

AN EXPLORATION OF HIV TESTING POLICY AND
SERVICES THROUGH A SOCIAL JUSTICE LENS

AMANDA J. HANCOCK

AN EXPLORATION OF HIV TESTING POLICY AND SERVICES
THROUGH A SOCIAL JUSTICE LENS

By

Amanda J. Hancock, B.Comm (Hons)

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Abstract

The objective of this study was to evaluate the congruence between HIV testing policies and everyday testing practices in a small urban centre in Newfoundland and Labrador (NL). Social justice principles were used to explore the challenges associated with anonymous testing in a small urban centre and how current service delivery practices may be affecting “at-risk” populations and other test seekers who require a higher degree of confidentiality. Framed within a constructivist epistemology, qualitative description was used to determine data collection and analysis strategies. The findings are presented within an expanded social determinants of health framework, which emphasizes health inequalities as a driver of poor health outcomes. Data were collected from four testing sites using individual interviews and a document review of policy-related documents. A reflexive journal was logged throughout data collection and used for verification during analysis, which included thematizing, diagramming and coding.

The applicable legislation was the Communicable Diseases Act, which requires name based reporting. Participants interpreted anonymous testing as being illegal according to this legislation. Findings demonstrated a history of offering anonymous testing at all testing sites and present-day practices that fit the definition of anonymous testing, but were referred to in official policy and understood by participants as being non-nominal. An alternate definition of anonymous testing is proposed where contact information is not requested or recorded and pre- and post-test counseling is delivered face-to-face. Redefining the provision of HIV testing services in this way supports the call to increase the visibility of social justice in Canadian public health policy. Eighteen recommendations are offered to guide this legislative and policy change.

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An Exploration of HIV Testing Policy and Services through a Social Justice Lens

1.0 Introduction

Human Immunodeficiency Virus (HIV) is a preventable sexually transmitted infection that causes acquired immunodeficiency syndrome (AIDS), which has no known cure. The word *testing* is used in this study to describe this preventative service; however, this inquiry was concerned with the voluntary counselling and testing (VCT) model as described by the United Nations Working Group on AIDS (UNAIDS) and the World Health Organization (WHO) (2004) and adopted by the Public Health Agency of Canada (PHAC) (2006a).

In Canada, three VCT options are differentiated by the type of personal information collected and the coding system used to label the specimen when it is sent to the laboratory for testing (PHAC, 2007a). In *nominal or name-based* testing, test-seekers must provide their complete personal information including their name and MCP number. This personally identifying information is then used to label the specimens sent to the laboratory for testing. *Non-nominal* testing requires collection of the same information as the nominal process; however, the label to identify the specimen is completed with something other than the test seeker's¹ full or partial name, such as an alphanumeric code. The PHAC (2007a) definition of *anonymous* testing states that the identity of the test seeker is not known to the provider and a code is used to label the specimen. To

¹ Where possible, I employ the term test seeker instead of "individual seeking an HIV test". I coined this phrase after reading Kodner and Spreeuwenberg's (2002) reference to "care-seekers" (p. 3)

summarize the PHAC definitions, with nominal and non-nominal testing, the test seekers' identifying information is provided and kept confidential. In anonymous testing, personally identifying information is never collected or recorded. The VCT model asserts the importance of maintaining three key elements – confidentiality, counselling, and informed consent. This inquiry focused on the first 'C', confidentiality.

1.1 Problem Statement

I became interested in formally studying this subject after noticing inconsistencies in public information about the availability of HIV testing in a small urban centre in Newfoundland and Labrador (NL). I was intrigued by the concept of anything anonymous in this small urban centre when I saw advertisements for anonymous testing in local and student newspapers (The Muse, 2008). Shortly after, I found academic literature suggesting that anonymous HIV testing had, in fact, been available in the small urban centre at one point in time; however, as of 2008 there had been “no anonymous testing for HIV or HCV available anywhere in NL” (Gustafson, Goodyear & Keough, 2008, p.192). Having seen the advertisements just weeks before, I wanted to know more.

Through my coursework, I had learned that PHAC had been created in 2004 to provide national guidance, leadership and coordination in public health with a mission to “promote and protect the health of Canadians through leadership, partnership, innovation and action in public health” (PHAC, 2008). I turned to PHAC for answers. Two tables in the epidemiology update (PHAC, 2007a) were entitled “HIV testing and HIV reporting by province/territory” (p. 15) and “Status of anonymous HIV testing by province/territory” (p. 16). These tables demonstrated the availability of the three types of

HIV testing in the various provinces and territories. According to these tables, seven provinces offered anonymous testing. Three of the seven provinces that offered anonymous testing (NL, Ontario, and Alberta) had footnotes explaining various conditions of province-specific testing service provision. The footnotes for NL's anonymous testing stated that all positive results become "part of the nominal/name-based system, in which counselling, follow-up care, and HIV data reporting are all done nominally" (p.15). A second footnote stated that anonymous testing was "available upon request but is not part of the official guidelines for the province" (p.16).

I looked for these "official guidelines"; however, they were not available from the Government of NL's Department of Health and Community Services at the time of the study (Gillian Butler, Personal Communication, April 2009). I used the Mesh terms *sexually transmitted disease*, *viral*, *anonymous testing*, *preventive health service*, and *public health* to search the academic literature listed in the Cochrane Database of Systematic Reviews and Pub Med, and found no studies describing the evolution of HIV testing delivery in the small urban centre, nor were there any descriptions of if and how anonymous testing procedures were carried out in practice. I also conducted an extensive search for grey literature and found similar results.

1.1.1 Research Question and Objectives

The question that guided my research was "Are HIV testing policies and everyday HIV testing practices congruent in this small urban centre?" The specific study objectives are listed here:

1. Review the HIV testing policies at each of the selected sites;

2. Determine policy guidelines for maintaining anonymity if anonymous testing is offered;
3. Examine every day HIV testing practices of the health care providers who have been or are presently involved in providing HIV testing information and/or administering HIV testing;
4. Articulate the similarities and differences between organizational policies and practices at community-based organizations and in public health settings;
5. Evaluate and interpret the congruence between established policy and everyday practices; and
6. Articulate the challenges associated with offering anonymous testing in a small urban centre in NL.

Given the complexity of these issues, I chose to study this phenomenon without introducing any kind of intervention or treatment. This is what Polit and Beck (2004) refer to as “non-experimental research” (p. 46). After formalizing the research question and objectives, I began a formal inquiry to find out what was involved in HIV testing, the policies that govern the process, and how it plays out at the locations where it is offered in the small urban centre.

1.2 Study Background

1.2.1 Personal Interest in the Area of Inquiry

Kaas (2004) describes public health as a “societal approach to protecting and promoting health” (p.232). Its goal is to improve the health of communities by favouring socially-oriented strategies and it is central to the societal actions and inactions that

influence the priority of items on policy-makers' agendas (DeCock, Mbori-Ngacha, & Maru, 2002). While every area of health services has its own focus, the specific aim of public health services is to improve the well-being of communities through social rather than individual action. This is unique from other health services that may be clinical in nature or focus heavily on treating individual illness. Kaas (2004) provides examples of other public health initiatives such as offering vaccinations, immunizing schoolchildren, engaging in epidemiologic research, offering maternity services for pregnant women, and maintaining a safe water supply.

I became interested in public health during a volunteer internship in South Africa from February to June 2007. It gave me insight on the impact of HIV and AIDS around the world and when it finished, I wanted to learn about the impact and existence of HIV and AIDS in my hometown. I was particularly interested in if and how HIV testing was being offered given that infrastructure and resources to provide care and services were far more sophisticated than those I had seen in Africa. I learned that HIV testing was classified as a public health and community service, one of many services that make-up the full continuum of health services provided by the regional health authority that serves the region in which the small urban centre was situated. In July 2007, I began volunteering with an AIDS-service community-based organization. I realized that even the most informed local HIV/AIDS advocates were challenged to clarify the differences between various types of HIV testing procedures from both a theoretical and practical standpoint (M.B., Personal Communication, September 2007). They had trouble articulating the differences between the various types of HIV tests, what was available in the small urban centre and the details of the process from a client's perspective. For

example, community advocates were uncertain whether or not anonymous testing was available and the differences of personal information requirements during non-nominal and anonymous testing.

I started an informal inquiry during which I spoke to local health care providers and policy-makers. The confusion about HIV testing extended beyond circles of the HIV/AIDS community workers and advocates. I heard several anecdotal accounts of the challenges involved in developing policies to govern this service as well as the practical dilemmas that were arising in clinical settings (S.B., Personal Communication, March 2007). It became apparent early on that researching preventative public health strategies, such as HIV testing, would require an understanding of the population for which the preventative strategy was intended. Research from across disciplines consistently supports that HIV infection is higher among some populations (Barnett, Whiteside & Desmond, 2001; DeCock, Mbori-Ngacha, & Maru, 2002; Dodds, Colman, Amaratunga, & Wilson, 2001), is associated with certain behaviour and activities (Goldenberg, Shoveller, Koehoorn, & Ostry, 2007; Higgins, Galavott & O'Reilly, 1991), and entrenched within the most marginalized communities (Spigelman, 2002).

In 2007, the categories used to identify the sub-populations that are over-represented in the occurrence of HIV infection in Canada included youth, women, older Canadians, Aboriginal people (First Nations, Inuit, Métis), men who have sex with men (MSM), injection drug users (IDUs), persons living in Canada who come from countries where HIV is endemic, and prisoners (PHAC, 2007a). In NL, the Department of Health and Community Services (2008) recognized the following risk factors for HIV exposure – MSM, IDU, a combination of MSM and IDU, recipients of blood and/or blood

products, heterosexual activity with a person who engages in risky activities, prenatal transmission, medical exposure, and non-medical exposure. PHAC (2007a) uses the term “high-risk” (p. 11) to describe these groups. Although I use the term “at-risk” groups, I am cognizant of the methodological challenges associated with the derivation of such categories. (These challenges will be discussed later).

1.2.2 Study Context

This section describes several historical events that influenced the unique unfolding of HIV in NL including a court case, regionalization of health services, a recent privacy breach by a local healthcare provider, and human resources challenges for infectious disease specialists in NL. Firstly, between 1990 and 1995, approximately 40 people in the Conception Bay North, a community just outside St. John’s tested positive for HIV (Bergman & Welbourn, 1995). This represented an extremely dense rate of infection given that there were only 5,000 people in the region and 156 HIV positive individuals in the entire province at the time. The unusually high rate of infection was traced back to Raymond Mercer of Upper Island Cove who knowingly infected his sexual partners (Elliot, 1997). Eventually, Mercer was criminally charged with two accounts of criminal negligence causing bodily harm for having unprotected sex without disclosing his HIV infection. Mercer pleaded guilty to infecting only two women though many locals suspected that the real number was much higher. In 1991, he was sentenced to two and a half years imprisonment and in 1992 his sentence increased to 11 years in a precedent setting court case. The sentence was appealed to the Supreme Court of Canada

and refused. In 2000, Mercer was denied parole and in 2003, Mercer was released after serving his complete 11-year sentence (CBC News, 2000).

Mercer's arrest, trial, and legal proceedings became the focus of national media throughout the 90's. This created a link in the minds of the Canadian public between Conception Bay North and HIV/AIDS. Economic activity was negatively impacted and declines in tourism revenues were attributed to the negative regional perception that had resulted from the Mercer case (Bergman & Welbourn, 1995). Actions taken by high profile institutions such as the Red Cross, which stopped collecting blood from the area, further stigmatized the community. An anonymous article in the *Canadian Medical Association Journal* (1998) used the informal term adopted by citizens who were aware of the localized spread of infection resulting from Mercer's index case when referring to the rural community as "the AIDS capital of Canada" (p. 1005). The article declared that the region may have finally lost this distinction. These events are a significant consideration when examining the availability of testing services in any small urban centre in NL. This recent history suggests there are lingering effects of stigma, a need for ongoing education, and a duty to provide testing services that offer the highest degree of confidentiality.

The second event in the unfolding of HIV in the province was a series of administrative and structural changes to health and community services announced by the Government of NL in September 2004 (Eastern Health, 2006). This process is referred to as the *regionalization* of health services and is further described throughout the document. Fifteen existing boards were transformed into four regional integrated health authorities – Eastern, Central, Western and Labrador-Grenfell. The original health and

community service organizations that were merged are now commonly referred to as “legacy organizations” (Joan Decker, Personal Communication, June 2009). Each came with their own stated organizational values, culture, policies, and practices. This is relevant to the study context because, as Dolan et al. (2005) explain; many Canadian coastal communities’ access to local health and social services has been negatively affected by this restructuring.

Thirdly, on November 22nd, 2007 a healthcare provider installed a file sharing program on her laptop while working from home. This caused her to unknowingly transmit 1,420 confidential medical files over the Internet that contained individual patient information including name, gender, health information, and test results for conditions including Rubella, Hepatitis A and B, Parvovirus, HIV, and other communicable diseases (Office of the Information and Privacy Commissioner, 2008). Awad, Sagrestans, Kittleson and Savelle (2004) discovered that “the fear of health providers breaking confidentiality is exacerbated when reports of specific instances of breaches are made public” (p. 123). This conclusion is further discussed within the context of the study’s findings, which supported that confidentiality concerns were an important barrier that impeded access to HIV testing services. This privacy breach is related to HIV testing in the small urban centre because it created a situation whereby a health care provider’s guarantee of confidentiality may not assuage the privacy concerns of individuals seeking HIV testing.

Finally, at the time of my study, the regional health authority was facing public discord for the loss of the province’s only infectious disease specialist who was responsible for treating patients with HIV and AIDS and many other communicable

diseases (Telegram, 2009). Community advocates were dissatisfied with the loss of this employee since it was the only infectious disease specialist in the province (T.W., Personal Communication, January 2007).

1.2.3 Locating the Study

Establishing a broad definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948) was an important development for public health. It marked the beginning of a paradigm shift through which society began to acknowledge the social factors that shaped people’s health. Documents like *The Lalonde Report* (1974) and *The Ottawa Charter for Health Promotion* (WHO, 1986) have been credited as instrumental to the recognition of the social determinants of health framework and the importance of community involvement in public health policy around the world. Evans, Barer and Marmor (1994) described the social determinants of health as powerful influences on “how healthy we are as individuals and societies” that determines “why some people are healthy and others are not” (p. xiii). Over time, the social determinants approach has “gained widespread acceptance as the appropriate framework for developing and delivering public health policy” (Graham, 2004, p. 105).

Due to its popularity in policy circles, I have not abandoned the social determinants of health as a framework for analysis. I have, however, whenever possible and relevant used recommendations that focus on expanding the social determinants framework to include and make explicit the *determinants of health inequality* drawing heavily from the work of Graham (2004). The concepts of social positioning and a range

of proximal, intermediate and distal factors to formulate recommendations for translating the expanded framework within the policy arena are discussed in the literature review and emphasized in the discussion to make sense of the findings. I have also used Labonté, Polanyi, Muhajarine, McIntosh and Williams' (2005) critical view of the population health approach. In response to their call to build upon explicit social values and analyses, I have made an attempt to strengthen this emphasis on social determinants of health inequality as a means to increase the visibility of social justice as an explicit value in Canadian public health. To explain the principles and importance of social justice, I draw from the works of Braveman and Gruskin (2003), Edwards and Maclean Davison (2007), Gostin and Powers (2006), and Rawls (1999).

Social justice is a commitment to the preservation of human dignity and respect for all members of the community (Rawls, 1999). It aims to advance human well-being and improve public health by focusing on the needs of the most disadvantaged. This approach recognizes that there are many factors that can lead to poorer health outcomes and that disadvantages extend to almost every aspect of social, economic, and political life. Gostin and Powers (2006) believe that stating social justice as an explicit value is an effective way to approach challenges in public health ethics and policy. Edwards and MacLean Davison (2007) identify opportunities to embed social justice within public health values in Canada. One such opportunity is a document entitled *Core Competencies for Public Health in Canada* (PHAC, 2007b), which reflects the strategic direction for the future of public health in Canada by listing 36 desired core competencies to formalize the essential knowledge, skills and attitudes sought in public health employees across the country. The document is intended to improve the effectiveness and quality of the

healthcare workforce by offering evidence-informed standards to ensure an appropriate practical representation of proficiency in the skill sets of providers, consultants, specialists, managers, and other public health officials. It is noted that the document lacked an explicit reference to social justice. Edwards and MacLean Davison (2007) argue that the way to improve public health policy and programming in Canada is through “the explicit recognition of social justice as a foundational value of public health” (p. 130).

I explore the benefits of anonymous testing and provide evidence that certain populations prefer anonymous testing (Bindman, Osmond, Hecht, Lehman, Vranizan et al., 1998; Hoxworth, Hoxworth, Hoffman, Cohn, & Davidson, 1994; Kegeles, Catania, Coates, Pollack, & Lo, 1990). Certain policy measures, such as partner notification, contact tracing and mandatory reporting make it impossible for people who prefer anonymous testing to access it. I feel that legislation requiring detailed mandatory reporting of personal information denies some people of their right to testing in the way they would like it. Therefore, they are being denied their rights to a health service that may help them attain the highest standard of health.

1.3 Rationale for the Study

The main goal of this study was to evaluate and interpret the congruence between the provincial policies about HIV testing as they were described in policy-related documents and everyday practices in the small urban centre. Doing this required formulating a clear and concise articulation of the procedures followed for the different types of tests with an emphasis on non-nominal and anonymous in the various settings at

which HIV testing was available. By doing so, I hoped to respond to a need identified by Baum, Gollust, Goold, and Jacobson (2007) for research that will enhance people's understanding of the ethical challenges faced by public health providers on a daily basis in order to prepare them to address similar challenges in future.

This may be of benefit to some of the people involved in public health services including providers, policy-makers, and scholars. The findings that resulted from this inquiry attempt to shed light on issues pertaining to anonymous testing as an appropriate specialized service that could be beneficial in any small urban centre in NL. It is hoped that highlighting areas of divergence between policy and practice, and making recommendations for legislative, systemic and practical improvements may inform academics and decision-makers engaged in future policy debates on the matter.

1.3.1 Anonymous HIV Testing - An Ethical Tension

Kaas (2004) describes the field of HIV/AIDS as one that has encountered many classic public health moral tensions, "from societal rights versus individual liberties, to justice and health care access" (p.234). HIV testing issues have evolved from being extremely controversial in the 1980s to now. In the early days, when treatment was not yet available, individuals who tested positive could end up worse off for having been diagnosed with a highly stigmatized disease for which there was no medication. Since anti-retroviral medications have become available, the ethical question of providing anonymous HIV testing has been widely debated. This section explains three processes that are often at the centre of the anonymous testing debate – partner notification, contact tracing and reporting.

Partner notification is a “secondary prevention process through which sexual partners and other contacts exposed to an STI are identified, located, assessed, counselled, screened and treated” (PHAC, 2006b, p. 16). Partner notification is carried out by the individual who has tested positive for a condition, who is referred to as “the index case” (p. 14). Contact tracing, on the other hand, also involves notification of past partners and other contacts exposed to an STI, however, it is carried out by a public health provider. The provider makes contact with a list of past partners and contacts based on information provided by the index case. The provider does not state the name of the index case during contact tracing. Kaas (2004) describes the public health benefits to partner notification and contact tracing as aiming to protect unknowing contacts from risk of infection. The possibility for complete or partial loss of confidentiality is a disadvantage of these processes. Even when the name of the index case is not explicitly disclosed, contact tracing can lead to the identification of the index case by default, circumstance or process of elimination.

The Canadian Guidelines on STI testing discuss the importance of provider/patient confidentiality for people “working in agencies receiving personal information” and the importance of informing service users that information is “reported to authorities only as required by law” (PHAC, 2006b, p. 15). There are a variety of circumstances that merit reporting to authorities by law; however, this document discusses mandatory reporting in the context of communicable diseases where the provincial government departments responsible for epidemiological surveillance are considered the authorities. In NL, this process is legislated by the Communicable Diseases Act. In the past, the distinction between collecting information for surveillance

and for contact tracing has been unclear for those accessing testing services (PHAC, 2006b). The difference between the two practices rests with the personal identifiers: it is possible to conduct surveillance without personal identifiers, but it is impossible to do contact tracing without personal identifiers.

Thirdly, mandatory reporting requires providers who confirm a communicable disease to report that case to the provincial government. Kaas (2004) summarizes the reasons for and against mandatory reporting. Advocates of mandatory reporting suggest it enhances the ability to understand the disease, which offers the possibility of targeting educational material and potential treatments towards those who are infected. The availability of antiretroviral medication strengthened the arguments of those in support of mandatory reporting by partially alleviating the imminent death stigmatization. Critics, on the other hand, maintain that mandatory reporting is an invasion of privacy. They remind us that mandatory reporting is not required for educational efforts aimed at prevention and its potential to deter people from testing due to fear of reporting. Furthermore, critics argue that reporting legislation requires extensive and detailed personal information beyond that which is necessary for surveillance.

The Canadian Guidelines on STI testing (PHAC, 2006b) offer no explanation as to how providers should proceed if a test seeker is hesitant or unwilling to provide personal information. This introduces the possibility that a health care provider may have to negotiate the terms of testing for him or herself. The Guidelines do not address the clinical or reporting procedures to follow when a test seeker does not provide personally identifying information even though this information may be required for legal reporting purposes. Individuals seeking testing may be apprehensive about providing personal

information for a number of reasons; fear of partner notification and mandatory reporting (Hoxworth et al., 1994; Lansky, Lehman, Gatwood, Hecht, and Fleming, 2002). The impact of mandatory reporting is thought to have the most severe impact on at-risk individuals who could be discouraged from seeking testing due to fear of the consequences.

1.4 Assumptions and Scope

In this section three important assumptions on which this inquiry was based are made explicit. Firstly, HIV testing is an effective strategy for preventing the spread of HIV/AIDS. This is supported internationally by the WHO (2006a) has declared that HIV testing and counselling are “key entry points for individuals and their families to access HIV/AIDS prevention, treatment and care services” (p. 5). Secondly, as demonstrated by Smith (1999), traditional health services have not and do not always service the needs of marginalized populations who can benefit from them the most. I respond to this by incorporating social justice principles (Braveman & Gruskin, 2003; Gostin & Powers, 2006; Rawls, 1999) Thirdly, I believe that steep social gradients are associated with steep health gradients (Labonté et al., 2005). That is to say, I support scientific knowledge and theory suggesting that social factors could play an important part in creating disparity at one or many points along the causal pathway that determines health. Therefore, improving the health of at-risk populations through any reasonable means, such as anonymous HIV testing, may reduce health inequity and improve the well-being of the community at-large.

1.4.1 Epistemological Assumptions

Qualitative methodology is aligned with my epistemological and ontological beliefs that there are multiple meaningful components of the social world from which knowledge can be derived. Crotty (1998) describes this as a constructivist epistemology, which maintains that scientific knowledge is constructed by humans.

1.4.2 Study Limitations

My initial goal was to include all settings that offered HIV testing services in the small urban centre. Due to the closure of the infectious disease clinic near the start of my data collection period, the acute care setting identified in the fact-finding phase was excluded early in the data collection period. Realizing the need to concentrate on clarifying non-nominal and anonymous testing policies and procedures, I focused on settings that had been associated with anonymous testing in the past. As a result, this inquiry is heavily grounded in community-based settings in an urban centre and does not reflect the provision of HIV testing services in acute care settings, family physicians' offices or walk-in clinics. These locations represent important points of HIV testing service delivery whose procedures and practices are different from community settings. Additionally, the findings may not accurately reflect the needs of Aboriginal communities given the geographic location of the study setting.

Benoit, Jansson, Millar, and Phillips (2005) define community as "persons located outside the academy, inside or outside governmental or administrative policy bureaus; the target population itself; persons proximal to the target population (such as service providers); or a constituency of citizens in a particular locale" (p. 265). When this

definition is applied to the HIV community in this small urban centre, the population is clearly small and close-knit. Fraser (2004) has suggested that in such situations, the researcher has a heightened obligation to protect individual participants' confidentiality due to the potential harm that could result from loss of confidentiality. It is possible for small amounts of demographic information to make individuals readily identifiable. Recognizing I was working with a small community, it was necessary to take extensive measures to protect the identities of the participants and their organizations. This was especially important in this study since, at times, individual participants would express personal views that did not reflect those of their organization or compliance with the law. A description of the steps that were taken to protect identity is provided in a later section. The term "small urban centre" was borrowed from Gustafson, Goodyear, and Keough (2008) and is used throughout this document in place of the name of the city to protect the identity of participants.

