (i.e., to both individuals and groups). In the current study, discourses related to solidarity emphasize considerations of justice and position testing as a 'public' act (e.g., for the 'greater good' of society) – an act that does not feature direct obligations but remains deeply 'social'.

The findings featuring relational discourses offer a degree of credibility to public health actions that rely (empirically) on or are (normatively) founded upon relational values. Indeed, these data underscore the extent to which bioethical theory that disregards relational considerations may lack a sufficient understanding of how individuals make autonomous (yet inherently relational) decisions for the 'common good', rather than based solely out of notions of self interest. Indeed, these findings suggest the need to continue moving normative theory within population and public health ethics away from framings that tend to disavow how thoroughly – from an empirical perspective – relational all individual choices and actions tend to be.

#### **4.4.2 Individualistic discourses regarding testing**

A set of ‘individualistic’ discourses also emerged, focusing on individual-level considerations (e.g., ‘costs’ and ‘benefits’ for Self) and their influences on men’s decisions to test. For example, some participants described how they would seek testing in spite of various social and structural constraints (e.g., HIV-related stigma; normative masculine expectations that do not emphasize health-promoting practices among men; opportunities to engage with the health care system and routine testing) for their own self-assurance (i.e., that they did not have a disease). This discourse emphasized the instrumental value of testing (e.g., the utility of knowing one’s status), while downplaying relational considerations (e.g., mutual interdependencies with ‘Others’).

Gender relations and men’s various (hyper)masculine identities also tended to feature more predominately within the individualistic discourses. For example, the men frequently deployed a masculinized discourse about individual autonomy (i.e., personal strength and freedom to make ‘autonomous’ decisions) to alleviate the extent to which HIV stigma presented a barrier to testing. Instead, the act of testing was (re)positioned as a masculine-affirming practice in which potentially feminizing traits (e.g., help-seeking) were transformed into masculine traits (e.g., being ‘cleaner’ than everyone else). In doing so, participants were able to ‘attain’ some of the moral obligations they feel towards themselves, while maintaining (or attaining) the ‘virtuous’ qualities they associate with hyper-masculinity.

#### **4.4.3 ‘Ethics as structure’**

The findings from the current study underscore the extent to which we must “see and accept the essentially ‘social nature’ of the ethical” (Dawson & Jennings, 2012, p. 76), particularly with regard to our understanding of various relational and individual imperatives to test. For example, the findings of the current study reveal how young men’s HIV testing practices are deeply influenced by social, structural *and* ethical influences. For instance, the moral considerations described within the current study reflected other social-structural phenomena, such as dominant and normative masculine expectations about men’s sexual health-related practices. Moreover, these findings show

how ethical considerations pertaining to testing practices are implicated within various constructions of masculinity, including instances in which ethical considerations (re)aligned men's conceptualizations of normative masculinity to also include qualities more commonly associated with femininity (e.g., care and compassion to Others, including 'distant' Others). As a result, these findings emphasize the need for more robust theory that positions normative dimensions and ethical considerations as being dialectically integrated within the social and structural influences on individual and collective health-related behaviour (i.e., 'ethics as structure'). Conceptualizing the influences of 'ethics' as being dialectically integrated within 'structure' may provide opportunities to more meaningfully advance both ethical public health policy as well as the field of population and public health ethics more broadly. For instance, in conceptualizing 'ethics as structure', we can more easily step away from the 'dogma of autonomy', which tends to be dominate within conventional approaches to bioethics (as outlined by Dawson (2010)), while still featuring individual autonomy as important and inherently relational.

Importantly, the empirical-normative approaches employed in this study are distinct from the empirical work advanced within the realm of descriptive ethics (i.e., an area of ethics that seeks to describe *what is* the case, rather than what *ought to be* the case). Instead, the current study and normative theorization positions empirical evidence as a means to determine various *experiential* dimensions of HIV testing practices, rather than providing basic descriptions of what men happen to believe and/or do. Within this approach, experiential data is assessed to determine the extent to which it aligns with various normative theories and/or arguments (e.g., the extent to which the data can substantiate various premises within ethical claims in this area). These techniques offer opportunities to distil how various public health actions differentially influence the testing experiences of young men (i.e., positively or negatively) – including how their own normative motivations are dialectically integrated within and influenced by these practices. In doing so, this work moves beyond some of the conventional orientations of bioethics in which the social dimensions and experiences of individuals are often 'presumed' rather than being empirically determined (and/or normatively assessed).

#### **4.4.4 Implications for the practice of public health and future research**

These findings raise important questions to consider within the practice of public health. For example, do the various normative discourses related to testing (e.g., individualistic and/or relational) have different implications for health equity and/or social justice? If so, is there a public health impetus to ‘advance’ efforts to encourage young men to ‘take up’ either relational or individualistic values in their HIV testing practices? Below, these and other implications are discussed among the existing literature in these areas.

From a health equity perspective, these data underscore how a public health reliance on traditional approaches to HIV testing (e.g., voluntary approaches) are unlikely to motivate men to test based on notions of solidarity (e.g., deciding to seek testing based on a recognition of mutual interdependences). Data in the current study show that many young men remain unmotivated to seek testing, despite believing that they *ought to* be testing more frequently. And, while routine HIV testing appears to be perceived of as a social (and institutionalized) catalyst for solidarity by some young men (and therefore to also potentially promote the conditions for advancing justice), most of the young men that we interviewed felt at ‘low risk’. And, unfortunately, the findings of the current study do not provide sufficient insight into how best to parlay conceptions of solidarity into individual testing behaviour.

Two additional implications surfaced concerning solidarity, relationality and autonomy. First, it is important to underline that enactments of solidarity are not necessarily or inherently ‘just’ (Krishnamurthy, 2013); for example, relational accounts of solidarity do not necessarily accord a ‘goal’ (e.g., one of social justice) of any particular leaning (Dawson & Jennings, 2012). Taken more clearly, there is nothing inherently ‘just’ about acts of solidarity, so they ought not to be featured as constituting intrinsic value or be positioned as any sort of moral arbiter; rather, it should remain the responsibility of public health to carefully ensure that policies and practices that ‘draw’ on notions of solidarity do so in ways that align with ‘other’ values in population and public health ethics, including careful considerations of health equity, social justice and (relational) autonomy. Secondly, testing based on individually oriented motivations also feature

strong public ‘value’ – an untested young man unaware of his sero-status may have negative implications for public health, regardless of his motivations to test. And, obviously, men who want to test ought to be afforded the opportunity to do so – in accordance with some of the most basic principles of applied medical ethics (e.g., justice; non-maleficence; beneficence; autonomy) and population and public health ethics (e.g., social justice).

From a normative perspective, there is indeed value in encouraging individuals to ‘move beyond’ individualistic actions with regard to issues that are inherently ‘relational’ (e.g., infectious diseases; vaccination programmes) and in which there is (empirically derivable) implications for shared interests (and thus, perhaps, various individual and collective duties and/or responsibilities). Future empirical-normative inquiry exploring how public health efforts can (or ought to) encourage individuals to ‘take up’ relational actions may be an important task for those within population and public health ethics – particularly if we are to meaningfully move beyond the individualistic orientations dominating the majority of normative inquiry in this substantive area.

#### **4.4.5 Strengths and limitations**

This study has several strengths and limitations. First, it is important to acknowledge that men’s experiences with health-related practices cannot be ‘essentialized’ to one discrete social identity, just as there is a need to reflect on how other, multiple and intersecting identities influence young men’s experiences. While the current study attempted to engage with these challenges by describing an array of social dimensions and structural contexts, given limitations associated with the study design, it is not possible to fully distil these influences. While the composition of the study sample reflects a diverse set of men within Vancouver, it is not meant to be ‘representative’. The findings are not claimed as generalizable to all men who embody various social identities, but they do include discourses regarding experiences and social processes that reveal the various individual and relational normative considerations that influence their decisions to test.



# Chapter 5

## Discussion and Conclusion

### 5.1 Overview

Taken as a whole, the current dissertation offers important insights pertaining to the empirical and theoretical gaps within the ethical discussions of HIV testing. Given the empirical findings and normative conclusions described within this dissertation, there are a variety of implications for public health policy and clinical practices related to HIV testing. These implications may be especially salient to consider amid the expansion of routine testing efforts on a global scale. The techniques and conceptual approaches used within this dissertation also may inform methodological and theoretical advances in empirical-normative inquiry within the realm of population and public health ethics.

### 5.2 Summary of findings

Chapter 2, *Advancing population and public health ethics regarding HIV testing: A scoping study*, provided insights into the breadth, range and foci of the dominant ethical issues pertaining to various HIV testing approaches within the peer-reviewed literature. Findings from this chapter reveal how ethical claims pertaining to routine and voluntary testing are frequently premised on assumptions that are largely unsubstantiated empirically. Specifically, these findings reveal a set of conflicting arguments claiming that HIV-related stigma will be either exacerbated or attenuated with either voluntary or routine testing without sufficient evidence and, in general, without a strong theoretical grounding. These findings also reveal how theory pertaining to structural and agentic influences could be put to work using empirical data.