A second methodological weakness of this inquiry was the wording of two sentences in the study invitation (Appendix A) that was made available to all participants and in the ethics application. The first statement in the study invitation was "all policy-related documents including meeting minutes, emails, briefing notes, or any other hard copies that have been or currently are used to direct testing procedures and inquiries" (Appendix A, p. 1). My intention here was to establish a broad definition of policy to impress a sense of my belief that informal documents can also determine organizational process. However, for a regional health authority that had just participated in an arduous court case in which emails were used as evidence, I believe this definition created resistance. The second statement in the ethics application was "if there are no HIV testing

policy documents, it will be considered a significant finding.” For community-based organizations that are short on the resources required to establish formalized policies, but still rely on funding from various levels of government, this likely created some initial resistance and may have influenced how the participants responded in interviews.

Finally, I use the term “at-risk” for ease of writing and I consider this to be a limitation for the following reasons. Labonté et al. (2005) believe that a blurred interrelationship exists between population health and social change. They attribute this vague relationship to the lack of attention paid to the role of social inequality in traditional population health analysis and discourse. This, in part, has been caused by reliance on raw data in the absence of ideological positioning and theoretical support. More specifically, while ample numbers and statistics support that higher income improved health outcomes, there is little in the way of qualitative inquiry that focuses on the social processes underlying health inequality. Other critiques of the population health approach include its reliance on quantitative datasets, ignorance of human agency, and the politicization of research knowledge. These areas of weaknesses have resulted in a failure to articulate clear and achievable policy options for governments. HIV/AIDS statistical data provide an excellent example of the epidemiological pitfalls that have permeated population health data described by Labonté et al. Categories are used to identify sub-populations that have historically been over-represented in the occurrence of HIV infection (PHAC, 2007a), which are referred to as at-risk groups. It is necessary to point out the potential for such classifications to propagate stigma, reinforce social exclusion, and risk underemphasizing health inequality (Graham, 2004). Most strikingly, they ignore intersecting identities and other compounding factors present in complex

social realities. One example illustrated by Namaste (2009) is that the MSM classification overlooks bisexual men and attempts to categorize intersecting and overlapping characteristics into neat epidemiological categories.

1.5 Significance of the Study

I began this inquiry with the intention of evaluating and interpreting the congruence between the provincial HIV testing policies and everyday practices. I hoped to gain an understanding of practical HIV testing procedures in the small urban centre, so that I could communicate this information to community-based organizations and other interested audiences. It was my intention to shed light on issues of disclosure and ethics as they pertained to anonymous testing using a social determinants of health framework that emphasized health inequality in the name of social justice. As I worked through this inquisitive journey, I felt optimistic about its potential to hold value beyond its originally intended scope into a broader field of health ethics.

This inquiry supports a progressive shift away from traditional bioethical decision-making and towards the formalization of a set of values to guide decisions in public health ethics as a field in its own right. Historically, bioethics has centred on sound decision-making in clinical and research-oriented settings about issues such as informed consent, patient agency, reproductive and end-of-life decision-making by emphasizing individual patients' rights to access health care systems and services (Baum et al., 2007). Specific values that guide decision-making in bioethics include individual autonomy, beneficence, non-maleficence, justice, fairness and utility. It rarely calls upon a broad definition of health that encompassed more than the absence of disease. The inadequacy

of an autonomy-focused, bioethical approach to community-level public health issues led to the acknowledgement of public health ethics as a field of inquiry in its own right. Kaas (2004) has described the emergence of public health ethics as the newest sub-field of public health as being distinctly separate from bioethics. The relationship between ethics and health as a common good is complex and encompasses fundamental tensions between conflicting values and guiding principles. As a result, public health is a particularly challenging area for policy-making and service delivery as it struggles to maximize population-level utility and justice while minimizing infringements upon individual rights (Thomas, Sage, Dillenberg, & Guillory, 2002). The primary ethical principles that guide public health include communitarianism, utilitarianism, evidence, justice, accountability, efficiencies, and political feasibility. Other values that Baum et al. (2007) describe as being taken into consideration include beneficence, non-maleficence, and autonomy. I hope to popularize the explicit use of the term social justice in such statements of values and guiding principles.

In managing public health, policy-makers and practitioners confront a number of ethical tensions and are forced to respond to socio-political, cultural and evaluative concerns. This is a reality at the macro level, with issues such as resource allocation and disease control, and the micro level, with day-to-day decisions about clinical priorities. I began to see the practical challenges of developing HIV testing policy as a matter of public health ethics that required attention: providers and clients do not always share a common understanding about the differences between confidential and anonymous testing. As a result, in the face of unclear policies and a shared language, health care providers may be left to negotiate potential tensions between the testing policy and

patients' preferences. A providers' response to a person seeking testing who refuses to provide his or her contact information is an example of a public health ethics dilemma. In the interest of population-level utility, the preferred option would be to do the test and hope the individual takes the initiative to contact the organization for the test results. However, abiding by organizational policy would require the healthcare provider to refuse the testing service because of the individual's unwillingness to provide contact information. Other ongoing controversies in the field include the legitimate scope of public health, the balance between public health and civil liberties, and the appropriate role of the government.

1.6 Thesis Outline

This document describes my research in HIV testing in a small urban centre, which was undertaken as a degree requirement for a Masters in Applied Health Services Research. Chapter one defines the research question and objectives and provides important background information including my personal interest in the area of inquiry, the context and progression of HIV/AIDS and health service delivery in NL, and the significance of the HIV testing services to the broader tenets of public health in Canada and social justice as an explicit value. It introduces the rationale of the study by detailing my own impressions about the availability of the service based on policy-related documents and information obtained from local providers and media. My epistemological assumptions are explained and the methodological limitations of the study are claimed. The significance of the study as a contribution to the broader field of public health ethics is explained.

Chapter two provides detailed literature on four broad sections – sexually transmitted infections, HIV, HIV testing, and policy-practice issues. It begins with an overview of sexually transmitted infections and the Canadian guidelines for reporting and surveillance. It discusses the importance of preventative measures and barriers to accessing testing. Next it provides information on HIV including the global impact, its presence in Canada and the issues of stigma and harm reduction. The third section provides information on HIV testing such as the voluntary counselling and testing model, the types of tests available throughout Canada, and information about testing services in NL. The fourth section discusses the meaning of policy and the evolution of public health policy in Canada. It provides an overview of Graham's (2004) expanded social determinants of health framework that are used to frame the findings and discussion. It reviews controversial issues of HIV testing and human rights and the practical challenges of anonymous testing in public health service delivery.

Chapter three provides detailed information on my methodology and methods. It describes the processes used to design the study, obtain appropriate approvals and various ethical considerations. It explains the constructivist epistemology underpinning this study. This chapter describes the qualitative descriptive process used to collect data from four testing sites using interviews and documentary analysis of current and past policy-related documents. It also explains the significance of the reflexive journal and the process used to develop key themes through diagramming, coding and thematic analysis.

Chapter four presents the study findings in detail. The first section provides an overview of the three organizations responsible for the four testing sites and a description of individual participants' perceptions of non-nominal and anonymous testing and risk-

taking behaviour. Introductory information about the testing policies and definitions provided by both community-based organizations and the regional health authority is also summarized. An overview of past and current HIV testing procedures at the four testing sites is provided, as well as concerns expressed by participants about these procedures. The last section of chapter four summarizes key areas of incongruence.

Chapter five discusses the meaning of the term anonymous as it is used in preventative public health initiatives and clarifies other potentially confusing terms. It explains my theory behind the areas of incongruence noted in chapter four. The discussion is divided into three main sections – the role of the Communicable Diseases Act in the incongruence, the need to increase clear communication about HIV testing policies and procedures, and the need for explicitly anonymous HIV testing in this small urban centre within a social determinants of health inequality framework. Eighteen recommendations are made for consideration with regards to required clarification and updates to provincial legislation, increasing communication of policies and procedures in formalized and community-based settings, disseminating information to the public and changes to federal documents. Finally, it describes how I plan to disseminate this research and suggests areas that merit further inquiry in future research.

2.0 Literature Review

The purpose of this literature review is to provide information that will allow for a meaningful examination of the practical implications between policy guidelines and public health practices. The chapter begins by expanding the traditional social determinants of health framework to include *determinants of health inequality* and presents principles of social justice as they apply to HIV testing and human rights. Background information on sexually transmitted infections and HIV is provided. The importance of HIV testing as a preventative health service and barriers to access are discussed. The availability of HIV testing across Canada is reviewed, and the advantages and disadvantages of anonymous testing are stated. Public health policy and Canadian guidelines for STI treatment, reporting, and practice are presented. The final section of the literature review addresses the challenges created by unclear policy guidelines at the point of service delivery.

2.1 Social Determinants of Health and Social Justice

The traditional social determinants framework is based on an understanding that one's location in the social structure of society has a major influence on health and well-being. Health improves at each successive stage of social advantage as defined by twelve key determinants. PHAC (2003) lists the following determinants – income and social supports, social support networks, education and literacy, employment and working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, gender and

culture. This section defines social position and health equity and provides rationale for expanding this traditional framework to incorporate Graham's (2004) identified areas for improvement.

2.1.1 An Expanded Social Determinants of Health Framework

Graham (2004) challenges the traditional determinants-oriented approach and highlights the need for researchers to place increased emphasis on the social processes that drive health inequalities to inform policies that will address health inequalities. Most importantly, when addressing a "policy audience" (p.118), Graham (2004) emphasizes the importance of differentiating between the *social determinants of health* and *social determinants of health inequalities*.

Determinants of health inequality are "those central engines of society that generate and distribute power, wealth and risks, differential exposure and vulnerability, and the differential consequences of ill health for more and less advantaged groups" (Graham, 2004, p. 112-3). Failure to distinguish them from traditional determinants of health that promote health and prosperity suggests that policies associated with positive trends in health determinants are also associated with persistent negative influences and disparities in their distribution. This is not the case because traditional health determinants and their associated benefits are not evenly distributed across population groups. Terminology used to describe this uneven interaction with health status must be available to affect change in public policy.

Social position refers to an individual's location in the social hierarchies around which his or her society is built. At the most distal level, social resources like education,

employment opportunities, political influence, income, and property affect the opportunities available in society. When these systems are accessed by members of society, the framework for analysis must consider the structural inequalities that are inherent within them. These structural inequalities exist throughout the education system, the labour market, property and wealth, and political influences. Depending on social position, some individuals will face more structural inequalities than others. As such, social position shapes an individual's ability to access intermediate factors that are more closely associated with well-being (social and material environments of home, neighbourhood, workplace, behaviour and physiological factors).

Braveman and Gruskin (2003) offer a definition of health equity that helps illustrate how social position impacts health. This definition was created to establish clarity in terminology when assessing whether local, national and international policies are leading toward or away from greater social justice in health. Explicitly defined, health equity is "the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage — that is, different positions in a social hierarchy" (p. 254).

The highest attainable standard of health is that which is displayed by the most socially advantaged group within a society. The health levels of this group demonstrate what is biologically possible and, in theory, could be attained by every human being within a society. Systemic inequities, however, put certain populations at a disadvantage with respect to their health. Examples of groups of people who experience social disadvantage due to systemic factors include people who are poor and members of a

disenfranchised racial, ethnic, or religious group, and others. Many complex and interrelated factors can lead to social disadvantage – some examples include poverty, substandard housing, poor education, unhygienic and polluted environments, and social disintegration (Gostin & Powers, 2006; Braveman & Gruskin, 2003). These circumstances can lead to poorer health outcomes and extend the disadvantage to most every aspect of social, economic, and political life. Discrimination, marginalization and stigma represent obstacles to health equity, or determinants of health inequality, for socially disadvantaged individuals. The relationship between poverty and HIV/AIDS illustrates how this expanded framework might be operationalized.

The nature of HIV/AIDS has been described as “complex and ever-changing” with an ongoing debate about the cause and effect of the complex social realities that are so often associated with HIV transmission and infection (Spigelman, 2002). For example, ‘is poverty responsible for HIV/AIDS because it forces people into situations where they are at higher risk of contracting the virus?’; or ‘is poverty a consequence of having HIV/AIDS by forcing people to leave the paid labour force in order to cope with living with this condition?’ Using an expanded social determinants of health framework, one could reason that these questions are doing exactly what Graham (2004) has cautioned against by “blurring the distinction between the social factors that influence health and the social processes that determine their unequal distribution” (p. 109). Specifically, these questions feed the assumption that “health inequalities can be diminished by policies that focus only on the social determinants of health” (p. 109). We must treat poverty as a driver of health inequality driven by social processes, and the widely recognized social determinant of “income” (PHAC, 2003) as a health determinant.

2.1.2 A Social Justice Approach

As Gostin and Powers (2006) remind us, there is no single organizing principle that can answer every question regarding the broad direction of public health; however, certain core commitments of social justice indubitably shed light on controversial areas of policy. As Braveman and Gruskin (2003) note, social justice and fairness can be interpreted differently by different people in different settings. As such, the principle of social justice is explained here. Social justice promotes fair distribution of the benefits and burdens of social cooperation (Rawls, 1999). With its roots in equity, social justice is committed to the preservation of human dignity and respect for all members of the community. Its aim is to improve public health by focusing on the needs of the most disadvantaged to advance human well-being.

Gostin and Powers (2006) provide examples of the public health policy imperatives that are emphasized in social justice approaches including “improving the public health systems, reducing socioeconomic disparities, addressing health determinants, and planning for health emergencies” (p.1054) with a constant emphasis on the needs of the most vulnerable. From a social justice standpoint, it is of heightened importance that policies and practices pertaining to conditions that impact the quality of life of at-risk groups are justified and are sensitive to the needs of the individuals in the group. An example of a public health policy that is insensitive to social justice would be a directive for an entire population to evacuate or seek shelter since many have neither private transportation nor the means to stock up on food or supplies that would allow for such an evacuation.

Young's (2006) parameters for achieving social justice focus on relating individual characteristics within the structural injustice along four dimensions - power, privilege, interest and collective ability. Each parameter is briefly explained and framed within an HIV testing and counselling context. Power refers to an individual's potential to influence a process and produce favourable outcomes. In HIV testing, test seekers have less power than public health service providers and policy-makers. Power differentials also exist within groups; for example, a test seeker who understands and advocates for his or her right to access a public health service has more power than a test seeker who does not pursue his or her right to the same service. While structural injustice is disadvantageous for some, it creates positions of privilege for others.

Privileged individuals have special moral responsibilities to take action that will correct structural injustice because they can adapt to changing circumstances without suffering serious deprivation. The researcher examining the service provision could be described as privileged because he or she will not likely suffer from changes to the service nor be affected by examining areas for improvement.

Interest describes the degree to which individuals wish to maintain or transform the structures that produce the injustice. In HIV testing, an at-risk test seeker may lack power and privilege, but he or she may display the most interest in improved anonymous HIV testing and counselling services. Therefore, that individual has the most interest in the policy change. This is consistent with Young's view that "victims" (p.128) often have the most interest in structural change.

Finally, collective ability refers to the "relative ease with which people can organize collective action to address an injustice" (p. 129). An example of a circumstance

that would enhance collective ability would be an upcoming HIV testing policy review. Social justice principles were used as a tool for analysis and interpretation is central to the study recommendations.

2.1.3 HIV Policy and Human Rights

The adoption and proclamation of the Universal Declaration of Human Rights in 1948 was the first global expression of rights to which all human beings are inherently entitled (United Nations, 2008). It includes those basic human rights principles outlined in the WHO Constitution (1946) and other human rights treaties including the right to a decent standard of living, education, health, freedom from discrimination, and freedom to participate fully in society. Canada is a member of the United Nations; therefore, these doctrines are embedded in our justice system. United Nations' membership requires compliance with the WHO's constitutional mandate for states to develop national policies and programs to support the fundamental right of every human being to "the enjoyment of the highest attainable standard of health" (WHO, 1946, 2006a, 2009b). The WHO strategy also highlights the need for collaboration at various levels and venues of service delivery to ensure that related initiatives will reach those at risk of sexually transmitted infections.

The concept of health as a human right is now used to demonstrate why clarifying anonymous HIV testing and counselling policies and procedures is favourable. Braveman and Gruskin (2003) claim that the right to health cannot be separated from other human rights because all human rights are considered "interrelated and indivisible" (p.255). The ability to access preventative health services is an essential part of the right to health.

Graham's (2004) definition of social position demonstrates that access to the opportunity to be healthy is uneven. Individuals in the lowest social positions face the most barriers to health. Barriers to accessing HIV testing may include discrimination, marginalization, stigma, low health literacy, and fear of confidentiality breaches.

Equalizing individuals' right to health requires addressing the most important drivers of social disadvantage and servicing the needs of the most disadvantaged before the needs of those in higher social positions. Failure to act on recommendations that would reduce barriers to the benefit of those in lower social positions is contrary to social justice principles. Acting on the recommendations offers an opportunity to equalize access to a preventative health services between individuals who occupy different social positions, which is the premise of health equity. In this way, failure to adapt systems to changing needs of the socially disadvantaged results in consistent denial of a fundamental right to health.

Political decisions and actions that would increase health may not always be politically desirable as determined by cost, public opinion, or other factors on which their success depends. Priorities according to social justice principles do not always occur because policy affects that negatively impact disadvantaged groups may not be evident to those in positions of power. It is important for those in positions of power to consider human rights in decision-making. Equalizing opportunities to be healthy requires addressing the most important social and economic determinants of health inequality. A wide and growing body of literature from low-income countries where HIV prevalence is high supports a human rights approach to testing, suggests there will be increasing needs for anonymous testing, recognizes the potential for variation between policy and

practice, and maintains that stigma is an important barrier to testing (Bell, Mthembu & O'Sullivan, 2007; Obermeyer & Osborn, 2007).

In Canada, advocacy groups like the Canadian HIV/AIDS Legal Network draw attention to domestic violations of human rights in the area of HIV policy to demonstrate how public policy can propagate fear about HIV systemically. At a Symposium on HIV Testing and Human Rights, 26 international experts declared that "practices of compulsory, involuntary, and 'routine' testing without informed consent contravenes basic human rights principles" (Canadian HIV/AIDS Legal Network, 2005). Despite efforts to keep the voluntary nature of testing at the "heart of all HIV policies and programs to comply with human rights principles and to ensure sustained public health benefits" (PHAC, 2006b, p.1), some Canadian HIV testing policies challenge the fair and equal application of the Canadian Charter of Rights and Freedoms (Department of Justice, 1982). Two examples are the immigration requirements at the federal level and blood tests for pregnant women and healthcare workers at the provincial level.

Foreign nationals applying for permanent residence in Canada and certain applicants for temporary residence are required to undergo an immigration medical examination. For persons over age 15 and under some other circumstances, this examination includes a routine test for HIV (Citizenship and Immigration Canada, 2009). The United Nations, however, does not support mandatory testing on public health grounds and recommends that all HIV testing be confidential, subject to the provision of informed consent, include pre- and post-test counselling and appropriate referrals to medical and psychosocial services are made for those who test positive (UNAIDS, 2004).

Policies for mandatory testing of pregnant women are in place in NL, Alberta, and British Columbia. Additionally, NL is moving toward mandatory testing of health care workers (College of Physicians and Surgeons NL, 2009; McLean, 2009). Movements towards compulsory and mandatory testing take away the ability of individuals to maintain confidentiality during the testing process and, I suspect, will result in an increased demand for anonymous testing as people clamour for confidentiality – real and perceived. The Canadian HIV/AIDS legal network (2005) highlights that in many mandatory testing situations, pre and post-test counselling is inconsistent and unevenly applied.

2.2 Sexually Transmitted Infections and HIV

A sexually transmitted infection (STI) is a type of infection that is spread primarily through person-to-person sexual contact. Some are treatable and cause no lasting health effects, while others are untreatable and may cause death. Sexually transmitted infections may also be transmitted from mother to child during pregnancy and childbirth, or through blood products and tissue transfer (WHO, 2009a). There are more than 30 different sexually transmissible bacteria, viruses and parasites, which result in a wide variety of conditions that can be symptomatic or asymptomatic. Globally, the most common STIs are “gonorrhea, chlamydial infection, syphilis, trichomoniasis, chancroid, genital herpes, genital warts, human immunodeficiency virus and hepatitis B infection” (WHO, 2009a). According to PHAC (2006b), the most common STIs in Canada include Chlamydia, gonorrhea, human papilloma virus, and genital herpes. HIV is described as “rare in general practice” (p. 4).

HIV is controllable but is ultimately an incurable sexually transmitted infection. The virus attacks the immune system and compromises its ability to protect our bodies from infection and disease. The immune system is comprised of cells, tissues, and organs whose primary function is to coordinate and execute the body's response to infection (CATIE, 2007a). CD4⁺ is responsible for activating and directing other cells in the immune system. Maintaining a certain threshold of CD4⁺ cells is essential to healthy immune systems. After HIV enters the body through one of the four bodily fluids (semen, vaginal fluid, blood, breast milk), it weakens the immune system by taking control of CD4⁺ cells. As the virus replicates it destroys more CD4⁺ cells and depletes their supply. As the immune system weakens, it gradually loses its ability to protect the body from disease.

HIV can be detected in the host either by looking for the virus or by detecting the host's antibody response to the virus. Following the initial infection, the antibody response can take up to six months to develop. This is called the window period; the person is infectious but the antibody remains undetectable. After a period of time, an untreated HIV infection progresses to acquired immune deficiency syndrome (AIDS). It is possible for HIV to be present in the body for a number of years before the immune system is severely damaged and the patient progresses to AIDS. AIDS is a clinical diagnosis which, by definition, requires the presence of an opportunistic infection or cancer. Two blood tests are important in determining the severity of the infections and the likelihood of the person progressing to AIDS (CATIE, 2007b). The first and most important measurement is the CD4⁺ count. In healthy HIV negative people, a normal count ranges from 400 – 1200 cells/mm³ in men and 500 – 1600 cells/mm³ in women

(CATIE, 2008). When the CD4+ count is less than 200 cells/mm³ the immune system is severely compromised and the person is at risk for an opportunistic infection. The second test, called viral load, measures the number of copies of HIV per millilitre of blood. This demonstrates the activity level of the virus and a higher viral load will cause greater damage to the person's immune system. Viral load can range from 40 copies per millilitre to over one million copies per millilitre. Greater than 30,000 copies per millilitre indicate a high risk of progression to AIDS. If a person is receiving treatment, less than 40 copies per millilitre is undetectable and therefore under therapeutic control (CATIE, 2007a).

2.2.1 Global Impact of HIV

The founding director of the WHO's former Global Program on AIDS described the socialization of HIV as an epidemic with three distinct phases. It started as an age of infection that focused on transmission; it transitioned to an age of AIDS and death; to a third, explosive age of social, cultural, economic and political responses that was characterized by stigma, discrimination and collective denial. The third stage was described as being as "central to the global AIDS challenge as the disease itself" (Mann, 1987). Since 1987, the global prevalence of HIV/AIDS has taken on a strong localized presence such that some regions are heavily affected and other regions have maintained a fairly low prevalence. For example, it is estimated that Botswana has one of the top three prevalence rates where approximately 24% of the country's population is believed to be infected, while Canada's is under 2% (UNAIDS/WHO, 2006). In 2006, the WHO (2006b) estimated that over two thirds of the 39.5 million people living with HIV are on

the continent of Africa. Of the 2.5 million new infections worldwide in 2007, 1.7 million (68%) occurred in sub-Saharan Africa (WHO, 2009a).