Chapter 3, *HIV stigma and the experiences of young men with voluntary and routine HIV testing: An empirical-normative inquiry*, used empirical data gathered in Vancouver, Canada, to examine whether and how routine and/or voluntary testing might attenuate or

exacerbate HIV-related stigma among young men. These findings revealed how HIV-related stigma can be internalized (and thus potentially exacerbated) through the act of voluntarily accessing testing. These findings also highlighted how (mis)interpretations of universal, routine practices may serve to (unintentionally) burden already disadvantaged population subgroups, particularly through stereotyping. The data also provided evidence to show how some ethical concerns related to routine testing could be alleviated or preempted through a variety of strategies, including the use of succinct and robust consent processes within clinical protocols that sufficiently explain the universal dimension of a routine offer.

Chapter 4, *An empirical-normative analysis of young men's discourse regarding HIV testing practices*, sought to determine the various normative 'motivations' that men advance within their discourses pertaining to their decisions to voluntarily access testing or to accept/decline a routine offer of HIV testing. The overall discourse reflected in the interview set was organized into two conceptual categories: (i) *Considering the Other in deciding to test: Relational considerations*; and (ii) *Individual (and autonomous) reasons to test or not test*. Within and across these categories, several dimensions emerged that revealed: (i) *Individual dimensions*, including discourses that incorporate considerations of the benefits and risks of HIV testing as they relate directly to the *individual who is considering testing*; (ii) *Interpersonal or relational dimensions*, including discourses that incorporate considerations of the benefits and risks of HIV testing as they relate to *another person or persons* (e.g., sex partners); as well as (iii) *Public dimensions*, which includes discourses that incorporate the perceived benefits and risks as they relate to the *broader public's interests* (e.g., the interests of the community; public health). These empirical findings were discussed in relation to the philosophical literature in this area, to interrogate whether the implementation of HIV testing can be realized as an enactment of solidarity.

### **5.3 Implications for population and public health ethics regarding HIV testing and the practice of public health**

The findings from this dissertation provide important insights into some of the theoretical and empirical ‘gaps’ regarding the ethical implications of various HIV testing practices. Specifically, while *young men* represent a population of particular concern with respect to HIV testing practices (Knight, Shoveller, Oliffe et al., 2012a; Knight, Shoveller, Oliffe, et al., 2012b), empirical evidence and normative consideration has not tended to emphasize the ethical underpinnings of interventions and their effect on young men’s experiences pertaining to HIV testing (Jurgensen et al., 2013; Durojaye, 2011). These findings reveal how a contextualized and gendered analysis of their HIV testing-related practices and experiences can distil how various individual, social and structural influences interact to shape their HIV-related practices and experiences. As such, these findings (re)emphasize the importance of contextualizing normative assessments through empirical methods in order to advance a larger degree of utility in practice (e.g., the capacity to develop normative theory and assessments that are applicable and prescriptive). As a result, this dissertation underlines the importance of empirical-normative inquiry in population and public health ethics that has previously been advanced in the realm of empirical ethics. For instance, scholars have previously argued that bioethics was overly deductive in argumentation, and that the prescriptive potential of bioethical frameworks were derived solely on ‘rational’ justifications of ethical theories abstracted from reality (Hedgecoe, 2004; Lopez, 2004). Similar to the dissatisfaction previously expressed by practitioners, these critiques argued that bioethics over-focused on developing and justifying ethical theories, with little attention to the practical utility or contextual conditions within patients’ and practitioners’ everyday and actual experiences.

While much of the previous literature in this area has rested on the assumption that various HIV testing practices may attenuate or exacerbate HIV-related stigma (e.g., Jurgensen, Sandoy, Michelo & Fylkesnes, 2013; Public Health Agency of Canada, 2013; Wynia, 2006), these arguments are frequently premised on arguments related to stigma that suffer from significant empirical and theoretical limitations and/or ‘gaps’ (as described in the findings and discussion in Chapter 2). The current dissertation provides

an analysis of HIV-related stigma that conceptualizes HIV-related stigma as a product of systemic social and structural inequalities (Parker & Aggleton, 2003). In doing so, these findings provide evidence regarding the various social processes that can and do influence how HIV stigma is either attenuated or exacerbated within various HIV testing practices/experiences. Indeed, when the universality of the routine offer is sufficiently communicated (e.g., avoiding ‘targeted’ practices – whether ‘perceived’ or ‘real’), these findings support normative arguments arguing that routine approaches can result in the reduction of HIV-related stigma by ‘normalizing’ HIV among young men.

The findings from this dissertation also have implications for better understanding how various normative influences feature within men’s ‘autonomous’ decisions to test. For example, within both Chapters 3 and 4 it is clear that young men’s decisions to test are strongly influenced by various contextualized social and structural conditions (e.g., the various masculine dispositions that they occupy (or seek to occupy); interpersonal relations, including with sex partners and clinicians; moral concerns to Self and Others; barriers to testing associated with HIV-related stigma). These findings underscore the importance of continually conceptualizing young men’s autonomy as relational due to men’s multiple and dynamic identities that are socially shaped, inseparable from the broader social and structural conditions (Baylis et al., 2008). Importantly, these perspectives do not position autonomy as an unimportant ethical principle; rather, relational understandings of autonomy offer opportunities to enhance a contextualized resolution and understanding of individual autonomy – one that seeks to the fullest extent possible to facilitate clinical interactions (including communication) that recognizes the various social and structural conditions/influences as ‘mattering’ to how individuals do (and should) choose (Entwistle, Carter, Cribb & McCaffery, 2010). The findings in this dissertation empiricize and underscore these theoretical influences, including how young men’s various masculine dispositions are dialectically interrelated to how they feature normative discourses regarding Self and Other.

These findings have important implications for the practice of public health regarding HIV testing and young men. From a health equity perspective, despite the overall support

for routine HIV testing practices within this dissertation, it remains unlikely testing approaches themselves can meaningfully address the social gradient pertaining to HIV. For example, in order to successfully ‘combat’ HIV, public health approaches will require both the remediation of ‘unjust’ social structures that contribute towards the inequitable distribution/concentration of disease, in addition to engaging sero-positive individuals into the HIV continuum of care. Taken as a whole, the findings of the current dissertation therefore (re)emphasize the importance of “upstream” influences flowing from unjust social and structural hegemonies (e.g., dominant masculine expectations about sexual health; societal ‘norms’ that stigmatize HIV). For example, within theories of social justice (e.g., Powers and Faden, 2006), the role of social structures in systematically clustering disadvantage within socially defined sub-groups of the population (e.g., “upstream” determinants of health) is emphasized as being explicitly ‘unjust’. However, the current dissertation also provides important empirical data to (re)emphasize that clinical interactions related to HIV testing represent an intervention that has the capacity to be preventative at an individual level (e.g. through pre- and post-test counselling) *and* structural level (e.g., opportunities to advance relational and justice-oriented considerations regarding the importance of testing among young men; reduction of HIV-related stigma).

There is important research to be done by those of us who wish to continue articulating and advancing our understandings of how an evidence- and theory-informed population and public health ethics ought to occur. This dissertation sought to bring significant advances to that project. In doing so, I related empirical inquiry to theories in philosophical ethics, such as Powers and Faden’s (2006) model of social justice, which importantly suggests a normative theory that situates morality within an empirical reality. It was not my aim to advance an extensive ‘defense’ of the normative superiority of Powers and Faden’s theory over other theories of justice; instead, I sought to emphasize that my empirical-normative methodology has important, wider potential for application within the field of population and public health ethics. Nonetheless, Powers and Faden’s theory of social justice does resonate well in the task of exploring the extent to which policy defaults (e.g., routine HIV testing) are ethical, as the theory provides opportunities

to reflect on the intended (e.g., health outcomes, as this pertains to the dimension of health within their theory), as well as unintended consequences and outcomes of the policy in ‘real-world’ settings (e.g., the dimension of respect within Powers & Faden’s (2006) theory of social justice positions public health practices based on stereotyping (e.g., based on sexual identity) as morally problematic and socially unjust) that pertain to notions of justice.

Chapters 2-4 each included a section that describes the various strengths and limitations associated with their respective approaches and conclusions (see Sections: 2.4; 3.4.4; and 4.4.4). Rather than reiterate those more specific points here, I instead describe a broader set of considerations that emerge from my own reflexive approach to the dissertation as a whole. To begin, the current dissertation is informed by a set of epistemological issues that require highlighting and warrant some unpacking. Specifically, by bridging empirical and normative approaches, the empirical-normative techniques used within this dissertation must be considered in light of the debate pertaining to the use and generation of empirical data within efforts to advance normative inquiry. Within the field of empirical ethics, the philosophical (e.g., meta-ethical; epistemological) and methodological implications of including and generating empirical data within the bioethical task of normative inquiry has been vigorously debated (see, for example, a target article and the subsequent responses by: Kon, 2009).

Many of the criticisms of empirical ethics have argued that there is a philosophical imperative to delineate between the factual and the normative, with some authors worrying that by bringing the empirical into the normative, the discipline may be at risk of losing the analytic method and abstraction required in bioethical normative inquiry (Callahan 1996; Goldenberg 2005). While the debate has advanced and evolved over the years, it is worth nothing – from a meta-ethical perspective – that Molewijk & Widdershoven (2012) argue that, in order to respond to these criticisms, all empirical approaches to ethics should be transparent and explicit about how the interactions between the empirical data, normative reasoning and the moral conclusion are handled. For example, Molewijk and Widdershoven (2012) argue that the various distinctions that

may arise when bringing the empirical into the normative can be attenuated through the explicit acknowledgement of one's rationale for engaging in empirical ethics. To do so, they recommend a transparent approach of meta-methodological reflection in which a series of issues are interrogated and systematically reported within a meta-methodology section. See Appendix C for reporting on the current dissertation's empirical-normative meta-methodology as outlined by Molewijk and Widdershoven (2012).

#### **5.4 Reflexivity**

In interpreting the results of this dissertation, my role as the principal researcher of this study should be considered (e.g., I conducted the data collection, data analysis, and co-led the project team with Dr. Shoveller). Given that the majority of the interviews took place at our research offices in the UBC School of Population and Public Health and that all participants were interviewed by myself (a 33-year-old, gay, white man) or the study Research Coordinator (a 30-year-old, white, straight-identified woman), there is a possibility that the context of these interviews served to influence young men's responses. We are older than most of the study participants (sample mean age of 21 years). As a result, the social positioning(s) of each interviewer may have influenced both how participants presented themselves, as well as how they responded to various questions. For example, some of the young men that we interviewed may have felt like they should not 'marginalize' specific sub-groups in their interviews (e.g., engage in 'fag' discourse), although they may do so regularly within other contexts (e.g., with their peers). In addition, the context of the interview may have also influenced how young men describe their health-related practices. For example, men who described that they could "easily" decline a routine offer or access voluntary testing may be deploying a masculine discourses in the context of the interview that does not align with how they would behave in a clinical interaction (i.e., in which the power relations may be somewhat different and/or polarized in 'favour' of what clinicians are perceived to be recommending). Nonetheless, while the literature is somewhat 'mixed' in terms of how the gender of interviewers influences the 'quality' of interview data (see, for example: Gailey & Prohaska, 2011; Seale, Charteris-Black, Dumelow, Locoock, & Ziebland, 2008), it is

important to reflect on the potential influence these factors may have within the current dissertation.

In thinking about how the interview process is structured, the importance of our attempts to create a ‘safe interviewing space’ has always been paramount in terms of ‘protecting’ study participants. As my previous research experience interviewing young men has also helped me to understand (e.g., Knight et al., 2012a and 2012b; Shoveller et al., 2009 and 2010), interview experiences can represent ‘intense’ – yet meaningful (and potentially transformative) – experiences for study participants as well as the interviewer. For example, many of the young men in the current study explained that they volunteered for an interview because they wanted to learn more about men’s sexual health and/or HIV testing. They said that they had not been afforded opportunities elsewhere and, as such, the interviews represented for them one of the first instances in which they could explicitly ‘reflect’ on various features of their sexuality and their sexual health practices. For example, during one interview, a young man ‘came out’ as gay for the first time. Indeed, interactions with participants frequently underlined how young men want more opportunities to express themselves, thereby underscoring how this generation of men may be amenable to public health interventions that seek to promote more socially just masculinities.

Overall, compared to my previous research with young men, the prevalence of ‘fag’ discourses (e.g., ‘gender policing’ through the subordination of queer men and/or men who do not align with dominant masculine ideals) and misogynistic sentiments were far less pronounced than within data that I have collected previously in Vancouver (from September 2006 to June 2011). While this may be an artefact of differing study sample compositions or the potential amplification of a specific type of response biases (e.g., social desirability bias) within the current study, it is also worth noting that these shifting discourses may also reflect changing socio-cultural norms pertaining to queer identities and gender relations. For example, the young men enrolled in the current study have been exposed to different socio-cultural and legal contexts than had those in previous generations. For instance, today’s young men have grown up in a world where same-sex



marriage is legal in many jurisdictions (at least in high-income countries, like Canada, where it was legalized in 2005). As well, Gay-Straight Alliances within public school systems in the Vancouver setting proliferated and become well-established ‘clubs’ at most schools during the years that this group of young men would have transitioned into adolescence and young adulthood.

Yet, some interviews also elicited experiences where myself (a gay man) and the other interviewer (a female) were exposed to discourses that reveal deep gender biases and other forms of discrimination (e.g., homophobia; racialization). Clearly, these discourses reflect broader social mores; but, on rare occasions when a study participant espoused those biases, there were moments when it was challenging to resist feeling uncomfortable with their viewpoints. For example, some men explained that the legal rights of people living with HIV should be severely restricted. Indeed, the first man that I interviewed for the current study explained that he believed people living with HIV should wear ‘markers’ to reveal their sero-positive status to both their sex partners and the community. When men described these sorts of beliefs, I tried not to reveal my own discomfort (or disagreement) with their narratives during the interview; instead, during the analysis and de-briefing sessions, I have positioned these sorts of characterizations as ‘data’. While some participants may have mistaken my interest in these views as ‘endorsements’, the semi-structured qualities of the interviews allowed for opportunities to focus on exploring the *reasons* that these men had expressed these opinions, in addition to how these feelings and perceptions may influence their own health-related practices and/or interactions with others (e.g., clinicians; peers). Understanding the meaning related to men’s health-related practices, experiences and discourses can provide important opportunities to meaningfully advance public health practices that can contribute towards more equitable social relations. Within the broader context of the current dissertation, these viewpoints indeed ‘matter’ (i.e., in as much as they influence young men’s experiences with various health-related practices), but can be normatively assessed as being illegitimate and/or ethically problematic. In other words, I am not seeking to simply describe what men happen to believe, but, rather, how their individual

beliefs, attitudes and masculine dispositions can influence their lived experiences with HIV testing practices.

## **5.5 Future research**

Normative-empirical inquiry regarding various approaches to HIV testing can provide insights into how to advance morally justifiable actions within and across contexts where morally- and socially ascribed meanings of HIV vary greatly. Indeed, in doing so, we can move beyond the highly individualistic orientations of much of the bioethical work in this area, as well as beyond normative work that tends to over-emphasize health maximization frameworks (and disregard other important considerations). For instance, this approach suggests that outcomes that may be considered ‘collateral’ to health outcomes (e.g., men’s lived experiences with various public health actions) within other approaches to population and public health ethics indeed do matter and ought to be subject to both empirical and normative inquiry in order to determine the best (i.e., ethical) course of action.

The potential for various population sub-groups to experience different reactions to routine testing offers behoves those in public health to effectively respond to their differential needs. For example, consider how the experience of being offered an HIV test might differ for an individual who is morally opposed to such a practice (e.g., based on their lived experiences in which HIV-related issues are highly stigmatized). Might a routine offer exacerbate perceptions of HIV-related stigma among these populations? Generating data in this area could offer insights into various strategies that could be implemented and tailored to ameliorate these experiences – both within and beyond the clinic (e.g., among public health’s on-going efforts to de-stigmatize HIV; clinical practices related to routinely offering testing that can respond to individual needs). For example, while the current dissertation reveals the gendered experiences of a set of *young* men, additional empirical work pertaining to *older* men and/or *women’s* experiences could benefit from additional empirical-normative inquiry in this substantive area. Indeed, many of the ethical criticisms against routine HIV testing are premised on the concern that women may experience intimate partner violence in the face of a sero-

positive diagnosis (Smith, 2011); empirical data might provide opportunities to better understand the extent or cross-cultural specificity of these sorts of premises. Moreover, research among older populations might also reveal a unique set of experiences for older people; and, thus, an alternative set of implications for developing ethically and socially robust clinical practices and public health policy or programming for older populations may unfold. In fact, within many of the interviews in the current dissertation, young men described how a routine HIV test offer could be perceived differently among older people, such as their parents or grandparents (e.g., some men described that they felt their grandparents would react with anger and extreme discomfort when offered an HIV test). Moreover, the implications of these issues – and the issues/findings raised within the current dissertation – also point to the need to consider the experiences and perspectives of health care providers.

Future research in other areas of the HIV continuum of care could also benefit from empirical-normative inquiry, particularly in settings where antiretroviral ‘Treatment as Prevention’ (TasP) programs are being scaled up rapidly. For example, British Columbia (Canada), France, and Brazil are scaling up TasP in order to reduce the incidence of HIV infection among various ‘at risk’ populations. New empirical-normative research that uses techniques associated with implementation science and theoretical frameworks from the social sciences (e.g., risk environment theory) (Knight, Small, Pakula, Thomson & Shoveller, 2014c) could make important contributions to ethical and effective scale up. For example, Knight et al. (2014c) argue for the use of effectiveness studies to examine how the social, political and economic contexts influence the capacity for successful “scale up” of TasP within and across various implementation contexts (and over the next four years, they are collecting data in Paris (France), Rio de Janeiro (Brazil) and Vancouver (Canada) to examine social, political and economic contexts as key influences on TasP scale-up).