The social and economic burden of the illness can have devastating impacts on a nation's economic and social structures. With over 30 million HIV/AIDS related deaths, the presence of the disease has caused a significant loss of human capital. If this trend continues, "the populations of the 60 most affected countries will be 115 million less than they would be in the absence of AIDS" (UNAIDS/WHO, 2006, p. 81). In countries that are considered poor based on household income, mortality has been concentrated in children under the age five and adults. This has resulted in orphaned children and significant economic cost of lost production due to death and disability (Barnett et al., 2001). Dodds et al. (2001) describe the impacts in high-income countries where affected individuals are faced with diminished quality of life and the financial burdens associated with antiretroviral drug treatment regimes.

2.2.2 Reporting, Surveillance and Prevalence

A notifiable condition is one that is considered to be of such importance to public health that its occurrence is required to be reported to public health authorities. When an infection is notifiable, information about the individual who tests positive is forwarded to provincial or territorial public health officials for surveillance. In Canada, chlamydia, gonorrhea, and infectious syphilis are reportable at the national level (PHAC, 2006b). Reportable information includes demographic data, such as the person's age and gender, risks associated with the transmission and laboratory data. The Surveillance and Risk

Assessment Division of PHAC's Centre for Communicable Diseases and Infection

Control is responsible for the surveillance of reportable conditions in Canada.

By 2003, positive HIV tests results and AIDS diagnoses were designated as notifiable in all Canadian provinces and territories. HIV infection is *not* legally notifiable at the national level, yet notification to PHAC is voluntarily undertaken by public health authorities in all provinces and territories on a non-nominal basis, which allows public health officials to monitor the incidence and prevalence of HIV (PHAC, 2007a). At the provincial level, positive results obtained through a non-nominal test may or may not require that the positive individual's name and health care number be reported within the province depending on the legislation outlined in the applicable jurisdiction. In NL, the guiding legislation is the Communicable Diseases Act (NL House of Assembly, 2007). This Act lists 54 conditions that should be reported to the deputy minister of health stating the "name of the disease, the name, age and sex of the person, and the name of the physician giving the notice, and shall by street and number or otherwise, sufficiently designated the house or room in which the person is living" where possible (Section 4). This Act includes HIV and AIDS as separate conditions classified as reportable infectious diseases.

At the end of 2005, it was estimated that 58,000 people in Canada were living with HIV infection. This represents an increase of 16% from 2002 estimates. This increase of persons living with HIV can be attributed to a rising number of new infections and to improved treatment regimes that keep diagnosed people alive longer. Since reporting began in 1985, 64,800 positive HIV tests have been reported across Canada (PHAC, 2007c). Between 2002 and 2006 there was little fluctuation in the number of new

positive test results; new cases reported annually ranged between 2,471 and 2,559. In 2007, the number of positive tests reported decreased to 2,432. More than 80% of positive tests in 2007 were reported from Ontario, Quebec and British Columbia. NL had one of the lowest rates of new infections.

The epidemiological categories used to describe the highest prevalence rates in terms of exposure category suggest that men who have sex with men account for over half of the estimated number of HIV infections. The second largest exposure category is persons who have contracted the disease through exposure to injection drugs (PHAC, 2007a). The third largest exposure category is called "heterosexual/non-endemic" (p.2), which refers to heterosexual contact with a person who is either HIV infected or at risk of HIV because they originate from a country where HIV prevalence is high, such as sub-Saharan Africa and the Caribbean. Nationally, there has been a notable increase in the proportion of positive HIV test reports attributed to women. Between 1998 and 2006, the proportion of positive tests reported that were attributable to women increased from 11.9% to 27.8%. The proportion of new infections is increasing amongst adults over 40 years of age. Aboriginal persons are also over-represented in the HIV/AIDS epidemic: they make-up approximately 3.3% of the Canadian population yet account for 7.5% of the estimated number of HIV infections in Canada. The overall infection rate among Aboriginal persons is about 2.8 times higher than among non-Aboriginal persons. At present, Canadian Aboriginal populations display higher rates of HIV infection and 53% of new infections were attributed to injection drug use in 2005 (PHAC, 2007a).

Since 1984, 249 positive HIV test results have been reported to the Department of Health and Community Services (2008). Of those 249 tests, 78% (n=195) were male and

22% (n=54) were female. During this time period, the top three modes of transmission that were reported by infected persons were 48% (n=119) men having sex with men (MSM); 31% (n=78) heterosexual contact with an infected person; and lastly, 8% (n=20) were recipients of a blood transfusion or blood products. Other reported modes of transmission were 4% (n=11) injection drug use (IDU), 2% (n=5) were a combination of MSM and IDU, and 2% (n=6) cases of prenatal transmission. In 4% (n=11) of cases, the risk factor was unidentified or not reported. The highest number of new positive tests was reached in 1991, when 15 males and 10 females tested positive for HIV. Since 1991, the number of positive HIV test results in NL has steadily declined (see Figure 1). New tests reported between 2003 and 2006 fell within a range of between 11 and six per year (PHAC, 2007c). Zero positive HIV tests were reported to the provincial public health authorities in 2007. In 2008, three positive tests were reported (Department of Health and Community Services, 2008).

This declining trend since the early 90's is reflected on a global scale and has been attributed to the effectiveness of ongoing education and prevention efforts. Three significant reports suggest that incidence of HIV is on the rise in Atlantic Canada (Atlantic Interdisciplinary Research Network, 2006; HRU & ACNL, 2007; Oxycontin Task Force, 2004).; however, the positive test results reported to the Provincial Government is declining. These reports further suggest there is a rising need for enhanced harm reduction services, such as anonymous testing, in future due to patterns of injection drug use, varied understandings and support for harm reduction, and migrating youth working in industry-based fields and engaging in risky activities.

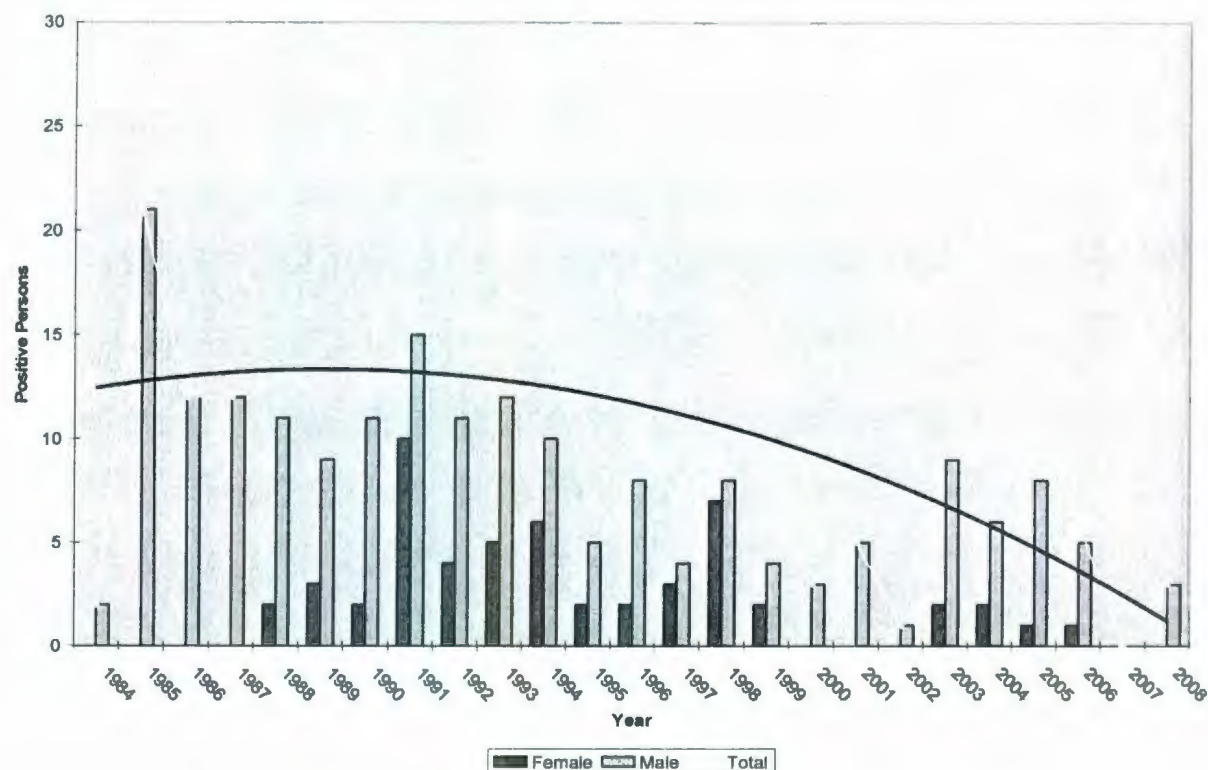


Figure 1: Number of Positive HIV Tests Reported, 1984-2008 (permission for use obtained from Department of Health and Community Services, Government of NL)

2.2.3 The Hidden Epidemic

The “hidden epidemic” (p.7) is a term used by PHAC (2007a) to describe the significant number of undiagnosed infections. HIV statistics reported by public health agencies are based on the official numbers of HIV tests that have been sought voluntarily and subsequently reported. Consequently, the number of positive test results in a region may not accurately reflect the new infections for that time period due to new infections amongst people who were not tested and are unknowingly infected. As a result, HIV statistics are generally understated.

Globally, it is estimated that approximately 85% to 90% of the 38 to 40 million people living with HIV remain undiagnosed (PHAC, 2006b). In Canada, it is estimated that approximately 27% of persons living with HIV in Canada are unaware of their status (PHAC, 2007a). The hidden epidemic is dangerous for a number of reasons. A significant risk to public health is posed by individuals carrying the disease unknowingly. On a community basis, it creates a false sense of security and results in inaccurate measure of the costs related to HIV. Under-testing may be caused by any combination of the barriers described earlier. Additional factors that may deter HIV testing include tendency of healthcare providers to discount the need for HIV testing of groups that are not traditionally stereotyped as being at risk for HIV and individuals believing they are not at risk for contracting the disease (Rees, 2003). These factors demonstrate that there are multiple layers of stigma and discrimination surrounding HIV testing services and the disease itself.

2.3 HIV Testing and Barriers

The importance of terminology is paramount when discussing HIV testing. The familiarity and plurality of meaning of testing nomenclature for the various types of tests affects the way we interpret the provision or availability of the service. This, in turn, creates an expectation of what will be provided or delivered during the procedure.

2.3.1 The Importance of STI Screening and Testing

Screening and testing are two distinct but related practices. Screening is a medical practice used to detect disease or body dysfunction before an individual would normally

seek medical care (Occupational Safety and Health Administration, 2000). Screening initiatives are more broadly targeted than testing due to their underlying intent to identify as many individuals as possible who may have a particular condition even when they are asymptomatic. Screening efforts become common during epidemics in which a disease, condition or agent of disease, whether life threatening or transitory, occurs in unexpectedly large numbers, in a given population, in a given time frame. The classification of something as an epidemic is a relative measure and varies in terms of the number of cases, geographic parameter, time frame, and size of the affected population. Testing, on the other hand, typically describes specific procedures used to confirm cases where individuals may be at risk for certain adverse health outcomes. The Ontario Ministry of Health and Long-Term Care (2008) makes an important distinction between screening and testing as it pertains to HIV, "HIV testing consists of a screening test and, if the screening test is positive, a confirmatory test" (p.2).

Patrick (1997) summarizes some of the public health benefits that are associated with accessible STI testing. Firstly, STIs are increasingly preventable and treatable. In many cases, delivery of testing is a narrow opportunity to communicate prevention education. Testing is an effective way to reduce the potential burden of such diseases on individuals, systems, and at the population level. The negative health outcomes of undetected and/or untreated STIs in the short term include persistent symptoms of the various infections and risk of transmission. In the longer term, individuals may be more seriously affected if the infection is chronic or if the original STI leads to a consequential condition such as pelvic inflammatory disease, infertility, and/or ectopic pregnancy. Goldenberg et al. (2007) describe STIs as "synergistic" (p. 719) because acquiring one

STI increases the risk of subsequently acquiring others. The importance of testing is internationally recognized in the WHO's (2006a) Global Strategy for the Prevention and Control of Sexually Transmitted Infections, which stipulates that prevention and control of all sexually transmitted infections must be linked to HIV prevention and sexual and reproductive health programs and services. Canada is a signatory of this strategy.

2.3.2 Types of HIV Testing

The UNAIDS/WHO Global Reference Group on HIV/AIDS and Human Rights (2004) made a clear distinction between four types of HIV testing and counselling - voluntary counselling and testing; *routine* testing; *diagnostic* testing; and *mandatory* HIV screening. My main focus is the types of testing offered under the voluntary counselling and testing model in NL. *Diagnostic*, *mandatory* and *routine* processes are briefly reviewed here for the sake of completeness. The definitions reflect the descriptions provided by the UNAIDS/WHO Global Reference Group on HIV/AIDS and Human Rights (2004) and, where noted, have been supplemented by descriptions provided by independent researchers. Recent developments in HIV testing, such as rapid tests and home testing kits, are excluded from this review.

Diagnostic testing occurs in clinical situations to aid in patient care management, specifically when a person shows signs or symptoms consistent with HIV-related disease (Obermeyer & Osborn, 2007). *Mandatory* HIV screening for blood borne viruses is carried out on blood intended for transfusion or manufacture of blood products and on donations involving transfer of bodily fluids or body parts. *Routine* testing is initiated by health-care providers where most users of a facility will be tested, but individuals retain

the right to refuse testing (Yeatman, 2007). Often referred to as *provider-initiated testing and counselling* (PITC), routine testing is gaining popularity in high prevalence areas, such as sub-Saharan Africa and the Caribbean. The PHAC (2006a) defines two forms of routine testing – opt-in and opt-out. Opt-in testing requires a universal offer of HIV testing to all patients, but it is only done if patients indicate that they would like the test. Opt-out testing, also referred to as routine testing with the right to decline, incorporates HIV testing into standard clinical workups and patients are informed that the test will be done unless they decline.

The Canadian HIV/AIDS Legal Network (2005) further explains that international advocacy groups differentiate between involuntary or compulsory testing and mandatory testing. The former, involuntary or compulsory testing, lacks some voluntary element such as informed consent, and occurs “at the behest of someone or some institution other than the person tested” (p. 2) and, sometimes, the result is not communicated to the person tested. The latter, mandatory testing, occurs when testing is performed “for some other benefit, such as donating blood, immigration, marriage, joining the military, or as a precondition for certain kinds of employment” (p.2). The Canadian HIV/AIDS Legal Network (2005) reminds us that except in the cases of donations of blood, organs or other bodily substances, international agencies working on HIV and public health authorities have “rejected both compulsory and mandatory testing as unethical violations of human rights and as ineffectual in public health terms” (p.2).

2.3.3 Voluntary Counselling and Testing

The predominant model under which individuals are tested for HIV is referred to as voluntary counselling and testing (VCT) and relies on “an individual’s right to decide whether or not he or she will be tested” (Yeatman, 2007, p.271). Voluntary counselling and testing emphasizes the need for voluntary, informed consent prior to testing as well as pre-and post-test counselling, and partner notification. Table 1 summarizes the characteristics of nominal, non-nominal and anonymous testing HIV testing. Information provided by PHAC (2007a, p. 14) is supplemented by information published by the Ontario Ministry of Health and Long-Term Care (2008), Kendall (2006) and Yeatman (2007). The only stated difference between nominal and non-nominal testing is that a non-nominal test is ordered using something other than the individual’s full or partial name, such as a code or initials. Anonymous testing differs because the person ordering the test does not know the identity of the person being tested although the procedure including the type of demographic data collected varies depending on the legislation and policies in place at the testing site.

Table 1: Description of Three Types of HIV Testing in VCT Model

Type Of Test	Confidential	Confidential	Anonymous
PHAC Name	Nominal	Non-nominal	Anonymous
Common Name	Name-based	Non-identifying or No-Name	Anonymous
Location	A variety of locations including clinics, health providers' offices.	Offered in similar locations as nominal testing.	Availability depends on province. It if is offered, it may be available at specialized clinics, organized and supported by public health departments and by some health care providers
Identity Disclosure	Person ordering the test knows the identity of the test seeker.	Person ordering the test knows the identity of the test seeker.	Name or identity of test seeker is not requested, recorded or reported.
Laboratory Ordering Process	Test is ordered using the name of test seeker.	Test is ordered using a code or the initials of test seeker (not including full or partial name).	Test is ordered and carried out using a code to ensure that the person ordering the test and the laboratory carrying out the test does not know to whom the code belongs.
Health Records	Test result is recorded in the health care record of test seeker.	Positive results noted in the health care record of test seeker.	Varies by province and territory. If the result is negative, this is not typically recorded on the client's health care record. Only the person being tested who may subsequently decide to give his or her name and include the HIV test result in the health care record.
Personal Information	Information collected varies by province/territory and testing site. Examples of allowable types of information include age, gender, city of residence, name of health care provider, country of birth, ethnicity, HIV-related risk factors of the person being tested, and laboratory data.	Information collected varies by province/territory and testing site. Examples of allowable types of information include age, gender, city of residence, name of health care provider, country of birth, ethnicity, HIV-related risk factors of the person being tested, and laboratory data.	Information collected varies by province/territory and testing sites. Examples of allowable types of information to collect include age, gender, ethnicity, and HIV-related risk factors. The care giver can visually identify the person who was tested, but is not able to link any result with that person.
Obtaining Results	Delivered in person by a healthcare provider and counselling is provided.	Delivered in person by a healthcare provider and counselling is provided.	The person being tested is able to access their result by, for example, entering their confidential code into a computerized data base to retrieve their result (Kendall, 2006).
Legal Disclosure	If positive, person who ordered the test is obligated by law to notify public health officials of the positive test result.	If positive, person who ordered the test is obligated by law to notify public health officials of the positive test result.	If positive, the person can no longer remain anonymous. The provincial legislation comes into effect, outlines reporting requirements (Ontario Ministry of Health and Long-Term Care, 2008) and requires that client give their name and health card number to receive health services.

2.3.4 Barriers to STI Testing

Goldenberg et al. (2007) summarize some of the barriers to STI testing in Canada. Limited access to information about symptoms, testing and treatment procedures as well as limited access to clinic-specific information, including the time and place where testing is offered, are barriers to testing. Characteristics of health service delivery systems can also inhibit testing including inconvenient hours of operation, wait times, and clinic location. Characteristics of healthcare providers can also serve as barriers to testing - gender, perceived judgmental behaviour, and inadequate training in sexual health service provision. Stigma, shame, and social discomfort as well as concerns related to anonymity and confidentiality may deter people from seeking testing.

2.3.5 Risk, Stigma and Harm Reduction

A risky activity is any behaviour that offers the possibility of a negative outcome including injury, illness, or death; for example, drug and alcohol misuse, smoking, or unsafe sexual practices. At-risk epidemiological categories are often negatively associated with risky activities that have led to a sexually transmitted infection. This negative association is referred to as stigma. Stigma is further discussed here to provide insight into factors that influence individual behaviour and choice and as an impediment to provision of equitable health care service delivery. Goffman (1963) defined stigma as an attribute that is deeply discrediting, spoiling, or tainting, which can make one feel inferior because of an inability to meet real or perceived expectations. It can be a response to a particular characteristic and can result when an individual or group appears deviant from the norm.

Since Goffman's original equation to "spoiled identity", stigma has received ample academic attention and documentation, which have unanimously concluded its negative social consequences (Vidanapathirana, Randeniya, & Operario, 2007). Some of the acts and attitudes involved in stigmatization include "prejudice, discounting, discrediting, and discrimination" (Herek, 1999, p.1108). Terminal conditions that have previously been stigmatized include leprosy, tuberculosis, cancer, mental illness, and many STIs (Brown, Trujillo, & Macintyre, 2003). Stigma adversely affects patients and their families, and decreases the effectiveness of public health policy and programming (Van Brakel, 2006). Persons who fear stigmatization are reluctant to acknowledge risk behaviour, avoid seeking prevention information, and may experience real or perceived barriers to prevention and other health-care services.

There have been specialized inquiries into the phenomena of HIV-related stigma, which is defined as the negative attitudes directed at the individuals perceived to have HIV or AIDS, as well as the individual, groups, and communities with which they are associated (Alonzo & Reynolds, 1995; Herek, 1999; Morrison, 2006). As Yang, Zhang, Chan, Reidpath (2005) demonstrate, HIV-related stigma is more intense than regular stigma because of the direct or indirect links between the cause and consequences of HIV with the individual carrying the disease. This may result in multiple layers of co-stigma; for example, a person who has HIV may be automatically linked with one or many of the following activities - injection drug use, sex work, and unsafe sexual practices. Similarly, certain stereotypes exist about HIV and individual characteristics such as sexual orientation, ethnicity, poverty, disability, and many others. Morrison (2006) describes HIV as an "illness of immorality" (p. 5); it is considered dirty and it is associated with

“imminent death, and exaggerated sense of danger” (p. 5). HIV-related stigma can lead to institutional and structural discrimination against persons living with HIV. Daily consequences of HIV-specific stigma include discrimination in insurance, housing, education, and employment and worsen the social, physical, and emotional challenges of terminal illness. As such, stigma poses a threat of increased vulnerability through ostracism, ridicule, and even physical attacks on the infected individual and his or her family. A systematic review by Vidanapathirana et al.’s (2007) and findings of Reidpath and Chan (2006) demonstrate that controlling HIV stigma is central to controlling the epidemic because of the barrier it creates between establishing the comfort level necessary for people to openly discuss the nature of the issues, access prevention and screening services, and seek treatment in the event of illness.

Viewing risky activities in a negative light is criticized by proponents of harm reduction. Coomber and South (2004) describe harm reduction as a public health concept that aims to reduce negative health consequences that can result from engaging in risky activities and is considered effective for addressing health and social problems, such as stigmatization of individuals who take risks. It acknowledges that people take risks as a normal part of everyday life and that a zero tolerance or abstinence approach is unrealistic and offers instead pragmatic interventions to make risky activities safer. Gustafson et al. (2008) summarize the types of programs that are designed to meet people where they are in terms of their personal risks and health practices; such as, anonymous and voluntary testing and treatment for HIV, Hepatitis C virus, vein maintenance, methadone treatment, safe injection access, and needle access. Voluntary HIV testing and counselling is a preventative public health service and is not considered a harm reduction

measure. Anonymous HIV testing and counselling, however, exhibits certain harm reduction principles. For example, it acknowledges risk as an everyday part of life, it respects individual autonomy, and it attempts to minimize stigma and feelings of shame or discomfort. Therefore, harm reduction principles were incorporated into this inquiry. Research has called for increased and improved access to harm reduction services in for those who engage in injection drug use, unsafe sexual practices, or exchanging sex for money (Health Research Unit [HRU] & AIDS Committee of Newfoundland and Labrador [ACNL], 2007; Goldenberg et al., 2007; Mehradbadi et al., 2008; Mitra et al., 2006; Romanowski, Preiksaitis, Campbell, & Fenton, 2003).

2.3.6 Role of Provider during HIV Testing

Providers of public health services possess an opportunity to significantly impact chronic disease prevention and control the spread of sexual infections in the long-term given their ability to offer testing, screening, diagnosis, management and treatment services to a wide range of clients (PHAC, 2006b). They have a higher volume of interactions in which preventative action can be encouraged within the general population. Gustafson et al. (2008) conclude that registered nurses are particularly well positioned to promote health and harm reduction approaches for at-risk populations in small urban centres. Kartikeyan, Bharmal, Tiwari, and Bisen (2007) explain that the burden of HIV-related stigma heightens the importance of the role of the health care provider during testing.

Possessing knowledge about the variety of social, economic, physical, mental, and personal factors involved in risk taking and transmission can help dispel negative

attitudes or biases towards test seekers. To provide quality care during HIV testing, it is necessary for providers to factor in the psychological and emotional stress the test seeker may have experienced in the recent past and could still be a factor at the time of testing. It is also important for them to display a positive attitude and create comfortable environment in which to discuss lifestyle, sexual and drug-using practices, fears and anxieties openly (Oyeyemi, Oyeyemi, & Bello, 2007). Scott and Irvine (1997) suggest willingly listening to the patient's queries and provide explanations that are easy to understand and free of medical jargon. Recommendations emerging from a needs assessment of people who inject drugs in the small urban centre emphasized the important role of health providers in empowering the individual seeking services to minimize stigma and effectively administer harm reduction services (HRU & ACNL, 2007). For example, instead of telling a person to stop an activity entirely, attempts should be made to build the person's confidence and provide timely and accurate information. Pergami, Catalan, and Hulme (1994) demonstrate that early interactions between patient and provider during testing and counselling are directly linked with the patient's health status; for example, the manner in which an HIV-positive test result is conveyed can affect the patient's stress levels and coping mechanisms.