## **5.6 Implications for methods: Advancing empirical approaches within population and public health ethics**

The techniques used in this dissertation provide a set of methodological considerations regarding research techniques (e.g., thematic and discourse analyses) that will be useful in advancing future empirical-normative inquiry regarding population health interventions. In general, the field of population and public health ethics has yet to fully embrace the generation of empirical evidence as an important project. And, there has yet to be a fulsome discussion about how the inclusion of empirical data ought to be treated in developing normative conclusions in the realm of population and public health. The methods used in this dissertation provide a ‘backdrop’ for advancing some aspects of this much-needed discussion regarding the potential utility of empirically oriented population and public health ethics.

Clearly, empirical approaches within population and public health ethics will be influenced by various actors, including those who are advocate for the generation of population and public health ethics-relevant data.<sup>14</sup> The current dissertation highlights how interdisciplinary approaches to empirical-normative endeavours (e.g., combining philosophy; sociology; public health) may be helpful. Indeed, in advancing theoretical and conceptual orientations pertaining to an empirical population and public health ethics, the intention should not be to create a new or ‘siloes’ discipline or field. Rather, I suggest that the current dissertation illustrates how it is possible to open up new interdisciplinary spaces and opportunities to advance a degree of rigour in normative and empirical inquiry in population and public health research. For example, the overall findings may be helpful in reconciling that ‘facts’ and ‘values’ in empirical work are intricately linked – and, by acknowledging that one is better able to explicate

---

<sup>14</sup> For example, the Canadian Institutes of Health Research’s (2012a) Institute of Population and Public Health identifies the development of methods and theory within the realm of population and public health ethics as a part of their strategic mandate, and the use of empirical evidence is leveraged as one potential pathway through which to achieve this aim.

transparently the dissertation's conclusions as they are derived. As Hurst (2010) suggests, in doing robust empirical-normative inquiry, the source origins of both the methodological and philosophical frameworks should be addressed to the fullest extent possible, in concert with clear, transparent rationales about how the empirical and the normative interacted to produce a moral conclusion (Molewijk & Frith, 2009).

Empirical-normative approaches to population and public health ethics would be most usefully pursued as an iterative project (rather than as a linear project), in which the normative informs the empirical questions to be asked *and* new empirical evidence constantly directs conceptualizations of what constitutes morally robust public health practices. 'Doing the right thing' in public health depends upon engaging in a set of robust, transparent and ethical empirical and normative analyses.

## Bibliography

- Aggarwal, A., Davies, J., & Sullivan, R. (2014). “Nudge” in the clinical consultation - an acceptable form of medical paternalism? *BMC Medical Ethics*, 15(1), 31.
- April, M. D. (2010). Rethinking HIV exceptionalism: the ethics of opt-out HIV testing in sub-Saharan Africa. *Bulletin-World Health Organization* 88(9): 703–708.
- Arksey, H., and O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8(1): 19–32.
- Armstrong, R. (2008). Mandatory HIV testing in pregnancy: is there ever a time? *Developing World Bioethics* 8(1): 1–10.
- Aziz, B. (2007). Testing times. *Nursing management* 14(6) 8–9.
- Basu, S., Smith-Rohrberg, D., Hanck, S., and Altice, F. L. (2005). HIV testing in correctional institutions: evaluating existing strategies, setting new standards. *AIDS and Public Policy Journal* 20(1–2): 3–24.
- Bayer, R., and Fairchild, A. L. (2004). The Genesis of Public Health Ethics. *Bioethics* 18(6): 473–492.
- Bayer, R., Gostin, L. O., Jennings, B., & Steinbock, B. (2007). Introduction: ethical theory and public health. In R. Bayer, L. O. Gostin, B. Jennings, & B. Steinbock (Eds.), *Public health ethics: Theory, policy and practice*. New York: Oxford University Press.
- Bayer, R., and Fairchild, A. L. (2006). Changing the paradigm for HIV testing—the end of exceptionalism. *New England Journal of Medicine* 355(7): 647–649.
- Bayer, R. 2010. Mass Testing and Mass Treatment for Epidemic HIV: The Ethics of Medical Research is No Guide. *Public Health Ethics* 3(3): 301-3.
- Baylis, F., Kenny, N. P., & Sherwin, S. (2008). A Relational Account of Public Health Ethics. *Public Health Ethics*, 1(3), 196–209.
- Bennett, R. (2007). Routine antenatal HIV testing and informed consent: an unworkable marriage? *Journal of Medical Ethics* 33(8): 446–448.
- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., and Clark, J. E. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report* 55(RR- 14): 1–17.

- Brewster, D. (2011). Science and ethics of human immunodeficiency virus/acquired immunodeficiency syndrome controversies in Africa. *Journal of Paediatrics and Child Health, Ethics of HIV in Africa* 47(9): 646–655.
- British Columbia Centre for Disease Control. (2012). HIV Annual Report 2012. Self published: Vancouver, BC.
- British Columbia Centre for Excellence in HIV/AIDS. (2014). STOP HIV/AIDS. Accessed 3 June 2014 at: <http://www.cfenet.ubc.ca/stop-hiv-aids/about>.
- British Columbia Ministry of Health, (2013). MSP Premiums. Accessed 19 August 2013 at: <http://www.health.gov.bc.ca/msp/infoben/premium.html#monthly>.
- British Columbia Ministry of Health (2014). HIV testing guidelines for the Province of British Columbia. Accessed 3 June 2014 at: <http://www.health.gov.bc.ca/pho/pdf/hiv-testing-guidelines-bc.pdf>.
- Callahan D. (1996). Ethics without abstraction: squaring the circle. *Journal of Medical Ethics*, 22(2): 69.
- Cameron, T. (2002). Mandatory HIV testing of newborns in New York State. *Journal of Health and Social Policy* 14(3): 59–78.
- Canadian Institutes of Health Research. (2012a) Population Health Ethics. Canadian Institutes of Health Research. Accessed 1 August 2013 at: <http://www.cihr-irsc.gc.ca/e/41867.html>.
- Canadian Institutes of Health Research – Institute of Population and Public Health. (2012b). Population and Public Health Ethics: Cases from Research, Policy, and Practice. University of Toronto Joint Centre for Bioethics: Toronto, ON.
- Celada, M. T., Merchant, R. C., Waxman, M. J., and Sherwin, A. M. (2011). An ethical evaluation of the 2006 Centers for Disease Control and Prevention recommendations for HIV testing in health care settings. *American Journal of Bioethics* 11(4): 31–40.
- Centers for Disease Control and Prevention. (2010). Expanded HIV Testing and Trends in Diagnoses of HIV Infection—District of Columbia, 2004-2008. *Journal of the American Medical Association* 304(3): 264-266.
- Chappel, R. J., Wilson, K. M., & Dax, E. M. (2009). Immunoassays for the diagnosis of HIV: meeting future needs by enhancing the quality of testing. *Future Microbiology*, 4(8), 963–982.
- Chouliaraki, L. & Fairclough, N. (1999). Discourse in Late Modernity: Rethinking Critical Discourse Analysis. Edinburgh University Press: Edinburgh.

- Coggon, J. 2012. *What Makes Health Public? A critical evaluation of moral, legal and political claims in public health*. Cambridge: Cambridge University Press.
- Cohen, S. M., Van Handel, M. M., Branson, B. M., Hall, I. H., Hu, X., and Koenig, L. J. 2011. Vital signs: HIV prevention through care and treatment—United States. *MMWR Morb Mortal Wkly Rep* 60(47): 1618–1623.
- Connell, R. (1995). *Masculinities*. Berkeley, CA: University of California Press.
- Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social Science & Medicine*, 74(11), 1675–1683.
- Courtenay, W. H. (2000a). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine*, 50(10), 1385–1401.
- Courtenay, W. H. (2000b). Behavioural factors associated with disease, injury, and death among men: Evidence and implications for prevention. *Journal of Men's Studies*, 9(1), 81-142.
- Csete, J., and Elliott, R. (2006). Scaling up HIV testing: human rights and hidden costs. *HIV/AIDS Policy and Law Review* 11(1): 5–10.
- Daniels, N. (2006). Equity and Population Health: Toward a Broader Bioethics Agenda. *Hastings Center Report* 36(4): 22-35.
- Daniels, N. (1996) *Justice and Justification: Reflective Equilibrium in Theory and Practice*. New York: Cambridge University Press.
- Darwall, S (Ed). (2003a) *Deontology*. Oxford: Blackwell Publishing.
- Darwall, S (Ed). (2003b) *Consequentialism*. Oxford: Blackwell Publishing.
- Das, M., Chu, PL., Santos, G-M., Scheer, S., Vittinghoff, E., McFarland, W. and Colfax GN. (2010). Decreases in Community Viral Load Are Accompanied by Reductions in New HIV Infections in San Francisco. *PLoS ONE* 2010, 5:e11068.
- Dawson, A and Verweij, M (Eds). (2007) *Ethics, Prevention, and Public Health*. Oxford: Oxford University Press.
- Dawson, A. (2011). Public health ethics and the justification of HIV screening. *American Journal of Bioethics* 11(4): 48–49.
- Dawson, A., and Verweij, M. (2012). Solidarity: a Moral Concept in Need of Clarification. *Public Health Ethics*, 5(1), 1–5.
- Dawson, A., and Jennings, B. (2012) The place of solidarity in public health ethics. *Public Health Reviews*, 34(1), 65-79.



- De Cock, KM., Mbori-Ngacha, D., and Marum, E. (2002). Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *The Lancet* 360(9326): 67–72.
- Dey, I. (1999). *Grounding Grounded Theory: Guidelines for Qualitative*. Emerald Group Publishing.
- Dixon Mueller, R. (2007). The sexual ethics of HIV testing and the rights and responsibilities of partners. *Studies in Family Planning* 38(4): 284–296.
- Doull, M., Oliffe, J., Knight, R., & Shoveller, J. A. (2013). Sex and Straight Young Men: Challenging and Endorsing Hegemonic Masculinities and Gender Regimes. *Men and Masculinities*, 16(3), 329–346.
- Duck, W. (2009). Black Male Sexual Politics: Avoidance of HIV/AIDS Testing as a Masculine Health Practice. *Journal of African American Studies*, 13(3), 283-306.
- Durojaye, E. (2011) The impact of routine HIV testing on HIV-related stigma and discrimination in Africa. *International Journal of Discrimination and the Law*, 11(4), 187-200.
- Earnshaw, V. A., & Chaudoir, S. R. (2009). From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. *AIDS and Behavior*, 13(6).
- Entwistle, VA., Carter, SM., Cribb, A., & McCaffery, K. (2010). Supporting Patient Autonomy: The Importance of Clinician-patient Relationships. *Journal of General Internal Medicine*, 25(7), 741–745.
- Fairclough, N. (1995). *Critical Discourse Analysis*. Boston: Addison Wesley.
- Fairclough, N. (2003) *Analysing Discourse: Textual Analysis for Social Research*. Routledge: New York.
- Fereday, J., and Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods* 5(1): 80–92.
- Fields, L., and Kaplan, C. (2011). Opt-out HIV testing: An ethical analysis of women's reproductive rights. *Nursing Ethics* 18(5): 734–742.
- Fleming, PJ., & Lee, J. (2014). “Real Men Don't”: Constructions of Masculinity and Inadvertent Harm in Public Health Interventions. *Journal of Public Health*.
- Flowers, P., Knussen, C., Li, J., & McDaid, L. (2012). Has testing been normalized? An analysis of changes in barriers to HIV testing among men who have sex with men between 2000 and 2010 in Scotland, UK. *HIV Medicine*, 14(2), 92–98.

- Frith, L. (2010). Symbiotic empirical ethics: A practical methodology. *Bioethics*, 26(4), 198–206.
- Frohlich, K. L., and Potvin, L. (2008). Transcending the known in public health practice: The inequality paradox: The population approach and vulnerable populations. *American Journal of Public Health* 98(2): 216-221.
- Gahagan, J.C., Fuller, J.L., Proctor-Simms, E.M., Hatchette, T.F., & Baxter, L.N. (2011). Barriers to gender-equitable HIV testing: going beyond routine screening for pregnant women in Nova Scotia, Canada. *International Journal for Equity in Health*, 10(1), 18.
- Gailey, J. A. and A. Prohaska. (2011). “Power and Gender Negotiations during Interviews with Men about Sex and Sexually Degrading Practices.” *Qualitative Research* 11:365-80.
- Goldenberg, M. J. (2005). Evidence-based ethics? On evidence-based practice and the “empirical turn” from normative bioethics. *BMC Medical Ethics* 6(1): 11.
- Gostin, L. O. (2006). HIV screening in health care settings. *JAMA: the Journal of the American Medical Association* 296(16): 2023–2025.
- Gustafson, R., Montaner, J., & Sibbald, B. (2012). Seek and treat to optimize HIV and AIDS prevention. *Canadian Medical Association Journal*, 184(18), 1971–1971.
- Hanssens, C. (2007). “Legal and Ethical Implications of Opt-Out HIV Testing.” *Clinical Infectious Diseases* 45(4): S232–S239.
- Hedgecoe, A.M. (2004). Critical Bioethics: Beyond the Social Science Critique of *Applied Ethics*. *Bioethics*, 18(2), 120-143.
- Heijnders, M. and van der Meij, S. (2006) The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health and Medicine*, 11: 353-63.
- Hurst S. (2010) What “empirical turn in bioethics?” *Bioethics*, 24(8):439–444.
- Jennings, B. (2003). Frameworks for ethics in public health. *Acta Bioethica*, 9(2), 165–176.
- Johansson, K.A., Pedersen, K.B. and Andersson, A.K. (2011). HIV testing of pregnant women: An ethical analysis. *Developing World Bioethics* 11(3): 109-119.
- Jurgensen, M., Sandoy, I.F., Michelo, C. and Fylkesnes, K. (2013). Effects of home-based Voluntary Testing and Counselling on HIV-related stigma: findings from a cluster-randomized trial in Zambia. *Social Science and Medicine*, 18: 18–25.

- Kalichman, SC., and Simbayi, LC. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, 79(6), 442-447.
- Katz, DA., Swanson, F., and Stekler, J. D. (2013). Why Do Men Who Have Sex With Men Test for HIV Infection? Results From a Community-Based Testing Program in Seattle. *Sexually Transmitted Diseases*, 40(9), 724-728.
- Knight, R., Shoveller, J., Oliffe, J., Gilbert, M., and Goldenberg, S. (2012a). Heteronormativity Hurts Everyone: Experiences of young men and clinicians with STI/HIV testing in British Columbia, Canada. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 17(5):441-59
- Knight, R., Shoveller, JA., Oliffe, JL., Gilbert, M., Frank, B., and Ogilvie, G. (2012b). Masculinities, 'guy talk' and 'manning up': a discourse analysis of how young men talk about sexual health. *Sociology of Health & Illness*, 34(8), 1246-1261.
- Knight, R., Shoveller, J., Greyson, D., Kerr, T., Gilbert, M., and Shannon, K. (2014a). Advancing population and public health ethics regarding HIV testing: A scoping review. *Critical Public Health*, 24(3), 283-295.
- Knight, R., Shoveller, JA., Carson, AM., and Contreras-Whitney, JG. (2014b). Examining clinicians' experiences providing sexual health services for LGBTQ youth: considering social and structural determinants of health in clinical practice. *Health Education Research*.
- Knight, R., Small, W., Pakula, B., Thomson, K. & Shoveller J. (2014c) A scoping study to identify opportunities to advance the ethical implementation of Treatment as Prevention: Priorities for empirical research. *BMC Medical Ethics*.
- Kippax, S. (2006). A public health dilemma: A testing question. *AIDS Care* 18(3): 230-235.
- Koku, E. F. (2011). Desire for, and uptake of HIV tests by Ghanaian women: the relevance of community level stigma. *Journal of Community Health*, 36(2), 289-299.
- Kon, A. (2009) The Role of Empirical Research in Bioethics. *The American Journal of Bioethics*, 9(6-7): 59-65.
- Krishnamurthy, M. (2013). Political Solidarity, Justice and Public Health. *Public Health Ethics*, 6(2), 129-141.
- Leung, WC. (2001). Should screening of student and qualified nurses for bloodborne infections be compulsory and infected individuals excluded from work? *Nursing Ethics* 8(2): 133-141.