2.3.7 Advantages of Anonymous Testing

The previous discussion of stigma has demonstrated its many negative impacts, some of which can be reduced with access to anonymous HIV testing. The advantages of anonymous testing will be discussed in this section using literature from a variety of local and international sources, followed by a summary of its potential to benefit at-risk

groups. Personal identifiers and reporting requirements are controversial; therefore, the disadvantages of anonymous testing are reviewed in the interest of presenting a balanced argument.

One significant advantage of anonymous testing is its ability to address concerns about identification disclosure by excluding the requirement to provide personal information. As Hecht et al. (2000) explain, the structure of HIV reporting requirements associated with nominal or non-nominal tests may deter or delay some persons from being tested. PHAC (2007a) is increasingly supportive of the belief that providing an anonymous testing option will improve access to testing. Free and open access to testing could increase the number of people who are aware of their HIV status and knowledge of one's HIV status can lead to earlier treatment and improved outcomes and a decrease in risky sexual behaviours (Bindman et al., 1998). For these reasons, anonymous testing is considered advantageous and beneficial to public health. Academic literature is increasingly highlighting the need for anonymous testing services in high-income countries (Jurgens & Palles, 1997; Jurgens, 2001; Obermeyer & Osborn, 2007). Attaching mandatory reporting and contact tracing requirements to anonymous testing erodes people's trust in confidentiality, which is a fundamental principle of the Canadian healthcare system and a guiding principle of the UNAIDS/WHO (2004) HIV testing guidelines.

Research demonstrating that anonymous HIV testing was of heightened benefit for at-risk groups became available shortly after anonymous HIV testing was first officially offered in the 1980s. Studies in multiple American states revealed that people who engaged in risky activities who presented for anonymous testing reported they would

not have been tested under other nominal or non-nominal circumstances (Higgins et al., 1991; Hoxworth et al., 1994; Kegeles et al., 1990). Bindman et al. reported other advantages including a decrease in risky behaviours and unsafe sexual practices, as well as earlier access to treatment and care after homosexual men and persons who inject drugs were tested. In general, early observations suggested anonymous testing was filling a gap by facilitating access to a preventative service for people who engaged in risky activities and wanted to be tested.

More recently, Canadian studies about HIV and testing for other sexually transmitted infections have concentrated on the manifestation of HIV and other co-infected conditions in at-risk groups. Romanowski et al.'s (2003) study of sexually transmitted disease clinics in Alberta demonstrated that injection drug use is the main risk activity related to transmission of Hepatitis C. Patten (2006) confirmed that Hepatitis C is often co-infected with HIV. A study of in British Columbia demonstrated a history of injection drug use and its association with sexually transmitted infections within an Aboriginal population and stated there is an urgent need for harm reduction services (Mehradbadi et al., 2008). A study conducted in rural British Columbia demonstrated that youth who have migrated to work in the oil and gas sector face five key barriers to accessing testing for sexually transmitted infections including limited opportunities for access, geographic inaccessibility, local social norms, limited information, and negative interactions with providers (Goldenberg et al., 2007). The study recommended providing harm reduction services for the workers, including drop-in testing and specialized training for health care providers. Finally, a study of women in Ontario who immigrated to Canada from HIV endemic countries, found they would prefer anonymous testing over

any other type of testing (Mitra, Jacobsen, O'Connor, Pottie & Tugwell, 2006). Reasons cited were clients' perceptions of enhanced client confidentiality and increased client control over the consequences of being tested.

2.3.8 Disadvantages and Challenges of Anonymous Testing

Mitra et al. (2006) defined "cons" (p. 294) of anonymous testing from a client perspective and a provider perspective. Many of the disadvantages of anonymous testing cited by providers are founded in risks posed to public health and potential for failure to address other issues associated with HIV transmission (Lansky et al., 2002). Absence of contact information is thought to interfere with the provision of information that is crucial to early intervention and preventing further spread of the disease. Hoxworth et al. (1994) highlight that there is no way of contacting persons who fail to return to collect their standard test results or their past or current partners. This results in poorer post-test follow-up, poorer continuity of care, and inability to assist the test seeker with partner notification. For example, in the event of a laboratory error, it would be impossible to follow up on cases in which there was a laboratory error of a false-positive, a false-negative, or a labeling error. Clients also identified many of these disadvantages and acknowledged that assistance with partner notification can be helpful and is, at times, appreciated. Mitra et al. (2006) cited additional disadvantages identified by clients as the lack of an established relationship with the provider.

Chou, Huffman, Fu, Smits, and Korthuis (2005) acknowledge that anonymous testing is not always clearly associated with an improved uptake of testing. Gustafson et al. (2008) highlight that another challenge, which is of particular importance to small

urban centres and rural areas, is related to one's ability to maintain anonymity in places where healthcare providers are limited and social circles closely connected. Furthermore, the ability to investigate disease trends and patterns and collect other important surveillance data is inhibited (Obermeyer & Osborn, 2007). Finally, anonymous testing may fail to address the main barrier to testing – fear of a positive result - any better than nominal or non-nominal testing does (Hoxworth et al., 1994; Lansky et al., 2002).

2.3.9 Anonymous HIV Testing by Province and Territory

Widespread division over sensitive issues, such as reporting, partner notification, and anonymous testing, has resulted in a unique evolution of HIV testing policy between provinces and territories (PHAC, 2007a) to the point that each province has different guidelines around its provision. PHAC (2007a) reports that anonymous testing is available in Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, and NL. Jurisdictions that do not offer anonymous testing include British Columbia, Yukon, Northwest Territories, Nunavut, Manitoba and Prince Edward Island.

Of those provinces that do not offer anonymous testing, Manitoba was the only province that was actively looking to expand its HIV testing services to be able to offer anonymous testing (Manitoba Health, 2006). British Columbia offers a flexible, non-nominal testing option at selected testing sites, which has been defined by the Provincial Health Officer, Perry Kendall (2006):

a flexible non-nominal testing option where testing is conducted without having to disclose one's true name. In this instance any care giver who is involved with discussing the result of the test with the person who had the

test is not aware of the true identity of their client/patient. However, this option may involve collection of patient information (such as age, gender, city of residence, name of diagnosing health care provider, country of birth), information detailing the HIV-related risk factors of the person being tested, and laboratory data

The absence of anonymous testing in these provinces may be associated with other external challenges such as difficulty maintaining anonymity, stigma and prohibitive provincial legislation. Where anonymous testing is offered, positive results may be reported nominally or non-nominally at the provincial level depending on the legislation. In NL and Saskatchewan, positive HIV tests are to be reported nominally, even if conducted anonymously (PHAC, 2007a). If an individual tests positive in NL, the result becomes part of the nominal system, in which the individual is offered counselling and follow-up care. Ontario reports positive HIV test results from anonymous tests non-nominally at the provincial level, and Alberta reports positive HIV test results from anonymous tests nominally at the provincial level (PHAC, 2007a).

Thirty-six percent of Canada's Aboriginal populations live in three Canadian territories where anonymous testing is not available (PHAC, 2007a; Statistics Canada, 2006a). Academic literature was consulted to find possible explanations for the absence of anonymous testing services within Aboriginal populations. Tseng (1996) highlights several barriers to implementing anonymous HIV testing in Aboriginal communities and found the main factor inhibiting such an offering was the high priority placed on other day-to-day health and social problems impeding overall living standards. Other potential obstacles include low levels of health literacy, lack of resources and government funding,

under-awareness, cultural issues, and language barriers. More recently, Bucharski, Reutter, and Ogilvie (2006) demonstrated the importance of culturally appropriate service delivery in HIV testing for Canadian Aboriginal women. This requires providers to understand the past and present life experiences of indigenous people. They identified barriers specific to Canadian Aboriginal women including an underlying fear of being judged—by the tester or others in the Aboriginal and non-Aboriginal communities; lack of anonymity and confidentiality; negative past experiences with testing; and the pre-test assessment of HIV risk behaviour.

2.4 Policy-Practice Gap

Policy development, implementation, and adherence is challenging due to the rapid pace at which healthcare evolves. Policy formulation faces competing pressures to be informed by evidence, but also to respond to public opinion. Public health practice and delivery of community services are areas that are replete with competing values, moral dilemmas and grey areas. There is a diverse range of needs that policy-makers must consider when formulating policies to be applied in these settings. The advantages and importance of policies that focus on the needs of at-risk populations and others who face systemic and/or other barriers due to social position when accessing care and services is fundamental to a social justice approach. An overview of the challenges of evidence-informed public health policy and practice is also presented.

2.4.1 Policy

In the simplest terms, policies dictate what *should* happen. A policy is defined as:

A guiding or governing principle that mandates or constrains action(s).

Policies are specific directives that prescribe limits and pinpoint responsibilities within an organization and are designed to influence/guide decision making and actions. A policy can be viewed as law, rule or expectation which provides a foundation from which an organization can realize its mission, values and strategic plan. (Eastern Health, 2009a)

On a national level, the Canadian Charter of Rights and Freedoms recognizes the “primary fundamental freedoms, democratic rights, mobility rights, legal rights and equality rights” to which all Canadians are entitled (Department of Justice, 1982). By law, formal policies must fall within the parameters of what is permissible according to the Charter. Oftentimes, policies do more than simply comply with legislation rather they become more robust as they are supplemented by targeted professional, organizational, and institutional codes of ethics and standards of practice.

Actions of healthcare providers are guided by the regulations that apply to their discipline as outlined by relevant federal, provincial and municipal legislation, professional associations and bodies, as well as applicable ethical and procedural codes.

Examples of provincial legislation that outline professional requirements by law include the 16 health professional statutes in NL, including but not limited to the Registered Nurses Act, the Social Workers Association Act, and the Dieticians Act (NL House of Assembly, 1999). In addition to legislation, standards of practice are regulated by a provincial professional body whose mandate is to protect the public interest and the public’s right to a competent health professional; for example, the College of Physicians and Surgeons of NL and the Association of Registered Nurses of NL. In addition to

professional practices bodies, various healthcare disciplines have developed codes of ethics to serve the interests of its members. Professional codes of ethics offer guidelines on which parameters can be set to govern the patient-health care professional relationship (Abdool et al., 2004). Examples include the Canadian Medical Association's Code of Ethics for physicians, residents, and medical students (Canadian Medical Association, 2004), the Canadian Nurses Association's code for registered nurses (Canadian Nurses Association, 2008) and the Canadian Physiotherapy Association (1989) Code of Ethics.

Though well-received by members of their respective disciplines and notable for the sense of solidarity they create, there are limitations to what legislation, professional practice standards, and discipline specific protocol can accomplish. Such limitations include their vague nature, broad scope, and failure to provide solutions for complex, real-life moral dilemmas. They lack the flexibility required to "prioritize principles when they conflict" (p. 34) and need to be practically resolved (Abdool et al., 2004). They are inadequate for guiding healthcare providers through ethically challenging public health decisions, such as HIV testing.

Common characteristics of policies include a formal written expression, intention to reflect desired organizational practices, and are often referred to as policy guidelines. The following two paragraphs demonstrate that policies need not be legislation or a policy manual, but they also exist in informal formats.

A best practices brief provides specific examples of what policy is. The brief recognizes that budgets are "critical statements of social policy" because they distribute resources and determine organizational limitations (Best Practice Brief, 2005, p.1). Similarly, "policy is reflected in strategic plans and memoranda" (p. 1) and translates into

practice when persons in leadership roles would be expected to make decisions or take actions. These leaders are mandated to provide input on “rules and regulations, manuals, requests for proposals, contractual agreements, enforcement actions” (p. 1), which can be uniformly and/or formally applied and may exist within many organizational levels and/or structures.

A study from a high-prevalence region uses the term *informal responses* to describe “undocumented practical responses to HIV and AIDS” (James, Dipo-Salami, Satali & Nairesiae, 2009, p.4). The authors note that although these informal mechanisms were not written down, they were effective for addressing HIV and AIDS in certain environments. Some of the disadvantages of written policies were noted by community-based organizations: they reduced flexibility, were time consuming, detracted from the human face of support, and created a divide between staff and the community. Instead, the authors preferred to utilize informal responses including “staff meetings, retreats, discussions, advice, information and advice to test” (p. 4).

2.4.2 Using Evidence to Inform Policy

Evidence-based healthcare is a major theme in medical, health and social sciences. Grypdonck (2006) summarizes the central focus of this concept as the practice of basing policies and practices based on scientific research studies. He describes how, traditionally, randomized control clinical trials and other forms of quantitative research have been widely accepted as superior and, therefore, dominated what is considered evidence. As Raphael (2000) explains, fields like health promotion have led the way in accepting and encouraging “alternative” (p.361) types of evidence for decision-making

given their ability to provide the right questions and answers for preventative health interventions. In this sense, alternative refers to anything other than traditional logical and positivist models of thinking. Traditional, positivist models that aim to test “nature with truth in the form of facts” (p. 361), are increasingly viewed as rooted in the biomedical model, and are giving way to post-modern programs and research protocols. This has led to a shift in terminology away from *evidence-based*, to *evidence-informed*. This term implies a wider definition of evidence and recognizes the value and credibility of other forms of research, including that of a qualitative nature.

Using any type of evidence to develop policy, however, can be challenging for a number of reasons. Jewell and Bero (2008) summarize the barriers reported by legislators and public health administrators who have attempted to use or have successfully used evidence to inform policy, planning, and practice. This American study found limited resources for collecting and evaluating research, budget cuts, growing mandates, complex policies, and challenges in organizational culture were seen as the most difficult challenges. Other barriers included the time and resources needed to determine the usefulness of research, limited access to research database, or lack of research skills. Given the similarities in public health policy challenges across North America, I have assumed these findings are generalizable to a Canadian policy environment. As such, it is reasonable to assume that similar challenges are faced by the administrators, legislators and policy-makers in this study.

2.4.3 Overview of Canadian Healthcare Systems Challenges

As a committed member of the United Nations, Canada's healthcare policies are expected to follow strategic directives from authoritative agencies including the WHO and PHAC. The majority of health care services are supported by public federal funds and delivered through provincially regulated systems (Health Canada, 2004). Public health is primarily within the purview of each province and territory (PHAC, 2008). As a result, vast inter-provincial differences exist in health and community services delivery. The lack of federal direction and coordination guiding the organization of healthcare has made it challenging to collaborate on issues that could benefit from nationally consistent policies. Inconsistent availability of HIV testing services across the country demonstrates this.

A further criticism of Canada's health care system that has profoundly affected policy-making is a process known as regionalization, which has occurred in all Canadian Provinces. Church and Barker (1998) describe regionalization of health services as an element of reform that is intended to control expenditures, provide more effective services, and allow for citizen participation in health care decision-making. In general terms, regionalization of health services involves a shift of responsibility for public health from a series of local boards to a larger regional agency. The challenges of regionalization include integration and coordination of the administration and delivery of services; consolidation of funding; creation of information infrastructure and measurement indicators for evaluation; and developing mechanisms for citizen involvement. To relate this to HIV testing in the small urban centre, Gustafson et al. (2008) explain that marginalized populations of NL have been the most negatively

affected by changes to community health services. Criticisms of regionalization include services that are inappropriate or inaccessible for localized needs, disempowerment of local program and communities, chronic instability, and lack of evaluative data.

2.4.4 Anonymous HIV Testing, a Policy-Practice Gap

Despite the display of support and anticipated need for anonymous testing that has been outlined, it is only officially available in seven provinces (PHAC, 2007a) and there is an absence of urgent provincial or federal government action to provide local access to this service. Anonymous HIV testing is a challenging public health policy and service delivery issue for many of the reasons (human rights, partner notification, contact tracing and mandatory reporting). From a legislative and policy perspective, prohibitive provincial legislation and unclear direction from the Public Health Agency of Canada about the availability and delivery of anonymous testing is challenging (Jurgens & Palles, 1997). Combined, these factors create challenges at a practical level for the providers at the point of service delivery.

As Herek, Capitanio, and Widaman (2002) point out, public health policy is created and implemented within a context where diseases are socially constructed. When a condition is highly stigmatized, public health policies can either protect those who fall ill from public prejudice or promote discrimination among them. Certain policies can violate the human rights of those living with or at risk of contracting the disease.

Neale, Geller and Weir (2000) observed that when policies and clinical guidelines are available, nurse practitioners who followed clinical guidelines during interactions with patients had higher levels of decision-making authority and success at work.

Additionally, the availability of clinical guidelines increased nurse practitioners' productivity by mitigating their need to interact with his or her collaborating physician. In the absence of policy guidelines, clinical directives, or a framework to guide ethically challenging clinical decisions, public health providers reportedly rely on their professional training and experience or view their personal moral foundations as sufficient (Baum et al., 2007).

One practical challenge of unclear anonymous HIV testing and counselling policy is for the provider and test seeker to establish common understanding. Providers and test seekers may have different notions of what constitutes confidentiality and anonymity. Awad et al. (2004) believe that test seekers are more conservative in their definitions of confidentiality, meaning they may be less willing to provide the personal information that the provider expects. In this way, confidentiality may be compromised by established practices in health services and by differential regard for clients' rights where the poor are the most disadvantaged. Obermeyer and Osborn (2007) attribute this unclear understanding to the uneven application of practices intended to protect confidentiality by providers. To clarify using an example, a provider who does not support principles of harm reduction and holds stigmatizing attitudes towards risk may perceive a test seeker from an at-risk group as irresponsible. Should this test seeker make a request outside of established practice, such as anonymous testing where non-anonymous is the official standard, the provider may view this unfavourably. The procedure is seen as an accommodation to protect an irresponsible test seeker. This demonstrates how a lack of clear direction in the form of policies leaves service providers to negotiate individual

requests at the point of service delivery, which may have different outcomes depending on the circumstance.

Through the *Canadian Guidelines on Sexually Transmitted Infections*, the Public Health Agency of Canada (2006b) has made a concerted effort to ensure that national prevention and control efforts are always “linked to HIV prevention and sexual and reproductive health programmes and services” (p. 11) to uphold this commitment in a visible and transparent manner. The *Canadian Guidelines on Sexually Transmitted Infections* are written and maintained by an expert working group of health professionals from across the country to provide updated, evidence-based recommendations for the prevention, diagnosis, treatment and management of sexually transmitted infections across Canada’s diverse population (PHAC, 2006b). The *Canadian Guidelines on Sexually Transmitted Infections* place an explicit onus on providers to take advantage of their proximity to users of the health care system and offer screening, diagnosis, management and treatment services to a wide range of clients. By making such a continuum of STI service available “providers have the potential to significantly impact chronic disease prevention and control in the long-term” (p.11). The document even acknowledges the ethical challenges related to practices required under STI services, such as reporting and partner notification. A shortfall of the *Canadian Guidelines on Sexually Transmitted Infections* (PHAC, 2006b), however, is the absence of directives that address what to do in the event that a client does not wish to provide personal identifying information.

Other practical challenges include every day job roles and responsibilities of public health providers. Everyday they grapple with new technology, changing societal

values, attitudes, and expectations in the face of scarce resources (Abdool, Pérez, & Lit, 2004). They may also be varying levels of experience, time, resources, or motivation to consider and incorporate ethics into their daily work. Ultimately, the literature on this topic confirmed the importance of policy guidelines to guide decision-making and deliver consistent and appropriate services.

3.0 Methodology and Methods

This chapter describes my methodological standpoint, the study design, the processes for obtaining ethics approval, and other ethical considerations. It explains the philosophical roots of the study within constructivist epistemology. It provides an overview of qualitative description as presented by Sandelowski (2000), which was used to collect data from four testing sites using individual interviews and document review. It describes data analysis including the document review process, diagramming the document trees, and thematic analysis. I drew from coding techniques described by Braun and Clark's (2006) and Strauss and Corbin's (1990), as well as Crabtree and Miller's (1999) use of templates to assist with thematic analysis. This chapter also provides justification for keeping a reflexive journal and using it as a tool for data verification. Murphy and Dingwall's (2003) criteria for assessing the truth claims of qualitative research are used to demonstrate the rigour of the study.

3.1 Methodology

Fierke (2004) explains methodology as including both ontology and epistemology and referring "to those basic assumptions about the world we study, which are prior to the specific techniques adopted by the scholarly undertaking research" (p.36).

3.1.1 Suitability of a Qualitative Approach

Belgrave, Zablotzky, and Guadagno (2007) acknowledge the need for detail when communicating qualitative research strategies and encourage researchers to explicitly link

methodological strategies with research goals. They recognize that important, understudied phenomena require multidisciplinary efforts to resolve. Understudied phenomena are characterized by a dearth of literature on the subject and are well-suited to qualitative inquiry. While some aspects of HIV are widely covered in academic literature, such as stigma (Bogart et al., 2008; Brown et al., 2003; Parker & Aggleton, 2003; Vidanapathirana et al., 2007), other aspects lacking study include the ethical and cultural considerations of testing policy (Bell et al., 2007; Hoxworth et al., 1994; Johnston & Conly, 2002). As Starks and Brown-Trinidad (2007) confirm, studies that “examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions” (p. 1372) are well-suited to a qualitative approach.

3.1.2 Methodological Standpoint

My epistemological and ontological standpoints are determined by the belief that multiple meaningful components of the social world exist from which knowledge can be derived. Crotty (1998) describes this as a constructivist epistemology, which maintains that all knowledge is constructed by humans. There are as many realities as there are perceptions and interactions: co-constructed realities can exist in particular contexts. Constructivism supports that a range of contextual factors, including the perceptions of the interpreter, influence an individual's interpretation of the truth (Murphy & Dingwall, 2003; Smith, 1985). Constructivism is contrary to positivism and objectivism, which maintain that one universal, infallible truth can become known through external reality. This created an opportunity for continuous enhancement of understanding and knowledge

through the use of qualitative description, which allows for multiple data collection strategies.

3.1.3 Evaluating Congruence

The purpose of evaluation is to assess outcomes and the process by which they were achieved (Nutbeam, 1998). The evaluation of health policies and programs has become an increasing priority worldwide with the ongoing reform of Canadian health systems, and the increasing emphasis on governments and organizations to use evidence to inform decisions and to be transparent and accountable (CIHR, 2005). This study was evaluative in nature because it poses basic questions about the congruence between HIV testing policy and practice, determines facts about policies through a document review, and examines providers' perspectives through interviews.

3.1.4 Study Setting

This study focused on HIV testing services in a location that fits Gustafson et al. (2008) description of a small urban centre where there is a perception that "everyone knows their neighbour's business" (p. 190). In the province of NL, over 213,000 or 42% of people reside in rural areas, where rural is considered to be anyone living outside centres with a population of 1,000 and outside of an area with 400 persons per square kilometre (Statistics Canada, 2007). Due to the clustering of the provincial population around urban areas, one of the four regional health authorities provides unique provincial programs and services. As such, people are often required to travel from rural areas to urban centres to receive specialized care and services. This geographic distance has long

been recognized as a barrier to accessing specializing health services, which are clustered in urban areas.

3.1.5 Study Participants

Organizational study participants were identified through an environmental scan of the literature followed by a regionally-specific fact-finding phase. Individuals who participated in interviews were subsequently identified by the site principals. My goal was to include all the locations in the small urban centre where people would go to seek information about HIV testing or to be voluntarily tested for HIV. Sexual and reproductive health is one of the programs covered by a regional health authority's health promotion and public health division (Eastern Health, 2009b). Since the Community Services division of the regional health authority was described as being responsible for providing screening and other related services for sexually transmitted infections, they were invited to participate in this study. The regional health authority's testing sites represented a formalized, public health testing environment.

In an effort to determine how a layperson may identify local testing services, I did a Google search for 'HIV testing in Newfoundland' and found several of the community-based organizations that test seekers may contact. I invited these organizations to participate in my study. Because of my involvement in the community I recognized the names of two organizations as reasonable choices for people seeking information and/or testing services. My familiarity with the Ottawa Charter for Health Promotion (WHO, 1986), especially with respect to capacity development of civil society through the active involvement of people and community, helped me recognize the value of this. Canadian

examples of successful stakeholder collaborations for HIV/AIDS testing are documented in Ontario (Ministry of Health and Long-Term Care, 2008) and British Columbia (Kendall, 2006). Bogart et al. (2008) further confirm that due to the stigmatization of HIV/AIDS, people tend to seek services from persons other than their family physicians including unaffiliated health care providers and community-based organizations. Consequently, these organizations were also selected to participate in the study.

Finally, the Atlantic Interdisciplinary Research Network for Social and Behavioural Issues in Hepatitis C and HIV/AIDS (AIRN) completed an environmental scan that synthesized the HIV/AIDS specific services available in each of the four Atlantic Provinces. For NL, the "HIV Interdisciplinary Care Team" (AIRN, 2006, p. 73) was identified as the primary provider of clinical services for infectious disease. Initially, the HIV Interdisciplinary Care Team was invited to participate in the study, but its operations ceased during the data collection period due to staffing issues (Telegram, 2009). Ultimately, one organization was responsible for two testing sites, so three organizations represented four testing sites. At the end of data collection, the policies and procedures of four testing sites had been reviewed and seven participants had been interviewed.

3.2 Methods

3.2.1 Qualitative Description

While qualitative description is not associated with any particular discipline, it may be influenced by any of the traditional methodological research frameworks described by Polit and Beck (2004) including phenomenology, grounded theory,

ethnography, ethology, discourse analysis and historical analysis (p.249). It draws from the ideals of naturalistic inquiry, which require a commitment to observing something in its natural state with little pre-selection or manipulation of variables and no commitment to any one theoretical view (Lincoln & Guba, 1985; Willems, 1967). According to Sandelowski (2000) the aim of qualitative description is to “create a comprehensive summary of events in the everyday terms of those events” (p.334) in which researchers stay close to their data and to the surface of words and events. Plain language was an important consideration for my research because I recognized that it would be necessary to effectively synthesize this information easily for a variety of audiences and, hopefully, highlight areas for policy change or examination. The motivation for choosing qualitative description was to achieve a writing style that would help me communicate the findings across disciplines to many stakeholders.

Qualitative description is consistent with constructivist epistemology as it allows for multiple data collection strategies and emphasizes the importance of avoiding highly abstract interpretations of the data. According to Sandelowski (2000), data collection under qualitative description can be achieved through an eclectic combination of sampling, data collection, and analysis techniques. This section describes the strategies that were used for data collection and analysis. The first step in data collection was a document review, which was analyzed using textual analysis and diagramming. The second step was individual interviews with seven participants, which were analyzed using coding techniques and the use of a template to complete thematic analysis. Finally, a reflexive journal was kept throughout the data collection process and used during data analysis.

3.2.2 Document Review

The goal of my document review was to find out the various organizations' HIV testing policies. If the setting was non-clinical, the goal was to determine past testing policies and current procedures for handling inquiries about testing. The correspondence that was used to invite organizations to participate in the study is shown in Appendix A. The study invitation provided the following explanation of a document review,

It is important to note that a policy need not be a manual. The document review will be of all policy-related documents including meeting minutes, emails, briefing notes, or any other hard copies that have been or currently are used to direct testing procedures and inquiries. (p. 1)

By including additional sources, I hoped to obtain access to documents supporting informal procedures and accepted practices that took place in the event that there was no formal policy. To begin the document review process, I met with the principals of each organization. The purpose of this first meeting was to describe the study, obtain written and informed consent, and explain the document review process. During the document review, a series of meetings were held during which I received documents, took them away for analysis, and initiated follow-up contact to ask questions. This process was repeated as many times as necessary. As such, document review data collection and textual analysis were overlapping processes. This section addresses the process that was used to select and collect the documents.

Based on the principal's understanding of the study invitation and the verbal explanation provided in the first meeting, initial documents were provided that explained the organization's testing policy, provided proof of organizational practices, or were in

any way pertinent to testing. Subsequent meetings and correspondence were held to clarify any questions on the documents that I had in my possession or to collect any additional documents the principal had to offer. The number and type of meetings required to complete the collection of documents and varied with the type of organization. The community-based organizations ranged from four to six meetings, while the regional health authority's entire document review process was completed in three meetings. There was a higher volume of email exchange with the regional health authority's principals than with the other two community organizations.

After my first meeting with the first participant, I realized that participants were somewhat hesitant to provide documents. During the meetings, several comments led me to believe that this hesitation was related to the variety of forms of documents that had been stated as eligible for inclusion in the document review in the study invitation (Appendix A). Upon realizing this, I shared my rationale for the broad range of documents that qualified for the document review and emailed the principal a copy of the Excel spreadsheet I was using to record document review information. This helped participants understand what I was looking for and how it would be stored. This also helped me communicate the importance of including historical evolution of policies to demonstrate changes to the organization's response to HIV testing and allowed me to collect a series of documents that reflected past and present organizational practices - even when a formal policy did not exist. In cases where a formal policy did exist, I included other forms of documents to supplement or verify the protocol in place at the organization. I later speculated that principals of community-based organizations may have been hesitant to provide supporting documents due to a phrase in the ethics

application that stated “if there are no HIV testing policy documents, it will be considered a significant finding.”

The initial findings of my document review were recorded in a Microsoft Excel spreadsheet that I referred to as a data tracking sheet. During the data collection stage of the document review, I referred to this as the *raw* data tracking sheet because it tracked the documents according to the chronological order in which I received them and did not reflect any kind of categorical organization. At the top of the sheet, the organization’s name and the principal’s contact information were recorded. Table 2 provides a short description of the headings used to take notes for analysis,

The first ten categories were descriptive statistics or procedural information about the document and were noted during the exchange of the documents. The remaining categories became significant in the later stages of data analysis.

3.2.3 Individual Interviews

An epistemological approach grounded in constructivism, relativism and subtle realism encourages a loosely structured interaction between researcher and participants so that an issue can be explored in a particular context. Through this exchange, data can be co-constructed or created. Flexibility in the sequence and phrasing of questions allows the participant and the researcher to do what Lofland, Snow, Anderson and Lofland (2006) refer to as “starting from where they are” (p.9). This approach encourages connections between personal emotions and perceptions and thoughtful reflection.

Table 2: Headings Used in Raw Data Tracking Sheet

Heading	Description
#	To identify the order in which documents were received.
Title	Recorded the title of the document, where no title was available an identifying phrase was generated
Description	A brief description of the content of the document
Availability	Identified who had access to the document and if it was a public document how and where it was displayed
Status	This described whether or not the document was in use at the time of the document review or out-dated
Date Received by Amanda	This is the date that I first received the document
Original document details	This describes who created the original document, when it was created, and why it was created
Most recent revision	This describes who did the most recent revision to the document, when it was done, and why it was done
Details of Previous Revisions	Describes what the last revision was
Update Procedure to Document / Policy	Describes the procedure for updating the document
Content	Provides a brief summary of the content
Noteworthy Excerpts	Summarizes the sections of the policy that refer to HIV testing
Contact Information Provided	Summarizes the contact information provided
Contact Information Requested	Summarizes whether or not the document required contact information
Storage Information	Describes where and how the document is stored
Comments	Records my thoughts during the initial document review phase

Interviews are a popular method of data collection for qualitative researchers in the social sciences (Nunkoosing, 2005). In fact, interviewing is probably the most commonly used method in qualitative research, (Lofland et al., 2006; Mason 2002; Nunkoosing 2005; Sandelowski 2002). Silverman (2000) goes even further by referring to interviewing as the “gold standard” in qualitative research (p. 291). Kvale (1996) describes interviews as “attempts to unfold the meaning of peoples' experiences, to uncover their lived world” (p. 1). At the most basic level, interviews are conversations.

To generate effective data, an interviewer must not just chat with a participant, but use skills to listen, probe, and encourage the sharing of relevant data. Nunkoosing (2005) describes a skilled interviewer as one who “uses his or her person to communicate with people to create stories” (p. 698). Finally, advocates of qualitative interviews often point to the policy relevance of the insights that can be gained if we avoid imposing our own structures and assumptions upon participants’ views of the world (Britten, 1995).

According to Sandelowski (2000), qualitative description interviews are typically moderately structured, open-ended, and individualized. I wanted to ensure that my interviews were conducted in a manner that would support my ontology that knowledge is situational and contextual: interview data is constructed through dialogue. The in-depth nature of individual interviews offered rich data, but as an independent researcher my ability to obtain and interpret data from numerous participants was limited (Murphy & Dingwall, 2003). One or two participants from each testing site were purposively chosen based on their closeness to the practical delivery of the service and/or their knowledge of the organization’s policy. Seven interviews were conducted with participants from community-based organizations and the regional health authority. Financial and temporal constraints prohibited further interviews. The average length of each interview was one hour and fifteen minutes. In total, there was approximately nine hours of recorded interview time. The interviews were transcribed into over 300 pages of data, approximately 43 pages per interview.

As suggested by Murphy and Dingwall (2003) the interviews were conveniently scheduled to meet the time constraints of busy participants. This was particularly important since participants were involved with providing public health services,

administering testing and responding to inquiries. Appendix B is a copy of the Interview Consent Form and Appendix C is a copy of the generic interview guide, complete with probing questions.

3.2.4 Document Review Analysis

Analysis, approached from a constructivist framework, is a process that allows researchers to play with the data by deconstructing and reconstructing the text in search of patterns and relationships in perceptions and interpretations. As Sandelowski (2000) put it, “all inquiry entails description, and all description entails interpretation” (p. 335). To keep my data analysis consistent with qualitative description’s objective to synthesize information to communicate it across disciplines, I analysed with the intention of creating “a straight descriptive summary of the informational contents of data organized in a way that best fits the data” (Sandelowski, 2000, p.339). The analysis of documentary sources is a major method of social research and is commonly used in qualitative studies (Mason, 2002). When performing textual analysis, it is important to ensure that documentary sources are subject to an ample degree of critical scrutiny. Mason offered this caution in light of the fact that the permanent and indisputable characteristics of text can be easily mistaken as a superior form of information. Relying on textual analysis was aligned with my constructivist beliefs as it would supplement individuals’ verbal accounts of testing procedures.

I photocopied the documents I received and created two envelopes per organization – one contained original documents and the other with photocopies. I did a first reading of the photocopied documents and took note of text that addressed past or

present HIV testing policies or practices or offered definitions of nominal, non-nominal, or anonymous testing. After the first reading was complete, it became evident that there were certain categories that could be used to group the broad range of documents. I used the following categories to organize the documents received from the three organizations 'education, prevention, and awareness', 'clinical', 'policy-related', and 'legal'. I adapted the data tracking sheet to demonstrate these categories by creating a copy of the raw data tracking sheet and organizing it according to the categories that had emerged. I now had an *organized* data tracking sheet that listed the documents categorically. This was in addition to and separate from the *raw* data tracking sheet that listed the documents in the order that I received them.

I then did a second reading of the photocopied documents. During this reading, I used the comments and markings I had made in the first reading to complete the 'Content' and 'Noteworthy excerpts' sections of my data tracking sheet. In the 'Content' field, I created descriptions of each document. In the 'Noteworthy excerpts' field, I typed verbatim those sections that were relevant to HIV testing. As I did the second reading, I added two columns to the organized data tracking sheet: 'Comments Round 2' and 'Organized data code'. Under 'comments round 2' I noted things that seemed relevant for subsequent analysis. Under 'organized data code', I systematically assigned a number and a letter to each document to represent the reorganized structure and to represent that they were no longer listed in the order in which I received them.

As the document review progressed and principals were able to retrieve historical files, there were several cases in which I had multiple versions of one document. I further categorized the documents into chronological categories according to the description that

had been entered under 'Status' on the data tracking sheet. 'Current' represented documents that were being used by the organization at the time of the study and 'historical' represented documents that were outdated or no longer in use or prior to a certain time period. For example, the cut-off date for 'Historical' documents at testing site #2 was 1995. At times, I felt overwhelmed with the amount of text and data and I wanted to find a way to effectively portray the textual analysis and the categories that had emerged in an 'at-a-glance' manner. As such, I looked to the literature to confirm the pedagogy of using diagrams to depict findings.

3.2.5 Diagramming

Diagramming is one of five analytical strategies described by Lofland et al. (2006) that offer a visual representation of one or more relationships among parts of something. This was not a pre-determined analytical strategy that I had planned on using, but it ultimately helped me and the principals make sense of numerous documents. I used the organization chart feature in Microsoft Word to depict each organization into two main categories (categorical and chronological), and various sub-classifications (education, prevention, and awareness; clinical; policy-related; legal; current and historical). The diagrams took on a hierarchical shape in which one box could have many sub-levels. I referred to these as document trees to reflect their resemblance to branches and created two document trees per organization (Appendix D).

After the interviews were completed, I returned to the organized data tracking sheet and copied and pasted from the column labeled 'Noteworthy Excerpts' to reflect the findings of each organization's document review in a Microsoft Word table entitled

Document Review Analysis. This table contains verbatim excerpts from the documents that demonstrate how each organization defines anonymous, nominal, or non-nominal and phrases from documents that indicate past and present organizational policies or provide evidence of organizational procedures.

3.2.6 Interview Analysis

I used thematic analysis to analyze the interview transcripts for its flexibility and fit with my overall epistemology and ontology (Braun & Clark, 2006). I also believed that thematic analysis would effectively portray my findings based on the research objectives. Thematic analysis can be used as a constructivist method to explore experiences and meanings and their emergence from individual and socio-cultural discourse. Thematic analysis is a foundational qualitative method of analysis, incorporating the core skill of “thematizing meanings” (Holloway & Todres, 2003, .247). Braun and Clark define it as a method “in its own right” (p.78). The flexibility of thematic analysis is due to its generic nature and associated theoretical independence and it is trustworthy because the researcher records and reports how themes were developed, why and how. As such, the following paragraphs explain my data analysis step-by-step.

To finalize the thematic analysis and highlight key findings, I used a blend of Strauss and Corbin’s (1990) coding techniques and Crabtree and Miller’s (1999) “template analysis” (p.8). In template analysis, the researcher identifies themes that are significant to the research and a template is developed to summarize the data into useful themes. Completing the document review helped me pre-determine three important themes for the template:

- statements that demonstrated past practices,
- statements that demonstrated current practices, and
- participants' definitions and perceptions of HIV testing.

With these three themes on the template, I did what DeWet and Erasmus (2005) refer to as a "close reading" (p.29) of all seven transcripts for the first reading of the interview transcripts. While reading the electronic transcripts, I copied and pasted statements that demonstrated past or current practices at the participants' organization into the template. I also copied and pasted statements that demonstrated the participants' definitions, perceptions, and understandings about nominal, non-nominal, and anonymous testing into the template. I then used the verbatim statements to create detailed descriptive summaries.

After categorizing data that were relevant to the three themes that had been identified in the document review, I did a second reading of three transcripts to systematically identify other important themes. By reading one transcript from each organization line-by-line, I did what Strauss and Corbin (1990) refer to as "initial coding". I started by identifying codes within the testing sites operating within formalized public health settings because these transcripts contained the most technical information. Twenty-six themes were identified. Subsequently, initial coding for other testing sites revealed an additional 36 themes. One of the characteristics of initial coding is that the codes are generally quite numerous and varied.

The purpose of my next reading was to do what Strauss and Corbin (1990) refer to as "focused coding", which allows the researcher to further refine the codes into meaningful categories. I entered all 63 initial codes into an Excel spreadsheet and

embarked upon a third reading with the intention of condensing the themes. During this reading, I copied and pasted verbatim excerpts from the seven electronic interview transcripts into the Microsoft Excel spreadsheet and populated each of the 63 initial codes. This process helped me refine the themes and select the focused codes. For example, after placing the initial codes side-by-side in a Spreadsheet, I realized that the four initial codes 'Summary of current policies', 'Summary of current practices', 'Loopholes within the current system', and 'Examples of incongruence between policy and practice' could be combined under one focused code 'Examples of incongruence between policy and practice'. I did this by selecting the codes that were the most relevant to the research question and would translate into meaningful findings for discussion.

In the end, six focused codes were added to the template – legislation, understandability of testing language, perceptions of at-risk groups and concepts of harm reduction, identified areas of weakness in current service delivery, perceptions about the healthcare providers' and community-groups involved in the HIV process and recommendations for change. The template now consisted of nine themes; three that had been pre-identified in the document review and six had been identified through initial and focused coding.

I created a new Spreadsheet with the three pre-identified codes and six focused codes. This was the final analysis template. I used the spreadsheet containing the 63 initial codes to populate the categories. Finally, I did a fourth reading of the seven transcripts to ensure the richest parts of the data set were reflected in the focused themes. At various points throughout each of the four readings, I listened to the original audio

files so I could be reminded of the context of the conversation as demonstrated by verbal intonation and emphasis.

3.2.7 Reflexive Journal

As a qualitative researcher, I recognized that my presence, beliefs, and opinions influenced the social context in which data were created and meaning was emphasized. Using reflexive journals is aligned with constructivist thinking, which emphasizes the importance of exploring perceptions, experiences and meanings and their emergence from individual and socio-cultural discourse. Murphy and Dingwall (2003) recognize the importance of practicing reflexivity to increase the reader's confidence in the findings. By making this 'paper trail' available, other researchers can either explore the transferability of the findings of this inquiry to other contexts, or repeat the procedures I have used with the rich detail provided in the reflexive journal.

I followed Ahern's (1999) tips for writing a reflexive journal and recorded personal thoughts and feelings that pertained to my area of research. I attempted to make my assumptions and biases explicit by recording the materialization of my own beliefs and world views into thoughts, attitudes, and opinions throughout the process. As I did this, I considered my own role in constructing the data. From January 30th, 2009 to May 25, 2009, I logged an 81-page reflexive journal to record my thoughts and challenges throughout the study design and data collection phase. Having the reflexive journal allowed me to better acknowledge the influence of my personal interpretations on the data and key findings. Rather than attempting to eliminate my personal influence, I attempted to account by consulting my reflexive journal during analysis. The contents of

my reflexive journal and its usefulness as a tool for analysis are further discussed in the following section.

3.2.8 Saturation

Bowen (2008) draws from the work of many researchers to provide his own definition of data saturation as the process whereby new participants are brought into the study “until the data set is complete, as indicated by data replication or redundancy” (p. 140). When new information is not being added and when there is substantial replication within categories, the data can be considered comprehensive and complete. Saturation became evident in three distinct ways – participants’ approval of the document trees, data repetition within individual interviews, and data redundancy between interviews with different participants.

After the documents were reviewed and the diagrams were complete, I emailed the document trees to one participant per organization and we set a time for the first interview. The participants who received the document trees on behalf of their testing site(s) were satisfied with the document trees and stated that there was no additional information required. Secondly, the structure and duration of the interviews allowed participants to express their opinions, perceptions, definitions and understandings for the type of HIV tests on multiple occasions. The following statements demonstrate how one participant defined anonymous testing at four separate points during the interview.

With anonymous testing, the only thing that attaches to you to that blood sample, and the results of that blood sample, is an I.D. code. So, say, if it

was for myself, my code would probably be T.U.² and like the first couple of digits of like my date of birth or something like that; but nothing... my MCP, my actual name, none... no information that, you know, is relevant to me is actually attached to that blood sample. So what you do is you present that code to whoever is presenting you with the results. And positive/negative – do you need counselling; do you need help? That's it.

...you're given a code from when you walk in the door. You don't fill in anything. You don't... I mean, they might ask you about your sexual history, but they're not taking your name; they're not taking your address; they're not taking your age. They might take your initials and your age and that might be your code, but you as a person in society and in... you know, a number under the health care system has nothing to do with your test.

That test has your code on it. You get the results back by that code. It's never put towards your name. So it is truly anonymous where is non-nominal is not anonymous. It's just... it's not... you know, your name isn't given to the lab.

...anonymous testing, you know, it's only you and the provider who's telling you results.

² Initials changed to protect confidentiality.

The detailed interview transcript analysis revealed multiple instances of such repetition, thereby confirming the completeness of the conclusions suggested by individual participants. I was also careful to avoid generalizing or drawing conclusions based on individual events or perspectives. As such, before a theme or finding was confirmed and used in the analysis template, at least six verbatim statements from multiple participants were required to support and confirm it. For example, the following nine statements were made by four participants from community-based organizations, which allowed me to conclude that participants from community-based organizations supported access to anonymous testing.

I think that having access to anonymous testing is essential, and I just don't think that it's there. Access to anonymous testing is vitally important and it's not there.

So, hence, the urgent need for anonymous or non-nominal, whatever you're going to call it, but it has to be insured, that the person whose health information is this HIV result, that the name is never connected to that file because if I go in to the insurance company and I lie and say – “Well, if I say yes they won't insure me,” right, “but if I say if I say no they'll never know - but if I had had a test through my doctor's office, or through the health care system using my MCP card, that could be traced because it's in the system, right?

Yeah, I think it would be good to have because it would probably get more people out getting tested because obviously some people think about it, but they don't want to... obviously, confidentiality is something that's, you know, on people's minds when they're talking to us about STI's.

So being able to get it done anonymously where they don't have to give their names or anything, that's, you know, critical for a lot of people because there is that fear that it might, you know, leak out somehow and people might find out, and people worry about that

Whatever the test is called, urgent need for a type of test that can never be connected to personal health information or that can be accessed by one's family physician.

...we can explain about confidentiality to them and how important it is, you know, because then at least they know that in the future they have a safe spot that they can go to, and ask questions. They can come to us, and we'll try and explain the whole confidentiality process and... you know, policy ... but if they... even if they're not comfortable... yeah, anonymous HIV testing would be preferable. I guess it depends on why they would be afraid that anyone would find out.

Interviewer: What does anonymous testing in [small urban centre], mean to you?

Participant: Failing of our system.

Interviewer: because it's not available?

Participant: Yeah, you know, it would be nice if it was available. It's sad that it's only available through, you know, special studies – or, you know, studies – but, yeah, in terms of anonymous testing, it doesn't mean much in Newfoundland because it's not available.

Counselling pre and post is very important as well, and keeping in mind that that needs to be done with anonymity and protection as well and then also that it's not rammed down people's throats.

I think the [anonymous HIV testing] protocol needs to be clear, and it needs to be enforced, or best-practiced or whatever it is you do with it. You know, it needs to be followed.

3.3 Rigour

Morse, Barrett, Olsen and Spiers (2002) define rigour as the verification strategies and self-correcting mechanisms adopted by the researcher to actively work towards reliability and validity in the analysis of qualitative data. As De Wet and Erasmus (2005) point out, systematic analysis can refer to any conscious use of procedures to organize a mass of data methodically so that it fits into a broader, structured whole. Murphy and Dingwall (2003) outline three guiding criteria to explain efforts taken to assess the truth claims of qualitative research - searching for contradictory evidence, combining different methods, and checking research findings with research participants. This section uses the

first two of these three criteria and an expanded version of the third criterion to demonstrate the rigour of this study. The purpose of this section is to present readers with enough information to allow them to decide whether the findings are adequately supported and gauge the quality of each stage of the study.

3.3.1 Searching for Contradictory Evidence

“Searching for contradictory evidence” (Murphy & Dingwall, 2003, p. 174) is central to the quality of qualitative research because it can limit error and strengthen the researcher’s claim to authoritative knowledge. This section describes the series of events that demonstrates how the underlying rationale for the entire study was to search for contradictory evidence, as well as steps taken within the study itself. The series of events that influenced my choice of research topic described in Chapter One demonstrates that the very reason I pursued this inquiry was to find contradictory evidence. Exposure to the conflicting information in PHAC’s (2007a) Epidemiology update, local advertisements (The Muse, 2008), unavailable official guidelines for NL and community advocates demonstrates this.