- Lima, VD., Hogg, RS. and Montaner, JSG. (2010). Expanding HAART treatment to all currently eligible individuals under the 2008 IAS-USA guidelines in British Columbia, Canada. *Plos One*, 5(6), 1-7.
- Lopez, J. (2004). How sociology can save bioethics... maybe. *Sociology of Health & Illness*, 26(7), 875-896.
- Macklin, R. (2005). Scaling up HIV testing: ethical issues. *Health and Human Rights* 8(2): 27–30.
- Mahajan, AP., Sayles, JN., Patel, VA., Remien, RH., Sawires, SR., Ortiz, DJ., et al. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *Aids*, 22(Suppl 2), S57–S65.
- McLaren, L., McIntyre, L., and Kirkpatrick, S. (2009). Rose’s population strategy of prevention need not increase social inequalities in health. *International Journal of Epidemiology* 39(2): 372–377.
- McLeod, C., and Sherwin, S. (2000). Relational Autonomy, Self-Trust, and Health Care for Patients Who are Oppressed. In *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. MacKenzie, C. and Stoljar, N. (Eds). Oxford: Oxford University Press.
- McQuoid-Mason, D. 2007. Routine testing for HIV-ethical and legal implications. *South African Medical Journal* 97(6): 416.
- Meera, R., and Sreeram, S. 2007. Provider-initiated testing and counselling in India for HIV. *Indian Journal of Medical Ethics* 4(4): 170.
- Mill, JS. (1860). On Liberty. John Stuart Mill's 5 Legendary Lectures on Personal Liberty. In *Harvard Classics*, 25. (2010).
- Molewijk B and Frith L. (2009) Empirical ethics: who is the Don Quixote? *Bioethics*, 23(4):ii-i.
- Molewijk, B. and Widdershoven GAM. (2012) Don’t Solve the Issues! *Cambridge Quarterly of Healthcare Ethics*, 21(04):448–456.
- Montaner, JS., Lima, V., Barrios, R., Yip, B., Wood, E., Kerr, T., Shannon, K., Harrigan, R., Hogg, R., Daly, P. and Kendall, P. 2010. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: a population-based study. *The Lancet* 376(9740): 532–539.
- National AIDS Trust. (2012). *HIV Testing Action Plan – to reduce late HIV diagnosis in the UK*. United Kingdom.

- Ngwena, CG., and Cook, RJ. (2008). HIV/AIDS, pregnancy and reproductive autonomy: Rights and duties. *Developing World Bioethics* 8(1): iii–vi.
- Nys, TRV. (2008). Paternalism in Public Health Care. *Public Health Ethics*, 1(1), 64–72.
- Nys, T. (2009). Public Health Paternalism: Continuing the Dialogue. *Public Health Ethics*, 2(3), 294–298.
- O'Grady, B., and Schüklenk, U. (2009). Rethinking mandatory HIV testing. *Bioethics* 23(8): ii–ii.
- Obermeyer, CM., Bott, S., Bayer, R., Desclaux, A., and Baggaley, R. (2013). HIV testing and care in Burkina Faso, Kenya, Malawi and Uganda: ethics on the ground. *BMC International Health and Human Rights*, 13(1), 1–1.
- Oliffe, JL., Chabot, C., Knight, R., Davis, W., Bungay, V., and Shoveller, J. A. (2012). Women on men's sexual health and sexually transmitted infection testing: a gender relations analysis. *Sociology of Health & Illness*, 35(1), 1–16.
- O'Neill, O. (2011). *Broadening bioethics: Clinical ethics, public health and global health*. Presented at Nuffield Council's Annual Lecture at the Royal Society of Arts.
- Parker, R., and Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine* 57(1): 13–24.
- Petersen A. (2013). From bioethics to a sociology of bio-knowledge. *Social Science & Medicine*.
- Petrini C. (2010) Theoretical Models and Operational Frameworks in Public Health Ethics. *International Journal of Environmental Research and Public Health*, 7(1):189–202.
- Pettifor, A., MacPhail, C., Suchindran, S., and Delany-Moretlwe, S. (2010). Factors associated with HIV testing among public sector clinic attendees in Johannesburg, South Africa. *AIDS and Behaviour*, 14(4), 9130921.
- Pierce, MW., Maman, S., Groves, AK., King, EJ., and Wyckoff, SC. (2011). Testing public health ethics: Why the CDC's HIV screening recommendations may violate the least infringement principle. *Journal of Law, Medicine and Ethics* 39(2): 263–271.
- Powderly, K. (2001). Ethical and legal issues in perinatal HIV. *Clinical Obstetrics and Gynaecology* 44(2): 300.
- Powers, M. and Faden, R. (2006) *Social Justice: The moral foundations of public health and health policy*. Oxford: Oxford University Press.

- Prainsack, B., and Buyx, A. (2011). *Solidarity: Reflections on emerging an emerging concept in bioethics*. United Kingdom: Nuffield Council on Bioethics.
- Public Health Agency of Canada (2013) *Human Immunodeficiency Virus: HIV Screening and Testing Guide*, 1–57. Accessed 1 February 2014 at: <http://www.phac-aspc.gc.ca>.
- Rennie, S., and Behets, F. (2006). Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bulletin-World Health Organization* 84(1): 52–57.
- Rennie, S., and Mupenda, B. (2008). Ethics of mandatory premarital HIV testing in Africa: The case of Goma, Democratic Republic of Congo. *Developing World Bioethics* 8(2): 126–137.
- Robertson, S. (2007). *Understanding men and health: Masculinities, identity and well-being*. Open University Press: New York.
- Salang Seloilwe, E. (2011). Commentary on 'Opt-out HIV testing: An ethical analysis of women's reproductive rights'. *Nursing Ethics* 18(5): 743–745.
- Sambisa, W., Curtis, S., and Mishra, V. (2010). AIDS stigma as an obstacle to uptake of HIV testing: evidence from a Zimbabwean national population-based survey. *AIDS Care*, 22(2), 170-186.
- Sanders, GD., Bayoumi, AM., Sundaram, V., et al. (2005) Cost-effectiveness of screening for HIV in the era of highly active antiretroviral therapy. *New England Journal of Medicine*, 352:570-85.
- Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness* 31(3): 441–455.
- Schuklenk, U. (1998) *Access to Experimental Drugs in Terminal Illness: ethical issues* (New York: Pharmaceutical Products Press).
- Schüklenk, U. (2003). AIDS: Bioethics and public policy. *New Review of Bioethics* 1(1): 127–144.
- Seale, C., Charteris-Black, J., Dumelow, C., Locock, L., and Ziebland, S. (2008). The Effect of Joint Interviewing on the Performance of Gender. *Field Methods* 20:107-28.
- Sengupta, S., Banks, B., Jonas, D., Miles, MS., and Smith, GC. (2011). HIV interventions to reduce HIV/AIDS stigma: a systematic review. *Aids and Behavior*, 15(6), 1075-1087.
- Shoveller, JA., Johnson, J., Rosenberg, M., Greaves, L., Patrick, D., Oliffe, J., and Knight, R. (2009). Youth's experiences with STI testing in four communities in British Columbia, Canada. *Sexually Transmitted Infections*, 85(5), 397-401.

- Shoveller, JA., Knight, R., Johnson, J., Oliffe, JL., and Goldenberg, S. (2010). “Not the swab!” Young men’s experiences with STI testing. *Sociology of Health & Illness*, 32(1), 57–73.
- Smith, W. (2011). When informed consent meets the everyday. *American Journal of Bioethics* 11(4): 43–45.
- Solbakk JH. (2012). Guest Editorial. *Cambridge Quarterly of Healthcare Ethics*, 21(04):419–423.
- Stangl, AL., Lloyd, JK., Brady, L., Holland, C. E., and Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*, 16(3(Suppl 2)).
- Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd ed. Thousand Oaks: Sage Publications.
- Ten Have, H.A., & Lelie, A. (1998). Medical ethics research between theory and practice. *Theoretical Medicine and Bioethics*, 19(3), 263–276.
- Thomas, D. R. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, 27(2), 237–246.
- Thompson, A. (2013). Human Papilloma Virus, Vaccination and Social Justice: An Analysis of a Canadian School-Based Vaccine Program. *Public Health Ethics*, 6(1), 11–20.
- United Nations. (2008). *2008 report on the global AIDS epidemic*. Geneva: Joint United Nations Programme on HIV/AIDS. Available from: [http://data.unaids.org/pub/GlobalReport/2008/JC1510\\_2008GlobalReport\\_en.zip](http://data.unaids.org/pub/GlobalReport/2008/JC1510_2008GlobalReport_en.zip).
- United States Global Health Policy. 2011. The Global HIV/AIDS Epidemic, November, 2011. Accessed 15 April 2012 at: <http://www.kff.org/hivaids/upload/3030-16.pdf>.
- Vancouver Coastal Health (2011). Hospitals begin routine HIV testing. Accessed on 15 April, 2013 at: Available at: [https://www.vch.ca/about\\_us/news/archive/2011-news/hospitals\\_begin\\_routine\\_testing\\_for\\_hiv](https://www.vch.ca/about_us/news/archive/2011-news/hospitals_begin_routine_testing_for_hiv)
- Vernillo, A. (2011). Routine opt-out HIV testing in dental health care—Its implementation and the advancement of public health. *American Journal of Bioethics* 11(4): 46–48.
- Visser, MJ., Makin, JD., Vandormael, A., Sikkema, KJ., & Forsyth, BW. (2009). HIV/AIDS stigma in a South African community. *AIDS Care*, 21(2), 197-206.

- Vonn, M. 2012. British Columbia's "seek and treat" strategy: a cautionary tale on privacy rights and informed consent for HIV testing. *HIV/AIDS Policy & Law Review* 16: 15–18.
- Young, R., and Meyer, I. (2005). The trouble with "MSM" and "WSW": erasure of the sexual-minority person in public health discourse. *American Journal of Public Health*, 95(7):1144-9.
- Young, S. D., Hlavka, Z., Modiba, P., Gray, G., Van Rooyen, H., Richter, L., et al. (2010). HIV-related stigma, social norms, and HIV testing in Soweto and Vulindlela, South Africa: National Institutes of Mental Health Project Accept (HPTN 043). *Journal of Acquired Immune Deficiency Syndromes*, 55(5), 620-624.
- Wahlert, L., and Fiester, A. 2011. The re-queering of HIV testing practices and the reinforcement of stigma. *American Journal of Bioethics* 11(4): 41–43.
- Wood, E., Stoltz, J.A., Montaner, J.S.G. & Kerr, T. (2006) Evaluating methamphetamine use and risks of injection initiation among street youth: The ARYS study. *Harm Reduction Journal*, 3(18), 1-6.
- Wynia, M. K. (2006). Routine screening: Informed consent, stigma and the waning of HIV exceptionalism. *American Journal of Bioethics* 6(4): 5–8.



# Appendix A. Socio-demographic questionnaire

THE UNIVERSITY OF BRITISH COLUMBIA



School of Population and Public Health  
Faculty of Medicine  
Mather Building, 5804 Fairview Ave  
Vancouver, BC V6T 1Z3

Tel: (604) 822-2772  
Fax: (604) 822-4994  
Website: www.spph.ubc.ca

## Sociodemographic Questionnaire

**Principal Investigator:**  
Jean Shoveller, PhD

**Interviewer's name:** \_\_\_\_\_

**Date of interview:** \_\_\_\_\_

**Participant's pseudonym:** \_\_\_\_\_

### To be completed by study participants:

1. Age? \_\_\_\_\_ years
2. How would you best describe your ethnicity?
  - Aboriginal [Inuit, Métis, First Nation (status), First nation (non-status)]
  - Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
  - African-Canadian
  - Chinese
  - Filipino
  - Japanese
  - Korean
  - Latin American
  - South Asian (e.g., East Indian, Pakistani, Punjabi, Sri Lankan)
  - South East Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese)
  - White (Caucasian)
  - Other Please specify:  
\_\_\_\_\_

3. Were you born in Canada or did you immigrate?
- Born in Canada
  - Immigrated to Canada
4. How long have you lived in Vancouver?
- \_\_\_\_\_ years OR \_\_\_\_\_ months
5. I am currently living:
- Alone
  - With friends
  - With my parents/family
  - With foster parents
  - In university residence
  - With my partner/spouse
  - In a shelter or on the street
  - Other \_\_\_\_\_
6. Are you currently involved in sexual relationships? (check all that apply)
- No, I am not involved in a sexual relationship at this time.
  - Yes, with a woman
  - Yes, with more than one woman
  - Yes, with a man
  - Yes, with more than one man
7. Do you consider yourself to be:
- Straight/heterosexual
  - Gay
  - Bisexual
  - Transgender
  - Two-spirit
  - Other Please specify: \_\_\_\_\_
8. Have you ever been tested for a sexually transmitted infection (STI) or HIV?
- No
  - Yes – please write the number of times you’ve been tested: \_\_\_\_\_times

What is your current postal code? \_\_\_\_\_



**Review the informed consent and interview structure:**

- ◆ This session will be audio taped and will last about 1 to 1.5 hours. We'll begin our interview by completing a brief questionnaire (3-5 minutes). Then I will ask you some questions about your experiences with STI/HIV testing. While we're talking, I'll ask you to tell me about what you had to do when you went for your STI or HIV tests, as well as some different testing 'scenarios'. During the interview, I'll be taking a few notes about the events and experiences you describe to me.
- ◆ Any questions about how we're going to spend our time today?

<b>Topic Area</b>	<b>Questions</b>	<b>Probes</b>
<b>1.Introduction</b>	a. Where did you hear about our study (e.g., facebook; poster)?  b. Tell me why you decided to volunteer for our study.	

<p><b>Topic Area</b></p> <p><b>2. Previous experiences with HIV testing</b></p>	<p><b>Questions</b></p> <p>a. Tell me the story about how you decided to go for HIV testing. You can start anywhere you want.</p>	<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>• What did you know about HIV testing at that time?</li> <li>• What kinds of information did you want [or need] to know?</li> <li>• Where did you go for testing?</li> <li>• Tell me about what it was like to interact with those nurses or doctors.</li> <li>• How did they respond to your needs and questions?</li> <li>• Tell me about how you asked for or were offered an HIV test.</li> </ul>
---	---	---

<p><b>Topic Area</b></p> <p><b>3. HIV testing (voluntary testing)</b></p>	<p><b>Questions</b></p> <p><i>I would like to talk about a situation in which you decide that you want to go for HIV testing. In this situation, you must decide that <b>you</b> want to be tested and <b>you</b> must find a clinic and request an HIV test.</i></p> <p>a. What are some reasons you might decide to go to a clinic to ask for an HIV test?</p>	<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>• Some people have told us they go for testing at the beginning or at the end of a relationship. What do you think about this, and is this something you consider important?</li> <li>• Some men have told us they go for testing after having sex that they considered ‘risky’. Are there certain</li> </ul>
---	--	---

Topic Area	Questions	Probes
	<p data-bbox="415 646 1058 748"><i>Some men have told us that certain groups of men are more 'at risk' of contracting HIV, and that these men should therefore test more frequently.</i></p> <p data-bbox="464 792 1073 862">b. What groups of men do you think should go to the clinic to get tested?</p>	<p data-bbox="1199 354 1892 456">kinds of sexual encounters that would make you more likely to get tested? What sorts of sexual behavior would you consider as putting you 'at risk' for HIV?</p> <ul data-bbox="1157 467 1906 976" style="list-style-type: none"> <li data-bbox="1157 467 1906 646">• Others have told us they prefer to be tested on some sort of regular schedule (for example, one or two times per year). What do you think about testing on a regular schedule? Is this something you would consider? Why or why not?</li> <li data-bbox="1157 797 1906 899">• Who might be at a particularly high risk of contracting HIV, and therefore need to engage more frequently with HIV testing services?</li> <li data-bbox="1157 911 1906 976">• Are there particular groups of men, for example, specific age groups, who should be going for testing?</li> </ul>

<b>Topic Area</b>	<b>Questions</b>	<b>Probes</b>
<p><b>4. HIV testing</b> (routine testing)</p>	<p><i>Now I want to talk about an approach where all patients who show up at a hospital or clinic – no matter what group they belong to – are offered HIV testing – even if they show up for something totally unrelated to HIV testing, such as a sprained ankle.</i></p> <p>a. How would you feel if you went to the hospital because you had an injury and you were automatically recommended to get an HIV test?</p>	<ul style="list-style-type: none"> <li>• What sorts of things would you want to know before you agreed to have an HIV test in this situation? For example: <ul style="list-style-type: none"> <li>○ What would you want to know about getting your results?</li> <li>○ What would you want to know about confidentiality? For example, would you want to know how your records would be kept?</li> </ul> </li> <li>• Can you think of any reasons why this sort of testing (i.e., in which you are offered an HIV test) might be something that you would like?</li> <li>• Can you think of any reasons why being offered a test in this way might have some disadvantages? Explain.</li> </ul>

<b>Topic Area</b>	<b>Questions</b>	<b>Probes</b>
	<p>b. Thinking again about going to a hospital or clinic because you were sick or injured, how do you think you would feel if your clinician asked you questions about your sexual history?</p> <p>c. How do you think this experience would be different if you really didn't want to be tested for HIV?</p> <p>d. How might this situation differ if your doctor or nurse described to you that it is routine policy to recommend that all patients be tested for HIV? For example, if they stated "It is now recommended that I ask everyone if I can add an HIV test to their blood work"?</p>	<ul style="list-style-type: none"> <li>• For example, how would you feel in this situation if you were asked if you are sexually active? Or, if you were asked: when is the last time you had an HIV test?</li>   <li>• How would you feel about having to tell a doctor or a nurse that you don't want to be tested, even though you were automatically recommended to get an HIV test because it is policy that everyone gets recommended for testing?</li>   <li>• Would this make you more or less comfortable in deciding whether or not to be tested?</li> <li>• Can you think of any benefits or drawbacks of this approach to testing?</li> </ul>



Topic Area	Questions	Probes
<p><b>5. HIV testing</b> (‘Targeted’ approaches)</p>	<p><i>Young men are sometimes ‘targeted’ in public health campaigns to get tested. For example, there are a number of public health campaigns that frequently target young gay men to encourage them to seek testing.</i></p> <ol style="list-style-type: none"> <li>a. Are you aware of any expectations related to men needing to be tested?</li> <li>b. Do you think other people expect that you should get tested for HIV?</li> <li>c. Some men have told us that ‘targeted’ approaches might not be <i>fair</i>, because it will imply that a group (e.g., gay men) is all at the same level of HIV risk, even though there are vast differences within groups (e.g., some gay men are abstinent or consistently use condoms). As such, ‘targeted’ approaches might make the rest of the community assume that all <i>gay</i> men or all <i>young</i> men are at risk of HIV. Tell me what you think about these ideas?</li> </ol>	<ul style="list-style-type: none"> <li>• Are there any groups of men who you feel should not be targeted in this way? Why?</li> <li>• Why do you think these expectations exist? Why do you think those people feel that way?</li> <li>• Have you ever felt ‘targeted’ by a campaign encouraging you to get tested for HIV? How did this make you feel? How did/would feeling ‘targeted’ influence your decision to get testing?</li> <li>• Do you think that certain groups should be ‘targeted’, even if there are unintended effects like the one I mentioned (i.e., that society will make assumptions about this group)?</li> <li>• How would you feel if you felt you were being ‘targeted’ or expected to go for HIV testing? Tell me about how this would influence your decision to get testing.</li> </ul>