Murphy and Dingwall (2003) advise that in addition to being the underlying rationale for a study, searches for contradictory evidence also occur within individual studies. Steps taken through my study design, data collection and analysis reflect my commitment to searching for contradictory evidence. With respect to the study design, I recognized that examining the congruence between HIV testing policies and practices in the small urban centre required including a narrower set of objectives that would capture the variety of settings in which testing was offered. Specifically, there were a number of

locations in the city where laypersons may have looked for HIV testing. Recognizing that the policies and practices at one setting may be totally different than another, I set out to thoroughly examine multiple locations. This minimized the possibility of drawing conclusions about testing procedures in the whole city without recognizing the context and setting in which they were being offered.

With respect to data collection, including many participants from each setting allowed me to search for contradictory evidence by including multiple viewpoints. Specifically, I included the principal of each organization, who was in a position of authority over the creation, implementation and enforcement of organizational policies, as well as one or two of the staff who were most closely involved with providing testing services to the public from each organization. With respect to data analysis, Murphy and Dingwall (2003) point out that the prior assumptions researchers bring to their study and those ideas generated in early field work can be valuable, but also very dangerous. Preliminary ideas can act as a filter through which researchers see the phenomena under study and the data they collect. As a result, they are alert to evidence that confirms their prior assumptions and fail to notice data that “contradicts or modifies these preliminary ideas” (p.175-6).

Recognizing that my theoretical inferences we’re always and irreducibly influenced by my own frame of reference and assumptions, I heeded the conclusions of De Wet and Erasmus (2005) to make my analytical procedures as transparent as possible. I did this by keeping a reflexive journal and by explicitly describing the process I used to complete the textual and thematic analyses. The manner in which I discovered my biases and the transformation of my opinions speaks to the rigour of my data collection and analysis.

Before starting my data collection, I was a strong supporter of anonymous testing as a widespread solution without really knowing why. This was indicated by statements of recommendation in a paper written for a policy course in the first year of my program, such as “Federal government should support widespread availability of voluntary, discrimination-free anonymous testing” (Hancock, 2008). After receiving feedback that widespread anonymous testing may not be a one-size-fits all solution, (V.M., Personal Communication, March 2008), I realized that this recommendation was based on my own opinion that had been formulated after reviewing a limited number of studies.

Since this preliminary position, a thorough literature review and rigorous data collection period helped me experience a broad range of perspectives on anonymous testing. Individual interviews and informal conversations with many employees and volunteers from the testing sites helped me gain a more comprehensive understanding of the issue. Before learning that anonymous testing had been offered as part of a study in this small urban centre, I realized that for a period of time I had negative feelings towards any advertising or offering of anonymous testing. I felt it was a malicious form of false advertising in which a person was essentially ‘duped’ into being tested by a false promise of privacy. This was indicated by statements from earlier drafts as I attempted to locate myself as a researcher

...the false sense of security felt by individuals who perceive they are visiting a truly anonymous site under NL’s current testing policy is noteworthy. The public health argument for anonymous testing is strong: it is better to test anonymously than not to test at all. However the bottom

line is that this procedure is less than transparent and what is labeled anonymous is, technically, non-nominal.

Even before participants had confirmed the availability of anonymous testing in the small urban centre was because of a temporary study, I became more open to the benefits of testing that was called anonymous after an informal conversation with an employee of a community-based organization. This was the first time anyone had articulated the challenges of understandability. This conversation inspired me to build the concept of health literacy into my literature review. I logged my thoughts after the conversation in my reflexive journal on March 19, 2009,

We also talked about the morality of advertising this type of testing as anonymous. [The participant] admitted that this (advertising and offering anonymous testing) had happened here at [Testing site #1] under several past employees as part of a study and suggested that this was because the meaning of non-nominal is not well-understood in the public eye; however, the word anonymous was and continues to be. [The participant] pointed out that whatever word was used was done with people's best interest in mind.

Finally, after speaking with an individual from a biomedical background, there was a period during which I was focused on the disadvantages of anonymous testing. In my reflexive journal on May 12, 2009 I wrote:

Today I saw downsides to anonymous testing when [the participant] talked about how *his/her* colleagues in other provinces where anonymous testing

is available encounter obstacles, such as limited ability to do partner notification.

Near the end of my data collection phase, my last entry in my reflexive journal on May 25, 2009 captured how my biases and personal attachment to the issue had evolved.

During the course of this review, I've wondered if NL's policy requirement that makes all positive individuals, even if tested anonymously, part of the nominal system the beginning of a long road of stigmatization and discrimination or is it an active precautionary measure that decreases the threat posed to the public health?

3.3.2 Combining Different Methods

Murphy and Dingwall (2003) describe "combining different methods of data collection within a single study" (p. 183) as a way to increase the reader's confidence in the soundness of the conclusions. I realized that examining policies and practices to capture areas of similarity or difference would require distinct data collection techniques. To examine the policies, I performed a document review to analyze documents that pertained to the organizations' HIV testing guidelines or described the organization's involvement with HIV testing. Since the practical challenges encompassed in HIV testing in a real-world setting could not be captured by examining only words and text, I conducted individual interviews with seven participants from four testing sites to explore the application of the policies in the various settings. To ensure that I was informed about organizational policies before having conversations about everyday practice issues, data collection at each site was a two-step process whereby the document review and

preliminary textual analyses were before conducting the interviews. Using multiple data collection strategies helped me confirm the details of key findings. For example, at a testing site where the official policy was for “non-nominal reporting” a participant provided detail about how that process is carried out in practice,

So if this has a positive on it (points to reporting form), [name of employee] who does all the data entry onto the C.D. [communicable disease] system – if one of these was positive, under the name [he/she] would have an alphanumeric code, say ST4252. That would be their name and age (points to form). The MCP [Medical Care Plan], [he/she] would generate. It would be 99. So the [provincial infectious disease epidemiologist] says, “Oh, but I need”... “You know, I need to have an MCP,” and [name of employee] says, “But you’re not going to get an MCP because we don’t collect MCP”.

3.3.3 Seeking Input

This section includes details on how I used Murphy and Dingwall’s (2003) technique of “checking research findings with research participants” (p. 186) and how I sought advice from experts to guide the direction of my study and refine data collection tools.

I verified the findings of my document review by corresponding with the principal at each setting. I did this by emailing each of the three principals a copy of the Microsoft Excel file with a list of the documents that would be included in the document review as well as two document trees that represented the findings of their document review. After

the file was received and had been reviewed, we discussed the document review findings in a face-to-face meeting. This gave me confidence that my document reviews and document trees included adequate sources of relevant policy-related documents. While I did not email participants copies of their interview transcripts, I verbally advised them to contact me after the interview if they made any statements during the interview that he or she wished to eliminate.

I recognized that I had my own personal biases and I was aware of Murphy and Dingwall's (2003) warnings against forming opinions based on early evidence and then seeking data to confirm this idea. I enlisted the support of experienced researchers, health care professionals, and policy experts at various points throughout the study. Prior to and during the document review, I met with and corresponded with Dr. Victor Maddalena on the focus and purpose of the document review. We devised a method for deciding which documents to include and a system for extracting and recording key pieces of policy-relevant information.

Before conducting the interviews, I received feedback on my interview guide from Drs. Gustafson, Mugford, and Storr who are experts in community-based health services research, epidemiology, and qualitative data collection respectively. Their feedback helped ensure that my interview guide reflected an exploratory approach rather than one that focused on the advantages of anonymous testing. An example of the types of revisions suggested to the draft interview guide by one of these experts process is contained in Appendix E.

Throughout the data collection phase, I adjusted the title of my study three times to incorporate external advice and the opinions of my participants. A committee member,

Dr. Mugford, suggested that my original title came across as adversarial and competitive, 'Anonymous HIV Testing in [city name]: Policies versus Practices'. I agreed with this and changed the title to 'Anonymous HIV Testing in [city name]: Are Policies and Practices Congruent?' This is the title with which my study received its initial ethical approval. I had completed two document reviews and three interviews before having a conversation that led me to change the title a third time. On May 8th, 2009 a participant expressed concerns that the title of my study implied a narrow view of the issue. Specifically, since the legislation does not allow anonymous testing, he suggested I change the title to 'HIV Testing in [city name], NL: Are Policies and Practices Congruent?' On May 14th, 2009 I submitted an ethics amendment form requesting official change to my title.

To strive for intercoder reliability, I shared my interview summaries with my supervisor, Dr. Gustafson to verify that I was correctly analyzing and interpreting key themes. Committee members Drs. Maddalena and Gustafson reviewed early versions of these chapters and helped me emphasize critical points in the write-up. Finally, I met with medical ethicist and researcher, Dr. Brunger, about how to approach ethical issues of disclosure in the write-up.

3.4 Ethical Considerations

As Rossman and Rallis (2003) point out, respect for the humanity of participants is of the utmost importance when using qualitative methods. Appendix F contains a copy of the ethical approval for this study that was issued by Memorial University of NL's Human Investigation Committee (HIC). Appendices A, B, and C contain the supporting

documentation that contains the approved test that was used to invite organizations to participate in the study, study information, and consent. Prior to the interviews, participants were emailed a list of interview questions, study information, and consent forms. At the time of the interview, these documents were verbally reviewed and the purpose of the study, and potential harms and benefits were reviewed. This study was also approved by the health authority's Research Proposal Approval Committee (RPAC). Appendix G contains the completed RPAC application form and the correspondence regarding the approval of this application.

As previously described, conducting research in small communities requires special ethical considerations when (Benoit et al., 2005; Fraser, 2004). Given the sensitive subject matter, legal compliance issues, and the challenges of confidentiality in small communities, my main ethical concern was about protecting the confidentiality of the organizations and the participants. This became evident as I was collecting my data and I realized that, at times, *discreet* practices may not have been in total compliance with the provincial legislative requirements of the Communicable Diseases Act. The term *discreet* is used to describe the availability of implicit anonymous testing at testing sites #3 and #4, but it is emphasized that non-nominal testing was the official standard of practice according to policy documents and reports from participants. The term *discreet* was chosen to reflect provider descriptions that suggested procedures that fit the definitions of anonymous were informally employed if necessary. These procedures included advertizing testing as no names, testing with a fake name, testing with no name if necessary, testing with a first name and last initial, reporting with codes instead of names, incomplete MCP information on provincial surveillance reports, limited

geographic information in provincial surveillance reports, referrals to acute care settings when they were operational using a non-nominal code, chart number, or initials.

After consulting with a medical ethicist within the Division of Community Health and Humanities who had encountered similar issues in write-up and analysis and my supervisory committee, we decided that care must be taken to protect the identity of the participants to prevent any professional or personal harm that could potentially result. As such, I have deleted specific details about the nature of operations at either site and removed organizational identifiers. Participating organizations are referred to as simply community-based organizations and the regional health authority. The individual testing sites are described as testing site #1, #2, #3, and #4 and, where possible, I have eliminated details that would disclose the locations of the testing sites. To protect the identities of individual participants I have attempted to remove identifying information about individual participants such as their job title and the specific number of participants from each testing site who were interviewed. Oftentimes, direct quotations were edited or a de-identified version is presented according to the specified notation. Additionally, personal communications are referenced with initials and limited information about the date of the correspondence. At times, citations that reveal the name of the participating organization have been altered. This was especially important in this study since, at times, individual participants expressed personal views that did not reflect those of their organization or compliance with the law.

Furthermore, it is necessary to declare two potential conflicts of interest as ethical considerations of this study. Firstly, I was a volunteer at one of the testing sites prior to and for some of the study duration. Before starting data collection, I realized that I would

be playing a dual role by undertaking a formal research inquiry at an organization where I was also a volunteer. As such, I took steps to create boundaries before starting the study. For example, I advised the staff with whom I had previously volunteered that any correspondence from my Memorial University email account would be considered formal and could be included as part of the study findings. I minimized my volunteering hours and involvement with the organization throughout the duration of data collection, analysis and write-up.

Throughout the duration of the study, I was offered office space, gifts, and asked to serve on the Board of Directors of one of the community-based organizations. I consulted a different medical ethicist on this matter and declined offers until such time as this document was approved by external reviewers. Secondly, I accepted a paid position with an organization that was participating in the study during the data collection period. The position was with a Human Resources department and unrelated to the clinical nature of this inquiry.

At the outset of the study I planned on transcribing the interviews myself. Due to the length of the interviews and the time required for transcription, I decided to enlist the support of a professional transcriber. To verify this change with the university's ethics board, I submitted a Request for Amendment to an Approved Application form. This amendment application also requested a change in the title of the study to protect participant's identity.

The sequence of the following dates that preceded the last reported update to the draft document is noteworthy. The health authority's RPAC granted permission for my study on March 3rd, 2009 (Appendix G). The study invitation (Appendix A) was emailed

to the public health division on March 26th, 2009. At the time of the document review, the last revision to the draft policy (Document E3) was on March 31st, 2009. This meant that revisions to this draft policy had been made after the organization had reviewed the study information and were ongoing throughout the duration of data collection. This was significant for two reasons. The version of the draft policy that was included in the document review could be significantly outdated by the time of publication. Also, revisions to the policy that were made after the study invitation had been received may have been influenced by the information provided in the study invitation or study information sheet.

4.0 Findings

The first section of this chapter provides an overview of the three organizations responsible for the four testing sites and a description of individual participants' perceptions of testing and risk. This is followed by a summary of the results of the document review and formalized definitions of HIV testing that were revealed. An overview of past and current HIV testing procedures at the four testing sites is provided, as well as concerns expressed by participants about these procedures. The final section summarizes key areas of incongruence between policy and practice.

These findings are based on analysis of document review resources, individual interviews, thematic analysis, and my reflexive journal. It is important to note that, at times, participants expressed their personal views, which may not have been representative of their organization. These findings are presented to minimize readers' ability to identify the four testing sites and the participants. Everyone who participated in this inquiry contributed to knowledge production and I expect that we will benefit differently from this experience.

References to documents included in the document review are depicted in Appendix D. Documents labeled 'A', 'C', and 'E' are classified as current documents and documents labeled 'B', 'D', and 'F' are historical documents. In many places, verbatim quotations from interview transcripts have been condensed to present the parts of speech most relevant to the discussion. Deletions of text are represented by '...'; emotions, body language, or other nonverbal cues that were understood between the interviewer and the participant are indicated by descriptions of the actions in parenthesis; finally, square

brackets are used where verbatim quotations have been altered to protect the identities of participants and/or other organizational employees or affiliates. Testing sites are referred to as testing sites #1, #2, #3 and #4 to protect their identity.

4.1 Organizational Information and Definitions

4.1.1 Community-based Organization #1

Organization #1 defined itself as a “non-profit, charitable organization that promotes positive sexual health across the province”. It was a pro-choice sexual health centre whose vision was “a province where all people experience positive sexual health” (Document B8). Its mission was “to promote positive sexual health through education, community partnerships, information and services within an environment that supports and respects individual choice” (Document B8).

This document review revealed 15 documents that were related to HIV testing, eight of which were historical and seven of which were current. Of the 15 documents, nine were for education, prevention and/or awareness; three were clinical; and three were policy-related. Appendix D demonstrates the organization’s document trees (p. 1-2). Analysis of document review resources did not reveal formal definitions for the three types of HIV testing; however, document B2 provided an explanation of confidential and anonymous testing processes and offered brief explanations of each,

HIV and Hepatitis B&C can be detected by a simple blood test. A doctor will give you a slip to have blood drawn at the hospital, or may draw the blood at his/her office. This testing is confidential, meaning that your MCP number and name will be attached to your file. If you are interested

in anonymous testing having no identifying information contact your local Health and Community Services Office. (Document B2)

4.1.2 Community-based Organization #2

Organization #2 believed in and encouraged “social and political advocacy to ensure individual and collective rights to non-judgmental education and support, thus encouraging responsible decision-making and personal empowerment” (Organization #2’s website, 2009). Its vision was to be a “consumer-focused, non-profit organization” that provided supportive programs and services aimed at preventing HIV/AIDS and supported persons living with and affected by HIV/AIDS. Its mission was to “prevent the spread of new infection through education, provide support to those individuals already infected/affected, network with other groups working in AIDS related areas on a regional, provincial, national and international level, and advocate for social and political change”. At organization #2, clients could access educational material, harm reduction services and a common area to lounge in while waiting to access services.

Appendix D demonstrates the organization’s document trees (p. 3 - 4). This document review revealed 40 documents that were related to HIV testing, six were historical and 34 were current. Of the 40 documents, 36 were for education, prevention and/or awareness and four were policy related. The lack of clinical documents reflected the fact that no clinical services were offered on-site at the time of the study. Analysis of document review resources revealed that this organization had formalized definitions for the three types of HIV tests in document C3. The definitions are stated below,

Nominal testing - the identity of the individual being tested is clearly known by the tester as well as the lab testing the sample. The individual's name appears on the testing requisition and result.

Non-nominal testing - the identity of the individual being tested is shielded by a code used by the testing clinic. The code is attached to the test requisition and test results. However, an individual can ultimately be traced to a test result. The identity of the individual may be known by the testing clinic.

Anonymous testing - the identity of the individual being tested is known only to the individual herself/himself. No record is kept which can connect the individual's identity with the test requisition or result. Requires a completely independent filing system (Document C3, p.1).

4.1.3 Regional Health Authority

The regional health authority served a regional population of more than 293,790 people and was the largest integrated health authority in Newfoundland and Labrador. Its vision was for "Healthy People, Healthy Communities" and its mission was to "provide health and community services along an integrated continuum within both its regional and provincial mandates and available resources to improve the health of people and communities" (organizational document). Participants indicated that there was never a

charge for HIV testing services provided by the Community Services division at any of its testing sites.

Appendix D demonstrates the organization's document trees (p. 5 - 6). This document review revealed eight documents that were related to HIV testing, three were historical and five were current. Of the eight documents, three were legislative acts and five were policy-related. Of the policy-related documents, two were internal documents that outlined specific clinical procedures for staff, two were HIV statistical epidemiology updates published by PHAC in 2005 and 2007, and one was the *Canadian Guidelines on Sexually Transmitted Infections* (Document E5) published by PHAC. Analysis of document review resources revealed that this organization had formalized definitions for the three types of HIV tests in document E3, which are stated here,

Nominal - The correct name and other identifying information (such as MCP number) is used on laboratory requisitions and patient record. Face to face Pre-test and Post-test counselling is undertaken as an essential standard of care (Document E3, p. 7).

Non-Nominal - Initials or a false name or an alphanumeric code are used instead of a name on a laboratory requisition, but the patient record, a confidential document, contains the true identification and contact information (e.g. telephone number, address). Face to face Pre-test and Post-test counselling is undertaken as an essential standard of care (Document E3, p. 6-7).

Anonymous - Initials or a false name or an alphanumeric code are used instead of a name both on a laboratory requisition and on any patient record. There is no address or contact information recorded that could lead to the identification or location of the individual presenting for testing.

Face to face Pre-test and Post-test counselling is undertaken as an essential standard of care (Document E3, p. 6).

It is important to note that the regional health authority's policies and procedures that were reviewed pertained to community settings only. The findings do not apply in acute settings or to the practices of family physicians who might otherwise be affiliated with the health authority. The regional health authority's policies and procedures described were in effect at testing sites #3 and #4.

4.1.4 Perceptions of Testing: "...whatever you want to call it..."

The interviews revealed that the meanings and procedural differences between non-nominal and anonymous have been vague for quite some time. The terms non-nominal and anonymous were and are often used interchangeably. Participants at all four testing sites reported having referred to a process in the past as anonymous that was, technically, non-nominal. During the interviews, participants were asked to explain their understanding of the three types of testing. This section provides a summary of the participants' understandings of non-nominal and anonymous testing, as well as a summary of the reported commonalities, shared understandings and perceived advantages and disadvantages.

To illustrate the context in which these conversations occurred, it is necessary to point out that participants unanimously agreed that HIV was a highly stigmatized condition and this impacted people's behaviour when seeking testing. They believed that in a truly anonymous test there is no possible way for an outside agency to link this code to the individual or obtain the result. Similarly, there was a common understanding that with anonymous testing the onus to return for the test results was entirely on the test seeker. The results were delivered to the test seeker when he or she returned in person with the code from the initial visit to obtain the results.

Beyond these shared understandings, there were three distinct understandings of anonymous testing. Procedures used for blood drawing, code sharing, results delivery, partner notification and reporting were key points of distinction between how five out of seven participants understood anonymous testing. Five out of seven participants described anonymous testing as a process in which there was a face-to-face exchange between the test seeker and a healthcare service provider. They understood that personal identifying information would never be requested, collected, or recorded. These participants felt that it was acceptable for the healthcare provider to ask about the client's sexual history during pre-test counselling. Similarly, these participants believed that the healthcare provider who administered the test was responsible for delivering pre- and post-test counselling. They accepted and understood the use of initials or other forms of representative association with personal information to generate a non-identifying and/or alphanumeric code. This code was then used to label the specimen when it was sent to the laboratory. Participants who shared this perception of anonymous testing felt that it could be set-up relatively easily in this small urban centre. Of the five participants who shared

this definition, four of them described a reporting process that reported aggregate, de-identified statistical information on occurrences of positive cases. One of these five participants felt that there should be no reporting component associated with anonymous testing.

The first of the two remaining participants had many concerns about offering anonymous testing. This participant described anonymous testing as an entirely faceless procedure for drawing blood during which there was no guarantee of pre- or post-test counselling and there was no human contact when results were delivered. This participant envisioned that blood was drawn when the test seeker stuck his or her arm through a curtain. The code would be generated by the test seeker who would write the code on paper and handed it through the curtain. The participant shared the belief that the onus was on the test seeker to return for the result. The participant believed that anonymous testing results were communicated using a posting method whereby results were posted on a wall and accessed when the person who had been tested returned to match their code to the posted result. In this way, there was no post-test counselling available at the time the result was delivered and no partner notification. This participant did not support the availability of this type of anonymous testing in the small urban centre and said there were three potential complications with this. Firstly, if someone came back with the non-identifying code or number, there was no way of knowing that it was the same person whose blood had been drawn since there was no identifying information to confirm this. Secondly, when people received their results from a posting of a code on a wall, there was no one there to counsel them. Thirdly, because there was no chart attached to the test it would be difficult to keep track of the services the individual receives over time.

Lastly, a participant who felt there was an urgent need for anonymous testing defined the processes used for code generation and sharing during anonymous testing differently than any other participant. This participant understood anonymous testing as a type of test where only the test seeker knew the code with which the test was labeled or saw the results. The healthcare provider would never see the code, rather the test seeker would write the code on the specimen before it was sent for testing. This participant explained that their personal understandings of anonymous and non-nominal had changed. Despite having called it anonymous in the past, the participant felt, in hindsight, it was better described as a non-nominal process despite the absence of any requests for or recording of personal and/or identifying information. The participant's explanation of this shift in understanding demonstrated a unique perception of the meaning of anonymous testing.

The participant described a process in which no personal information was requested or recorded at intake as non-nominal. The participant made this distinction on three grounds; first, on the basis that the code that was used to label the test was shared with the nurse; second, that the nurse saw the results before the client; and third; because positive test results had been reported to public health without any names attached. This does not fit with the technical definitions provided by other testing sites, which suggest that non-nominal testing requires some attempt to record the true identification and contact information of the client. According to these definitions, the difference between non-nominal and anonymous testing is not merely the sharing of a code; rather whether or not contact information was obtained with the intention of contacting the individual to follow-up on the results. The participant went on to describe a procedure for drawing

blood that was similar to the first five participants', but described a process for accessing the results whereby the test seeker's code and accompanying result were posted on a wall. Only the test seeker knew the code and he or she would be entirely responsible for coming to check the result. It is important to note that this participant believed that the records of a person who had been tested could be accessed by third parties and linked by MCP number,

HIV is a condition that the insurance companies don't want to cover. So, hence, the urgent need for anonymous or non-nominal, whatever you're going to call it, but it has to be ensured, that the person whose health information is this HIV result, that the name is never connected to that file because if I go in to the insurance company and I lie and say – "Well, if I say yes (I have been tested for HIV) they won't insure me," right, "but if I say if I say no they'll never know - but if I had had a test through my doctor's office, or through the health care system using my MCP card, that could be traced because it's in the system, right? And then the insurance company will swab your cheek anyway and test for HIV.