Topic Area	Questions	Probes
<p><b>6. HIV-related stigma</b></p>	<p><i>In thinking about the different ways in which you can be tested (so, either you going to the clinic to ask for an HIV test or by having the clinician recommend you be tested during a visit), I would like to talk about stigma and HIV. By stigma, I mean the disapproval society might associate with HIV because it goes against what's considered "normal". HIV is an infection that many consider to be a stigmatized health condition.</i></p> <p>a. For some people, getting tested for HIV makes them feel dirty or ashamed. Why do you think some people feel this way?</p> <p>b. Some people feel like others, such as friends, doctors, nurses or sex partners might judge them for getting an HIV test. For example, some people fear being judged as immoral. Or that others will think they have engaged in 'risky' sexual behavior. Why do you think some people feel this way?</p>	<p>• What do you think about these ideas?</p> <p>• How does getting tested make you feel?</p> <p>• Do you think some people or some types of people might be more likely to feel this way? Why?</p> <p>• What do you think about these ideas?</p> <p>• Who would you tell if you got tested for HIV? Who wouldn't you tell? Why?</p> <p>• Do you think that others might feel differently about you if they knew you got tested for HIV? Why?</p>

<b>Topic Area</b>	<b>Questions</b>	<b>Probes</b>
	<p>c. Some people have told us that the effects of HIV-related stigma can include a variety of outcomes. For example, some men have told us that people who are thought to have HIV might be avoided.</p> <p>d. In thinking about the different ways you can be tested for HIV (so, either voluntarily, in which you must find a clinic and ask for an HIV test, versus the routine approach in which you are offered the test, while visiting the clinic or hospital for an unrelated reason), how do you think HIV stigma might ‘play out’ differently?</p>	<ul style="list-style-type: none"> <li>• Can you describe any other ways that people might be treated differently if they are thought to have HIV?</li> <li>• How do you think you would be treated if people knew you had HIV? Do you think your family would treat you differently?</li> <li>• How do you think this would influence your sex life?</li> <li>• Do you treat people differently (or would you) if you knew that they are HIV positive? Explain.</li> </ul> <ul style="list-style-type: none"> <li>• Do you think the effects of HIV stigma could be worse within one of these approaches? Why?</li> <li>• Would you prefer being offered a test or asking for a test?</li> </ul>

Topic Area	Questions	Probes
<p><b>7. HIV Criminalization</b></p>	<p>a. Are there any legal reasons that might influence your decision to go for testing?</p> <p><i>You may be aware that there is a law in Canada that makes it illegal for people who are HIV positive to withhold this information from their sex partners. In the event that they do not tell their sex partners that they are HIV positive, they can be criminally charged.</i></p> <p>b. Tell me what you knew about this law?</p> <p>c. Does this law influence your decision to go for HIV testing?</p>	<ul style="list-style-type: none"> <li>• Were you aware of this law?</li> <li>• What do you think about this law?</li> <li>• Where did you hear this information?</li>   <li>• Do you think there are men who might want to get tested (e.g., more often) because of this law?</li> <li>• Do you think there are groups of men that might avoid testing because of this law?</li> </ul>

<b>Topic Area</b>	<b>Questions</b>	<b>Probes</b>
	<p>d. Do you think there are benefits associated with this law?</p>	<ul style="list-style-type: none"> <li>• Do you think this would influence the spread of HIV? For example, do you think it could increase or decrease the likelihood that people could get HIV? Explain.</li> <li>• Some people have told us that they think about this law as something that will help stop the spread of HIV, whereas others think it is more about punishing people with HIV who are not being responsible? Tell me what you think about these ideas.</li> <li>• Given what we have discussed regarding this law, do you think this law is a justifiable law – a law that we should continue to have? Tell me why you think this.</li> </ul>

Topic Area	Questions	Probes
<p><b>8. HIV Treatment, including TasP and PrEP</b></p>	<p><i>Some people have told us that because there are more advanced HIV treatment opportunities, some of the concerns related to HIV are no longer as important.</i></p> <ol style="list-style-type: none"> <li>a. What do you know about HIV treatment?</li>   <li>b. Providing treatment to people who are HIV+ can also make them less infectious – in other words, if somebody who is HIV+ is receiving treatment, they will not be as likely to give HIV to someone else. This has been referred to as ‘<i>treatment as prevention</i>’, because the treatment is offered to patients to prevent HIV transmission, regardless of whether or not the individual is at a stage of HIV infection that requires treatment for their individual benefit (e.g., so they don’t become sick). What are your thoughts on offering treatment to individuals who are HIV+ in order to prevent them from transmitting HIV?</li> </ol>	<ul style="list-style-type: none"> <li>• Tell me how the availability of HIV treatment might influence your decision to go for HIV testing? How might the availability of treatment affect the testing decisions of your friends (guys/girls)?</li>   <li>• How acceptable do you think it would be if you were HIV+ and you were offered treatment so that you would not be infectious, rather than for your own health-related concerns?</li>   <li>• Some have argued that it might be <i>unfair</i> to treat an HIV-infected person in order to prevent them from infecting others because it places another demand on people who might be very vulnerable people (e.g., poor people; people who use injection drugs). Can you tell me what your thoughts are on the ‘fairness’ of this approach?</li>   <li>• When you think about people who are HIV-, are there any groups who you think should definitely be receiving treatment because they are at such a high risk of getting HIV? Why?</li> </ul>

	<p><b>Questions</b></p> <p>c. Another approach to HIV prevention is to offer treatment to people who are <i>not</i> HIV positive. Providing treatment to people who are <i>not</i> HIV+ will decrease their chance of getting HIV. What are your thoughts on this approach – i.e., providing treatment to people who are not infected so that they will be less likely to acquire HIV?</p>	<p><b>Probes</b></p> <ul style="list-style-type: none"> <li>• Some people have told us that they think it isn't a good idea to provide HIV treatment to HIV- people who use injection drugs or have unprotected sex with multiple partners. What do you think about this?</li> </ul>
--	--	--

<p><b>Topic Area</b></p> <p><b>Conclusion</b></p>	<p><b>Questions</b></p> <p>a. Is there anything else you would like to tell me about your experiences or thoughts related to HIV or HIV testing?</p> <p>b. Do you have any questions for me at this time?</p>	<p><b>Probes</b></p>
---	---	----------------------

## Appendix C. Questions for writing a metamethodology section in empirical ethics papers as outlined by Molewijk and Widdershove (2012)

### 1. What makes this study an empirical-normative study?

Data was collected with the *a priori* intention to explore a set of ethical arguments that have been identified as unsubstantiated assumptions, followed by a set of empirical approaches to ‘fill’ these ‘gaps’.

### 2. Why did the authors choose to do an empirical ethics study?

Based on the results of a systematic scoping study of ethical arguments pertaining to the shift from voluntary to routine testing approaches, many of the arguments were deemed to be either theoretically and/or empirically unsubstantiated. These discussions also neglected to consider men’s gendered health-related behaviour. The current study was developed to engage in an empirical-normative analysis in order to advance normative deliberation in the area of young men and HIV testing.

### 3. Have normative reasoning and moral theory influenced the research design and the choice of research methodologies, and, if so, how?

This study was designed with an underlying emphasis on issues pertaining to social justice and health equity. To do so, this study draws on multiple theoretical frameworks from within the realm of population and public health ethics, with a particular emphasis on the mainstays of public health, including health equity and social justice.

### 4. Which disciplines participated in the design of the study, the collection of the empirical data, and the writing of the conclusions?

Sociology; moral philosophy; health sciences.

### 5. What normative conclusions are drawn on the basis of the empirical data collected?

Based on the findings of the empirical data, this study seeks to determine whether or not various practices associated with voluntary and routine testing approaches are morally permissible among young men in Vancouver, Canada.



**6. Which methodology has been chosen to combine empirical data and normative reasoning?**

The method of reflective equilibrium has been chosen to combine empirical data with normative reasoning and theory. In this approach, moral theories, moral intuition, as well as social theories that contextualize live experiences, are combined to seek a temporal equilibrium. In this approach, the theoretical dimensions of ethical theory must be reconciled amongst other ethical arguments (e.g., as described previously within the literature) in order to be considered acceptable or morally permissible (Daniels, 1996).