This participant was challenged to find a solution to delivering post-test counselling with a system that used a wall posting to deliver results and felt it is dangerous for people who are positive. The participant specified that, preferably, the list would be posted in a healthcare facility,

with anonymous you would put a code on something, and not even tell the person drawing your blood, and the results would then be posted after such a period of time, and you would go and look and say, "Okay, there's

Mary"... "Little Miss Muffett or 'x', 'y,' 'z,' 1, 2, 3, that's me," and nobody knows that but you because you wrote it on there. And the problem with that is what if you freak out and walk away and you don't get your post-test counselling, right?

Despite feeling that there was an urgent need for anonymous testing, this participant felt the posting process to obtain results was potentially dangerous for people who received positive results. The participant expressed strong beliefs about the human contact and sensitivity required to deliver results in a way that was best for the individual receiving them and would prefer a system in which positive cases were reported to public health officials and partners were notified voluntarily by the individual. This participant eventually summarized by saying that the defining aspect of anonymous testing was the inability to link any evidence that an individual had ever been tested from HIV from his or her permanent medical records. The participant later clarified that the importance of this was associated with the benefits it would have for people whose test results came back negative because it would allow them to maintain confidence that other areas of their lives would not be negatively impacted. For example, they would be able to continue to respond negatively to questions on insurance forms asking if they have even been tested for HIV.

There were some notable differences in the way participants from community-based organizations and the regional health authority understood anonymous and non-nominal testing. Participants from community-based organizations were more likely to demonstrate strong support for anonymous testing and felt that widespread access to this service was urgently needed. This urgent support for anonymous testing persisted despite

a range of differing perceptions about anonymous testing and even uncertainties about how certain aspects of anonymous testing could or should work. These participants suggested offering anonymous testing would facilitate access to preventative HIV services in two ways; firstly, by using a non-technical term that would be understood by people and, secondly, by relieving stress associated with fulfilling the information requirements in nominal and non-nominal tests. This stress was largely related to fear of third parties - people or organizations - finding out about the test. Three participants from community-based organizations reported that they would go out of province to seek HIV testing because they did not trust the current system to keep results private and confidential.

Other participants acknowledged the need to increase the number of locations and times during which STI testing was available, but felt the current manner in which testing was delivered offered an adequate degree of protection for a person's identity. When it came to out-of-province testing, many participants from the regional health authority felt the current system was trustworthy and should not require that people to leave NL to get tested. They did acknowledge, however, that some individuals seeking testing were less than forthcoming about personal information or had distrust in the system. These participants reported varying degrees of support for anonymous testing, depending on their definition and understanding of anonymous testing. The range of opinions expressed by participants demonstrated that some were against anonymous testing, others thought the current system was fine, and others thought that increased availability of anonymous testing could benefit some people.

At various times in the interviews, participants whose experience was largely within formalized public health settings described clinical practices that supported and reflected the principles of harm reduction without using the term harm reduction. This supports previous studies in the region that determined providers had varied and inconsistent understandings of harm reduction concepts (HRU & ACNL, 2007). It could also mirror a philosophical understanding of HIV testing as merely a service that is not necessarily a harm reduction approach. Some examples of everyday practices that were geared towards making the HIV testing services accessible for everyone included allowing testing with a fake name, testing with no name, testing with a first name and last initial, reporting with codes instead of names, withholding MCP information from provincial surveillance reports, and providing limited geographic information in provincial surveillance reports. For example, one participant following a non-nominal procedure saw no reason to change the way testing was delivered, but reported a willingness to test people regardless of what personal information they were willing to provide. Finally, one participant believed that anonymous testing would encourage people to be tested, could be set up quite easily, and would attract people who engaged in risky behaviours.

Several perceived disadvantages of offering anonymous testing included the possibility of test seekers not returning to obtain results, the limited ability to do contact tracing, and the potential for coding confusion. One participant identified the worst case scenario in terms of protecting the public's health whereby public health officials would be unable to contact a positive individual responsible for transmitting the disease to someone else.

4.1.5 Perceptions of Risk: "...some of these people need to be tested regularly..."

Participants from all four sites acknowledged the concept of risk and the reality that engaging in certain behaviour places people at an elevated risk of contracting HIV and other blood borne diseases. They acknowledged the importance of providing specialized services for people who engaged in risky activities. Participants believed that a type of testing that is called "anonymous" would encourage people to get tested who might not otherwise. All participants recognized the need to incorporate a discussion about risk into face-to-face pre-test counselling in a skilful way. Many participants believed there was a relationship between an individual's desire to be tested anonymously and their tendency to engage in risky behaviour and/or their exposure to other negative psycho-social circumstance. Examples of risky behaviours that were cited by participants included unprotected sex, sex for money, injection drug use, sharing of drug paraphernalia. Financial instability and low literacy levels were the two most commonly cited examples of negative psycho-social circumstances cited by participants.

Participants used the term "repeat customers" to describe test-seekers who repeatedly engaged in risk-taking behaviours. They described the differences in pre-test counselling styles as well as the frequency between tests required for test seekers who showed no desire to make behavioural changes that would reduce their involvement in health damaging activities. This was different than the cases in which a test seeker required a one-time only test after an isolated incident or as a preventative course of action. One participant was concerned that frequent access to anonymous testing would be used as a way to gauge exposure to risk and result in continually unsafe practices without making any effort to reduce risky activities or encourage behavioural changes.

For this reason, this participant thought that anonymous testing should be made available in the small urban centre, “not widely” but “for a small number of people”.

4.2 Testing Site #1

Thematic analysis based on the document review and individual interviews suggested that testing site #1 was following a nominal testing procedure in which testing was done off-site.

4.2.1 Current Testing Procedures

Documents A5 and A7 were particularly helpful in demonstrating the policy at the time of the document review. This information was supplemented with information provided by participants to create a detailed account of the procedures employed at this site.

Document A7, entitled [*Testing site #1*] *Policy Manual*, was written for staff and volunteers. It was classified as current and policy-related and is referred to here as the policy manual. It was an 86-page document containing 29 separate sections. One hard copy of the policy manual was stored in a binder on a shelf and was distributed to staff and volunteers upon request. Staff had received electronic copies of the policy manual via email. As a result, the electronic copies of the document were stored on full-time employees' desktop computers at their workstations. The version of the document I received was in use at the time of the study, but also under revision. This revision began in September 2008 and was still ongoing in February 2009. Staff updated the document

as needed. In the event of a significant change to the contents of the policy manual, the updated electronic version would be sent to staff via email and discussed as necessary.

Section 23 of document A7 outlined *Clinic Procedures and Guidelines*, which described policies for confidentiality, professional obligation, chart recordings, hormonal contraceptives, test results, incident reports, disposal of urine samples, clients and MCP numbers and harassing telephone calls. Staff and volunteers were instructed to follow these policies at all times, for all clients, and all STI tests unless otherwise noted. The following sub-sections of the document were most relevant to HIV testing - confidentiality, chart recordings, test results, clients and MCP numbers. Statements that were specific to blood work results outlined HIV testing policies, since HIV was one of the few tests offered at the testing site that required a blood test.

Section 23.1 Confidentiality

- All client documents will be stored in cabinets. Client charts are not to be left in a public area.
- No client information can be released without the clients consent. In order for information to be released, clients must sign a "Consent to Release Information" form.
- Only one file will be maintained for each client.
- All clients will sign a confidentiality agreement when visiting the centre for physician care.
- Staff and volunteers shall avoid unnecessary conversation regarding clients and must refrain from talking about clients in front of other clients and volunteers.

- Staff and volunteers must verify clients MCP number before releasing test results to a client via the phone and/or in person. (Document A7)

Section 23.3 Chart Recordings

- All conversations and visits with clients will be documented in client charts in ink with date and signature.
- Staff is responsible for ensuring that test results are promptly recorded in the Test Results Binder and that necessary referrals are made to other health care professionals when needed.
- The Client Services Coordinator is responsible for ensuring that test results are promptly recorded in the Test Results Binder and that necessary referrals are made to other health care professionals when needed.
- Inactive client charts will be house at [Testing site #1] for 10 years starting from the date of the last visit. However, if the patient is not 18 years of age at the time, the 10 years does not start until they turn 18. (Document A7)

Section 23.5 Test Results

- The treating physician must sign test results before they can be provided to clients
- Blood test results are to be provided to a client by the physician only when the test results are positive. When the results are negative, the nurse can provide test results. **No blood test results can be given over the phone by staff or volunteers.** [emphasis in original]

- Pap test results and other STI screening results can be provided to clients by telephone, or in person; only after the client provides his/her MCP number for identification.(Document A7)

Section 23.8 Clients and MCP Numbers

- If someone does not have access to their MCP number, due to whatever reason, they can:
 1. Provide Family Doctor's Name and [Testing site #1] can contact them for it (or check with their guidance counselor...etc);
 2. Go Online at www.gov.nl.ca/mcp and fill out a form for MCP care replacement and a card will be sent to them; or
 3. Go directly to 57 Margaret's Place [Office where MCP applications are processed], off Newtown Road, and fill out a form in the office and a card will be produced on the spot. ID must be produced, and there is no fee.
- [Testing site #1] will not take any clients who do not have a MCP Number or Provincial Health Card, unless they pay fee for service. A doctor will not be asked to take clients and not be paid for this visit. If a decision is made to do this [Testing site #1] will pay this expense, so please consider how serious or necessary you think this appointment is beforehand (Document A7).

As outlined in section 23.2, staff and volunteers had access to client charts to record conversations, visits and update contact information. Participants confirmed that

client charts were filed alphabetically using a three-letter filing system in a filing cabinet at the front desk. They also reported that any client chart over five years old was moved to a different area. Security measures, such as locks on the filing cabinets, or a destruction plan for client charts were not discussed. Conversations about file access led to discussions about the orientation and training that staff and volunteers receive. The volunteer manual was Section 28 of document A7. While I did not receive a verbatim copy of the volunteer manual, a participant described the training process.

...there's a two-day training – voluntary training course – that we undertake with them, so it's... but that deals with a lot of, you know, different aspects of our operations. They also shadow experienced volunteers and staff, so before they're left on the desk to answer phone calls, they shadow. The staff are also trained, you know, pretty much the same way. You know there's the training manual... Yeah, and then they're also encouraged to just sort of keep reading that. Read the pamphlets; and if they ever have any questions, we encourage them to speak to us... And every now and then, you know, we'll see them make a mistake. In which case, we'll type up a little memo for everyone to read just so that everyone can learn by everyone's mistakes.

Participants confirmed that referrals for tests requiring blood work were written by one of the physicians working in the clinic. There were multiple physicians and nurses who shared the responsibility of operating the clinic, which according to document A4 (Services and Resources) ran from 9:00 a.m. to 5:00 p.m. on Monday, Tuesday and Friday; 12 p.m. to 8:00 p.m. on Thursday, and 12 p.m. to 5:00 p.m. on Wednesday. As

mentioned in Section 23.3 of document A7, there was a "Test Results Binder" (p. 42).

This process was explained by a participant, who referred to the "Test Results Binder" as the "Test Tracking Log",

So whenever a piece of paper comes on it from laboratory services, [name of employee] dates it, gives it to the doctors and they sign off on it. They either tell [name of employee] to call back that person (to book a follow-up appointment time) or to file it away. So, you know, there's not a result that comes in here without a doctor looking at it... ...At the end of clinic, [name of employee] will look at the file and see what tests were ordered for the test tracking log. [Name of employee] has to know what was ordered so [he / she] can keep an eye on it and make sure we get the results back... ...If we don't get the results back, [name of employee] can contact the person and say, "Hey, did you go get that requisition filled?" "Yes" or "No," okay. If we haven't got the results back yet, [name of employee] calls the lab; gets the lab to send them over. Because sometimes the lab will send them to one our physicians' offices, not us. Which is kind of a pain in the butt, but that's why we have a test tracking log.

To summarize, the process of monitoring test results and recording which tests had been received in the binder involved one employee. This employee looked at the physicians' and nurses' records at the end of each clinic, took note of which laboratory tests were ordered that day, and entered them into the test tracking log. The employee used this information to identify tests that remained outstanding if results had not been

received after a certain period of time. When this happened, the employee would pull the client chart, contact the client, and inquire about the status of the test for which they had been referred. If the client reported having already had the test, the employee would then call the laboratory to inquire about its location, and request that it be sent to the testing site. If the client reported that they had not had the test, the employee would then encourage them to do so.

Section 23.5 of document A7 confirmed that positive test results were to be delivered by the physicians and negative results may be delivered by a nurse practitioner or a physician. No blood test results were to be given over the phone by staff or volunteers. Participants clarified that blood test results were to be delivered in person, which eliminated the possibility of delivering them via any other form of one-way communication, such as email or post. When a laboratory test result was returned to the testing site, it was first received by the employee who was responsible for the test tracking log and then given to the clinic physicians. Depending on the result, the physician who had reviewed the blood work may request the employee contact that person for a return appointment.

At times, people called testing site #1 to inquire about results and became upset when they will not be given results over the phone. A participant describes how such inquiries were handled.

If someone calls in and wants to know if their test results are back, we'll look. "Oh yeah, you had that blood taken on so and so date. Perfect, yeah, we got them back so you want to make an appointment."...And sometimes people ask, "Why can't you tell me the results over the phone, and we say,

“Really sorry, but regardless if you have a positive or a negative result, you were told when you came in that you have to get the results back from, you know, a general practitioner.” Sometimes they’ll get mad; but, you know, it’s just like – “You know what, I’m really sorry; I can’t tell you anything further.” If you go to any other office, and if they’re at all on the ball, they’ll tell you the same thing because if we just said to people, “Oh, you don’t have to worry about that; you don’t need to come in,” We can’t say that for a negative result because what if the day comes where we’re like, “No, you got to make an appointment.” We stick to the same rules - no matter what.

Section 23.8 of document A7 also addressed what to do when a client did not have an MCP number. The policy asked employees to consider the negative financial impact on the organization when a client is unable to pay for an appointment. While it did not explicitly state that employees were to refuse services to someone without an MCP number, participants confirmed that its staff and volunteers would not make an appointment in its clinic for any client who did not provide the personal information requested on the intake sheet. When asked about what would happen if a client was hesitant about providing personal information, a participant described a scenario where an individual would be refused service:

Interviewer: What would happen if a person came refusing to give information?

Participant: “Sorry.” (shakes head, shrugs shoulders)

Interviewer: You have to say no and send them away?

Participant: (Nods)

The participant reported several reasons for following this procedure. Firstly, physicians in the clinic were bound by the Communicable Disease legislation and they feared that any violation of that legislation would result in the operation of the clinic being shut down. The loss of the clinic would mean a loss of essential revenue that the organization relied on to pay the overhead of the testing site building. Secondly, they did not have the resources to fund and administer anonymous testing.

We can only function here as a clinic because our doctors pay our overhead fees... Our doctors get paid by MCP. They're not paid by any program, any study... I mean, government funded and, you know... so it's not fair for our doctors to provide a service after going to school for so many years and using our clinic's supplies, you know... I'd love to be able to do it... But it's not possible, and on top of that, we don't have the means to deal with anonymous testing.... We don't have someone here to keep track of codes or to, you know, put a confidentiality code on a lab result. We can't, so we just don't have the means for it here. I would love it – *love it* if we did.

Since the policies described above were written for employees and volunteers, it was helpful to consult documents that articulated testing procedures from a clients' perspective. Document A5, entitled *Intake Sheet*, was classified in the documentary analysis as current and clinical. The document was last updated in February 2009. Prior to that, the same intake sheet had been in use since 2004 (Document B6). During the document review, the employees noted inaccuracies in the 2004 version of the intake

sheet. As a result, the intake sheet was updated during the course of the document review. The blank electronic version of the form was stored on the employee's computer who was responsible for updating as needed. The Executive Director's approval was required before reprinting the revised versions at the end of the update process. Blank hard copies of the intake sheets were stored in a drawer at the front desk.

Document A5 required clients to provide the following information - personal information, medical coverage information, medical information, history of sexual activity, STI risk factors, and reproductive history. It also contained a confidentiality policy and contact instruction agreement for the client to sign. There was space for office use to record visit dates and clinic notes. Upon arrival, clients were required to fill out an intake sheet. Participants reported that whenever this form was distributed, clients were verbally advised that the form was entirely optional and that name, birth date and phone number were the most important pieces of information. Both the historical and current versions of this form made it clear that it was the client's responsibility to initiate contact required to check on test results. Participants also reported that a number of efforts were taken to ensure that clients knew it was their responsibility to return to obtain the results of their blood work, such as verbal instructions from staff and volunteers and reminder signs posted in the waiting areas. Participants confirmed that this testing site had never been required to deliver a positive HIV test result and described the process that might happen if they were required to do so based on their experience with other positive blood test results.

Participant: And I think that maybe, you know, if a positive (HIV test) result came back, we'd probably call that person and say, "Hi," you know,

“your test results are back. So if you want to make an appointment”, but that’s really up to the doctor’s discretion because our policy is, and people know, that when they’re getting blood drawn that they are responsible for getting, you know, their results back.

Interviewer: Is that made clear?

Participant: Oh, it’s very clear. Verbally, in signs, in the confidentiality agreement – you know, we can’t tell people enough that they have to make the appointment. If... you know, and a lot of people don’t get their blood work done, you know, so [name of employee] is always calling up people, you know – “Did you get that done?” “No.” “Okay, perfect, just want to know so [he / she] can write in my book saying ‘not completed’.” Because we keep track of every single blood test that... well, we keep track of every single test that is ordered by the doctors so...

When completed, the intake sheets were used to start or update a file on the client. The intake sheets were placed in the client charts and stored using the procedures that were described earlier. Client charts could be accessed by all staff and volunteers.

4.2.2 Past Testing Procedures

The document review revealed that testing site #1 had offered anonymous testing in the past. Four documents were helpful in understanding past practices and their lingering effects; document B7, *Policies for HIV Testing at [Name of testing site]*, document B1 *STIs and Your Relationship*, document A2 *The 5 W’s of STI Testing*; and document B2 *When and where to get tested for STIs*.

Document B7 was classified as historical and policy-related. Participants estimated that it had been created in 2004 and had last been accessed in 2005. It outlined policies pertaining to anonymous testing when on-site anonymous testing had been offered through a partnership with a private organization. It was unclear if the 2004 arrangement was also part of a study or if the private organization offering the anonymous testing was separate from studies described by participants. The following excerpts from Document B7 demonstrate the process that was used for anonymous testing, "if the client wishes to have anonymous testing, then the requisition will not be used" (p. 1), and

On-site HIV testing is available at the office of [name of testing site #1] on Thursday evenings from 5:30pm – 7:30pm. [Name of private organization] will be providing [name of testing site #1] with an on-site nurse to complete the blood draw and counselling. (Document B7 p. 1)

Prior to initiating the test, clients will be informed that if the result comes back positive for HIV, the nurse will ask the client for his/her name, names of previous and current partners for purposes of contact tracing, and information on where to seek medical attention. The nurse will practice due diligence in obtaining this information and assure clients that this information is confidential. All information will be reported to the Medical Officer of health. If names are not provided, all other information will be forwarded to the Medical Officer of Health (Document B7, p. 2).

[Testing site #1], staff, board, volunteers, or physicians will not be held responsible for files maintained solely by [Private organization] and overseen by [name of physician]" (Document B7, p.8)

When this was offered, clients could be tested on-site or they could obtain a referral for blood work. If the client wished to have anonymous testing, a requisition form would not be used and the blood would be drawn on site. Document B7 outlined pre and post-test counselling requirements for anonymous testing, reporting processes, and requirements for partner notification. It specifically stated that as part of pre-test counselling, the client was to be informed that if the test came back positive, the nurse would ask for the client's name and past partners so this information could be reported to the Medical Officer of Health. Document B7 absolved testing site #1 from the responsibility pertaining to the files maintained by the private organization that was offering anonymous testing. Not all of the participants from testing site #1 were employed with the organization in 2004 when this anonymous testing had been offered.

Two historical documents in the education, prevention and awareness category also made reference to anonymous testing. Document B2 was an 11-page booklet that had last been updated in 2005. Document B1 was a six-panel pamphlet that had last been updated in 2005. Both documents were replaced in June 2007 by updated educational pamphlets (Documents A1 and A2). Documents B1 and B2 no longer existed in hard copy and were retrieved by searching for 'Testing' on an employee's computer. Each of these historical documents provided the phone number to a formal public health setting to call for information about anonymous testing. This was evidence that in the past inquiries

for anonymous testing had been referred to sites operated by the regional health authority's Community Services division

Participants reported that anonymous testing had most recently been offered as part of a study between 2006 and late 2007. For intermittent periods during these years, testing site #1 provided the space and supplies for an independent healthcare professional to come in and offer on-site anonymous testing. Specimens were coded and taken to a lab for analysis. Participants recalled that the code was generated using the date of the test and some form of client number; it did not require initials or birth date or any information that was considered remotely identifying. The healthcare professional provided pre-test counselling when blood was drawn and post-test counselling when the individual came back for the result. It was the clients' responsibility to return for their results. No employee of the community-based organizations ever saw the results. After the study had finished, people would occasionally call testing site #1 and inquire about the anonymous testing because they had seen an advertisement for it or they had heard about it.

Classified in the education, prevention, and awareness category, document A1 was intended to provide "information regarding STIs, testing and safer sexual practices". Hard copies of the pamphlet were displayed in the waiting room for the public to read and take if they wished. Bulk copies were also mailed to schools and community groups upon request. The electronic version was stored on an employee's computer who was responsible for updating the document as needed. Documents A1 and A2 replaced documents B1 and B2 around the same time or near the end of the study described by participants through which on-site anonymous testing had been offered. Due to the timing of the offering of anonymous testing with the time of the study, some of the text in the

document A1 confirms that on-site testing had been available in the past and contains references to anonymous testing.

A [healthcare professional] will provide both men and women with a slip to have blood drawn to test for the following infections: HIV, Hepatitis B&C and Syphilis. At some clinics, they draw the blood on site, but the majority of the times a patient will be required to go to a hospital to have blood drawn. This testing is confidential. If you are interested in anonymous testing (no identifying information), please contact your local Health and Community Services office. (Document A1)

This reference to “some clinics” likely refers to the days on which the study clinics were held as this was the only time blood was drawn on-site and anonymous testing was offered. Recognizing that this was a temporary arrangement, the pamphlet refers inquiries for anonymous testing to the regional health authority.

4.2.3 Participants’ Concerns: “...failing of our system...”

Participants reported that they would like to be able to offer on-site anonymous testing and felt that offering the service in the past had been beneficial. One participant described the absence of anonymous testing as a “failing of our system” that did not provide a “secure” option for testing. Specific concerns expressed by participants at testing site #1 about its current testing procedures include understandability of testing terminology, the inconvenience of having to go off-site to have blood drawn, public misconception about services offered at other testing sites, as well as uncertainty about the quality and privacy of services at the sites where clients were being referred.

Participants highlighted fears reported by their clients about being tested in a formal environment, as well as fear of the many potentially negative impacts of people finding out that he or she has been tested for HIV. They also communicated a number of reasons their clients provided for feeling apprehensive about seeing a family doctor about sexual health concerns.

Participants preferred the term anonymous because its meaning was more easily understood by the general public. This was because it was used more often than a word like nominal, which was perceived as technical and uncommon. This was demonstrated by the following response to a question about the general public's understanding of the word nominal,

Because that's not a term that's commonly used. I don't even think people would know what nominal means. It's just one of those terms that's not commonly used, so I don't know why people would know what it means. In terms of STI testing, it definitely... you know, it just... it adds that extra level that... you know, anonymous is pretty standard. Even nominal testing, I don't think people would understand that.

Another participant, who also explained common references to anonymous testing as being related to the understandability of the term, preferred the term confidential over nominal or non-nominal,

Interviewer: So as far as calling non-nominal testing anonymous goes, why does that happen?

Participant: People get the meaning. They think “it’s just non-nominal – oh, no names!” No, no, (shakes head) It should all be called confidential HIV testing.

Another concern was that the testing procedure in place at this testing site required three visits; the initial appointment to obtain the requisition to have blood drawn, the visit to the laboratory to have the blood drawn, and the follow-up appointment to receive the results. These were referred to as “stops”. The inability to offer on-site testing required a client to make frequent stops and was regarded as a deterrent to testing. One participant said,

For chlamydia or gonorrhea, they either just take a swab or sample of your urine and get that tested which is... you know, it’s a one stop whereas for HIV it’s two stops; and then you have to make an appointment again to get the results back, so that’s actually three stops, three appointments – you know, three stops... steps that you have go through in order to get it done.

Participants reported that there were times when their own clinic was “blocked” and they could not possibly respond to every client given this high volume of inquiries. Staff and volunteers often fielded urgent phone calls requesting same-day clinical service. At times, people were referred to other testing sites, walk-in clinics, or their family physician. Participants reported a number of concerns about referring people to these settings.

There was a variety of concerns with another testing site in the city. For example, there was a perception that this particular site had capacity to see more people than were being seen at the time of the study. There was also potential to be recognized at the

testing site. One participant voiced concerns about the gaps in the delivery of testing at this site because STI clinics were offered intermittently,

I wish that it [HIV testing] was easier to get done because the way it's set up now, you do have to go to blood clinics except for... unless you want to go to [name of other testing site]; but apparently they're taking a break from it until June 19th or so. So, you know, right now there's nowhere to go where you're sort of on your own where you don't have to worry about bumping into so and so.

Other concerns with this testing site were related to participants' beliefs that the public either was unaware of its services, or had a misconception about the services. One participant noted that many people thought anonymous testing was available at that site when, in reality, the official protocol was non-nominal. One participant said, "People think that [name of other testing site], offers anonymous – no, it's non-nominal". Another participant attributed the public's lack of awareness about the service to the physical appearance of the building,

I think there might also be a misconception about [name of other testing site]. I don't think people really realize what they do there. When you look at the building, you wouldn't necessary think that there is a clinic in there.

One participant believed there was a \$120 fee required to be tested at a formalized public health setting, "... if you can't afford the amount of money to pay for the test, that shouldn't be a problem either. There should be government-funded anonymous testing". Another concern about being tested at a site operated by the regional health authority was the perception that positive cases would be reported to the government. Participants

assumed that a positive HIV test result would automatically appeared in Meditech and could then be looked up by healthcare professionals. Meditech is an electronic system of personal health information accessible to all healthcare professionals providing clinical care. Participants demonstrated low levels of trust for healthcare professionals in formalized settings to be entrusted with confidential information. One participant compared the ability of employees of a community-based organization to the level of trust she felt for healthcare professionals in formalized settings in NL,

... at [local formalized healthcare site], people talk. You know, people who work there and staff and... I mean, at [community-based organization] they sign a confidentiality agreement, and are very choosy about the people they pick... if [community-based organization] ever found out that someone told someone else about someone being here, let alone what their test results were, you know (shakes head). Newfoundland is small.

Participants from testing site #1 pointed out that there were many potentially negative effects of people becoming aware that an individual had been tested for HIV. These negative impacts included stigma and discrimination, negative impact on an individual's ability to obtain insurance, find a family physician, increased barriers to accessing future medical treatment, and restricted opportunities for travel and employment. Other fears were linked to ideas about the requirements of formalized testing sites; for example, negative associations about reporting to the province and mandatory partner notification.

Yeah, well then there's the implication that all the tests are confidential because it's within your health care system but the health care system is like you and everyone...and then the health care system gets accessed by the insurance system: ...and then the employment system ...and then everything is a big vicious web.

Participants also confirmed that while the organization supported and encouraged regular visits to family physicians, they did not typically recommend family physicians as the client's first point of contact for HIV testing. They recognized that many clients accessed their services because they did not want to see their family doctor. They cited a number of reasons clients had stated for not wanting to see their family physician about sexual health concerns including "too many family connections", "uncomfortable", "worried what might get said to the rest of the family", or fear of not being able to get an appointment with their family doctor soon enough.

4.3 Testing Site #2

Analysis of documents and interview transcripts suggested that testing site #2 was directing inquires about HIV testing to other locations and offered no on-site clinical services at the time of the study.

4.3.1 Current Referral Procedures

This section provides details about the processes in place at testing site #2 that were followed when responding to inquiries about HIV testing and referring people to

services. There was not a formal policy manual that outlined procedures for responding to inquiries about HIV testing, rather the employees who responded to testing inquiries followed an informal process. This was possible because of the employees' tenure with the organization. Having been exposed to a variety of situations over time had provided the longstanding employees with access to informal training about how to react in different situations. Exchanges between co-workers and with clients were frequent enough to keep employees informed about changes to a testing service and general occurrences in the community. For example, the employee who was responsible for fielding incoming calls and greeting patrons sat in close proximity to the employee who was described by participants as the most knowledgeable about the harm reduction services and the availability of testing services throughout the city. The receptionist knew to direct any callers or walk-in inquires for HIV testing services that required more information than a phone number to this employee.

Document C7, entitled *HIV Testing Public Health NL - Phone Numbers*, provided a textual example of the implicit processes that were followed at this site. This document was classified as current and policy-related document. It had been generated by an employee "a few years ago" (J.G., Personal Communication, April 2009). The update procedure for this document was for that same employee to make revisions as needed. The last revision was made to the hard copy a few months before the document review began when the phone number for public health's main switchboard was penciled in on the poster. At that time, the employee made the same change to the electronic document and emailed it to another employee. As such, the electronic file and the hard copy file were listed as separate documents in the document trees (Appendix D).

At the time of the study, an employee was planning to update document C7 in the near future. The document listed contacts for the Health and Community Services offered by the four regional health authorities throughout the Province. There were six phone numbers for the eastern region, three for central, two for western, one for Grenfell and two for Labrador. This demonstrated evidence of the practice of referring inquiries for HIV testing services to a formal public health setting. Posting this document at eye level allowed the person answering the phone to have a quick-reference guide when people inquired about HIV testing either in-person or on the telephone.

Document C9, *HIV Antibody Testing in NL*, was classified as current and policy-related. Information about update procedures and intended use of the document was limited since it had been created by a past employee. Participants were unsure if it had been intended for external distribution or internal purposes. The file was retrieved for the purposes of the study by performing a file search for documents with *test* in the title on a current employee's computer, which still contained documents belonging to a past employee. This document stated that the only type of testing available in NL was non-nominal testing. It outlined the purpose and advantages of anonymous testing, which seemed a natural fit with participants who described the history of the testing site as having offered anonymous testing in the past and its ongoing advocacy and support for anonymous testing despite the lack of formalized documents.

4.3.2 Past Referral and Testing Procedures

A participant described how anonymous testing had formerly been offered on-site as part of a research study. Similar to testing site #1, anonymous testing had been offered on-site through a partnership and was advertised as anonymous testing.

We used to offer testing. We don't at the present moment. I think it was in 2004 – a [healthcare professional] from public health was doing some research into a rapid HIV Hep-C test. So there was a partnership struck between the [healthcare professional] and us, which resulted in a [healthcare professional] working out of our office... .. So we turned one of the offices into a clinic; and if anybody came in for... like if anybody called us for an HIV test, we could say, "You could do it here as part of a research study." "It's anonymous and" yada, yada, yada. So that [healthcare professional] was working with us for three hours a week or so, people would come in because we had advertised we offered testing, anonymous testing.

It is important to point out that this participant had referred to the study testing as anonymous at the time it was offered, but during the interview felt that the testing that had been offered was, technically, non-nominal. This is discussed in detail in a later section. The participant described the coding process that the healthcare professional had used to deliver the anonymous testing under the study.

Because [name of healthcare professional] knew who it was just by virtue of the fact that, you know, we use(d) a code that's alphanumeric... So it's your first initial, your mother's first initial – of your first name; your

father's first initial; the month you were born, two digits; and the year you were born, two digits. So you know, it's alphanumeric and it's very random and it's not very likely it's going to be repeated and, you know, so the [healthcare professional] used that code. The person would have to come back in two weeks and get their results, which is when the counselling would be offered.

One participant described the advantages of offering HIV testing at a community-based organization over offering it at a location associated with the formal healthcare system. The participant pointed out that community-based organizations have more flexibility to practice a non-judgmental, harm reduction approach using the time period when testing services were offered on-site at testing site #2 as an example,

I think it's something that we certainly adhered to when we had things running here, was a real level of care that involves taking people where they are, full respect for people's privacy and personhood, and without any value judgments placed on that at all, and doing more than just sort of saying that that's the approach we take, but ensuring that it becomes paramount to who we are in the practice... We're completely non-judgmental and non-discriminatory - ensuring that is part of our regular practice on a daily basis. You know, on a person-by-person, client-by-client basis, and sometimes it's easier to do that as a smaller NGO than it is when you're part of something that's a little broader in scope like a healthcare organization. As a non-profit organization with a certain mandate, there is more flexibility to be able to kind of be that way.

The study had allowed testing site #2 to provide space for licensed professionals to come in and do clinical testing procedures. When the study ended, employees looked into continuing this service, but could not due to the increased liability insurance and operational resources that would result. A participant described the challenge of offering testing after the study ended,

the board took a look at the liability situation, and when we had the testing... under the research project, all the liability was within the research project. The [healthcare professionals] had their own licenses and liability insurance, right? Now the research is over. The [healthcare professional] is working for [name of other testing site] now so they are still covered by their own liability practice insurance, right; and the clinic here then becomes our program [name of testing site #2]. So the health care liability insurance would have to be paid by us. To have a health clinic operating in our building, and the board looked at it and said, "Okay, we've gone from a non-profit with no real assets except office equipment and furniture," right, "to a community based non-profit that owns [list of assets]; and if that clinic were to be sued because of some mistake"... Or, you know, any... that's an invasive procedure because you're drawing blood, right? Any invasive procedures brings up the liability issue, so the board suspended the clinic, suspended the operations of the clinic. So, in other words, we had to close the clinic temporarily because if people came in to get testing, and you say, "No, we're not testing, but the [healthcare professional] is here" – you know, close it,

right, until this whole liability insurance thing is ironed out; and since then we've been trying to work different ways to do it because as a community based non-profit, we don't have the money to buy the health care insurance from [name of insurance company], right? So we tried to work with [the regional health authority] in a number of different ways to make it work, and it just didn't work.

A participant questioned whose responsibility it should be to pay the operational expenses of testing, such as healthcare professionals' salary and insurance to operate the clinic.

And it's something that, you know, we may look ahead to. We just have a little... we have a very small little station there, but the challenge within comes from our end in ensuring that we're able to connect up the dots on it, that we have liability coverage to be able to do that, and who does it fall under? Does it fall under us as an organization, or does it fall under [the regional health authority]? And there's been a little bit of greyness there from my understanding, and so we've had to kind of step back from that a little bit based on liability, and looking at it as something that we hope can become part of our factor right back into our work plan again.

4.3.3 Participants' Concerns: "...they all had different answers..."

Participants reported that they would like to be able to offer on-site anonymous testing and felt that offering the service in the past had been beneficial. Concerns expressed by participants about their current referral procedures examined in this section

include understandability of testing terminology, uncertainty about the services received at other sites to which they referred clients to access testing services, inconsistent or unsatisfactory communication with the regional health authorities in NL, and a general lack of understanding of specific aspects of the formal testing and reporting processes in place at the regional health authority. They had concerns about quality of service as well as the degree of privacy maintained in the process. There were also concerns about the quality and consistency of care provided by family doctors and other healthcare providers as well as the increasingly technological systems used to store personal health information.

Participants from testing site #2 expressed similar issues about the meanings and use of testing terminology understandability as participants from testing site #1. This participant equated the issue of understandability as being more severe for people with lower literacy levels, "if you use words that are too big - if someone has a literacy issue, they're not going to get the message. So and again that's why I think the word anonymous is...more understood by everybody than non-nominal".

Participants' believed that the poster series transition, which involved documents D1 to D5 and C1 to C5, was an example of poor communication with the regional health authority. These documents were two sets of posters that had been updated as a result of an exchange between testing site #2 and the regional health authority. This exchange demonstrated some of the rationale for the uncertainty participants at testing site #2 felt when referring people to formalized settings for testing. These ten posters were classified as belonging to the 'education, prevention, awareness' categories and demonstrated the type of activities undertaken by the organization to promote testing services.

Reportedly, the historical posters (D1 to D5) had been updated to the current set of posters (C1 to C5) due to a request from the regional health authority. The historical poster series was prepared for display and distribution at a Hepatitis C Symposium in 2008. It was a joint venture between testing site #1 and several other community-based organizations who did not participate in this study. The poster campaign advertised the availability of testing services using images of tattooing, drug paraphernalia, and unsafe drug and sexual practices. It contained three contact numbers – two for public health settings and one for testing site #2. Participants reported that public health officials' concerns with the historical posters were related to the potential role they could play in driving traffic to the public health setting. They were concerned that widespread advertisement of the service using posters with explicit images would result in an increased number of inquiries and appointments that the public health clinics did not have the resources to handle. To compromise, the historical poster series was revised by removing the phone numbers for the public health settings from the poster. These revisions led to the current poster series, which contained the same five images and overall message, but a revised list of phone numbers. Despite the fact that testing site #2 was not providing testing services, their phone number was the only contact number on the current poster series. The ironic part was that telephone inquiries to this testing site were being referred to the same public health setting whose number had been included in the original poster series but removed for the revised version.

The community-based organization's main concern with the regional health authority was the unclear communication about what HIV testing policies were in place and what service were offered in what locations. While the poster incident provided a glimpse of

this, the specific concerns were captured in document C10. Document C10 was entitled *Letter to Chief Medical Officers*.³ This document was provided for the purposes of the document review and was classified as current and policy-related. The document was a copy of an email that had been sent by the participant in March 2009 to all Regional Medical Officers of Health, representing the province's four health districts. The electronic copy of this email was stored on a participant's computer and one hard copy was printed for the purposes of the document review. The correspondence requested clarification about the type HIV and Hepatitis C testing that was available at testing site #3 in the small urban centre. It also inquired about alternate locations that offer testing throughout the whole province and plans for expansion within the region. The following excerpt from the document clarified the organization's position on the availability of anonymous testing:

Given the stigma associated with HIV and HCV many people are reluctant to come forward to be tested for either of these infections due to their fears of anyone finding out that they have even been tested regardless of the results. Due to the fact that illicit drug use (injecting, smoking or snorting)

³ This document was titled 'Letter to Chief Medical Officers of Health' during the document review data collection phase because that was how a participant described it. It was noted in data analysis that there is only one Chief Medical Officer of Health at the provincial government. This letter was addressed to the Regional Medical Officers of Health who are employed at the regional health authority level. As such, the document is inaccurately titled.

can be major method of transmission, we believe that there is a clear need for easy access to this less stigmatizing method of (anonymous) testing.

(Document C10)

The participant who sent the letter described the purpose of the correspondence and the dissatisfaction with the responses received.

We were going to write letters and express our concerns, and one of the members said, "Well, did we ask the medical officers of health what the procedure was?" So I asked them three questions. Where are testing services available; if they're non-nominal or anonymous; are there plans to improve on access to anonymous or non-nominal testing; and what was the third question...How do you plan to promote the fact that this testing is available, and they all answered. (In response to) do you offer anonymous or non-nominal – they all had different answers, and nobody addressed expansion, and nobody addressed education around availability.

Another participant summarized concerns about the inconsistency and uncertainty about the regional health authority's policies that had resulted from this correspondence.

What concerns me sometimes is that what the protocol is maybe not be adequately communicated. In talking to some of our staff who are more directly involved with testing and harm reduction. In trying to find out and get a straight answer on it, depending on who you talk to...you can talk to two or three or four different people, and sometimes the view is a little bit different as to exactly whether or not anonymous or non-nominal testing takes place, so that's frustrating... it kind of ties into maybe the next

question which is where we send people because we sometimes don't know where to go ourselves.

Amidst this unclear communication, testing site #2 continued to refer inquiring clients to the regional health authority's testing sites - both the community and acute care settings. Participants felt that beyond the procedure for making the appointment at testing site #3, they did not have a good understanding of the processes. One participant commented,

Now we send them to [the regional health authority] and, you know, people have showed up (here), walked in, say, "Can I get a test or"... have to turn them away. Mostly it's phone calls. Mostly phone calls, and then the odd walk-in or... And then they are referred to the regional health authority, and given basic information about how...told well, it's just like what you do is you phone up and you make an appointment and, you know, just tell them you want an appointment to see the nurse. You don't have to tell the reception what it's about. You want to see the nurse in the clinic, and then you'll see right now [nurse], or whoever is up there, and, you know, it goes from there. Like I don't know what their protocol is...

Similar to test site #1, participants cited additional concerns with referrals to testing site #3 because of the provision of multiple services at one location. Due to the high volume of traffic and services available at that site, the participants worried about the possibility of clients being recognized by social workers who also worked in the building where testing site #3 operated,

...but that's not a solution either because it's up in [testing site #3] where Child Protection Services is. So if a woman is going in to get tested and her children are in care, I don't care who says what about boundaries and stuff like that, the social worker sees her going in, she's going to be, "What the hell are you doing down at this clinic?"

Participants referred to the acute care setting identified in the AIRN (2006) environmental scan as "the HIV Clinic" and reported that it was closed at the time of the study. A participant noted being unsure about the acute care settings' openness to confidential testing when the clinic was open,

Without a nurse practitioner in place (at the acute care setting) – and we understand someone is being hired - ...is there someone there who can carry out that testing? Are people who just suspect they might be HIV positive allowed to seek treatment there? Or maybe they don't suspect at all; they just want to get tested. They may be reluctant to go to an HIV clinic based on the fact that... you know, their status is unknown, and that comes down to stigma, and I think that is something that... the stigma is bigger than just having the HIV clinic as a place that people could possibly go for testing.

Ultimately, participants did not know what it meant to be "in the system" at the regional health authority within a formalized setting of care and services. They did not have a clear understanding about what happened to test results; specifically, what was recorded in their permanent medical record depending on the type of test, location of test, and result of test, how were the results recorded, and who could access them. There was

an elevated sense of concern about the possible consequences of there being a record of having had an HIV test – even if it was negative. There were questions about potential for outside agencies ability to access a person's medical records, particularly insurance companies. Without this information, they did not feel they could accurately inform their clients or members of the general public about what to expect when they went for testing. One key informant stated,

If you're positive and that's in Eastern Health's database...now I know Eastern Health has a database of HIV positive people, but it is not a part of the larger Eastern Health database. But still if you end up in the hospital somewhere along the way the fact is that that test is on file is going to be seen by somebody, and is it someone you know? Is it someone you would ever want to know your status? The stigma of HIV is not to be underestimated.

As a result of concerns and uncertainties about referring clients for testing at formalized healthcare settings, participants did not feel they could accurately inform their clients or members of the general public about what to expect when if they decided to seek testing service at either location. In general, participants felt unsure of where the regional health authority stood on privacy and confidentiality issues related to HIV testing. One participant from testing site #2 used the term privacy six times to voice concerns about what the current testing and reporting procedures,

With regard to reporting, it's one more HIV positive test result... I think by even narrowing it down to, you know, we have one from White Bay - why is it necessary to have that information? Are we going to name

streets? Or say it's a blue house?...I think it kind of comes down to how we respect people's privacy.

This participant also noted his concerns with the technological shift towards electronic health records.

When you're out around the bay, you know, what's to keep it from being Aunt Nelly who's working at the clinic or who is part of the mental facility? It brings up a whole other issue in and around privacy and privacy legislation about some of the changes going on with the pharmacy network right now. We have some concerns that the province is going to change the way that we receive our medications and everything else, that it's all going to be electronic.

The participant continued to describe a scenario when a positive HIV test result is displayed on an electronic health record and at the touch of a button, all healthcare professionals can access this information.

Finally, concerns with referrals to family physicians and healthcare providers at walk-in clinics, were related to clients' reports of stigmatizing treatments and unacceptable testing and counselling practices. Participants had heard "horror stories" from their clients and people within the community about the stigma clients faced when seeking HIV testing from family physicians. They doubted family physicians' ability to deliver adequate care, referrals, and client counselling on HIV testing. They relayed anecdotal examples during which family physicians had delivered test results over the phone, made inadequate referrals to HIV services, provided inaccurate information, and adjusted the type and quality of care provided based on a person's HIV status. As a result,

staff at the community-based organization felt uncertain about the ability of healthcare providers to deliver non-judgmental services and consistent levels of care. Other concerns related to stigma included clients not feeling safe to request testing within an existing client-physician relationship or there was a fear that requesting an HIV test would damage a positive relationship.

4.4 Testing Site #3

Testing site #3 was following a draft non-nominal testing policy. Participants reported that non-nominal testing was the *preferred* testing procedure when it was possible to obtain a test seeker's personal identifying and contact information. If necessary, participants would carry out a test without contact information. In such instances, participants reported following up with efforts to collect the individual's contact information at a later date. Certain practices fit more closely with various definitions of anonymous; however, the official testing protocol was non-nominal because that was the regional health authority's policy to comply with legislation. This testing site received the most referrals for on-site testing services from community-based organizations.

4.4.1 Current Testing Procedures

Testing site #3 offered on-site testing services at one half-day clinic per week on Wednesdays from 9:00 a.m. to 12 p.m. Appointments were occasionally booked outside of these hours to service demand. Testing site #3 was located in a building where other public health services were offered including but not limited to social work,

immunization and breastfeeding services. It was reported that testing site #3 was busier at certain times of the year, such as the start of the university fall term and around Christmas and New Year's at which time extra clinics were offered to service demand.

When someone called to book an appointment at testing site #3, they first spoke to a receptionist. Only the first name and last initial were recorded during this initial phone call and instructions were given to prepare them for the appointment. Specifically, the caller was advised to tell the receptionist that they were there for '[name of nurse]'s clinic' upon arrival. In this way, the client would not have to declare the reason for their visit or verbally identify the reason for their visit in a potentially busy waiting room. From that point on, the receptionist referred to the client by the first name and last initial with which the appointment was made if, for example, a name had to be announced to indicate the next client's turn was up.

Document E3, *Testing, Treatment and Reporting of Sexually Transmitted Infections, HIV and Bloodborne Infections*, was a 13-page document classified as current and policy-related. It was described and labeled as being in draft format. According to a participant, document E3 was originally created to update policies to reflect the changing needs of health service delivery for HIV testing, treatment and reporting in a community setting. Internal consultations to develop the policy had been ongoing for since 2007 (a year and a half prior to the study). Participants suggested that due to the numerous and ongoing nature of revisions to document E3, including earlier versions in the document review would be futile because they would be replete with inaccuracies and irrelevant statements. As such, earlier versions of this document were not available for inclusion in the document review.

Consultations had been held with employees and other key stakeholders to develop the draft policy. Through this collaborative process, the policy had been drafted with the intention of reflecting actual practice settings. Staff involved with delivering these services and performing related procedures had been emailed a copy of the document. Due to its draft status, there were no documents available at the time of the study that attempted to communicate this policy to patients or clients. A senior level employee was responsible for updating the draft policy document. Participants could not estimate a date when the policy would be finalized due to the lengthy approval process for organizational policies. When finalized, there were plans to make the policy electronically accessible to all staff.

This draft policy applied to all community health staff in the regional health authority. The following positions were named in the policy as the providers who could deliver the service – communicable diseases control nurses, community health nurses, and nurse practitioners. Participants explained that a community health nurse, nurse practitioner, or any public health nurse required additional credentials to be qualified as a communicable disease nurse who could perform STI testing. This included successful completion of vein maintenance and phlebotomy courses, demonstrated familiarity with *the Canadian Guidelines on Sexually Transmitted Infections* (Document E5), previous community experience, a mentorship with an experienced communicable disease nurse involving clinical observation, and clinical orientation and evaluation. The healthcare providers responsible for administering testing in community health settings noted that offering STI testing was just one part of many job roles they were required to perform and report to their manager about.

The draft policy specified that the official procedure to be used in all public health settings was for non-nominal testing and reporting. "All tests will be undertaken using non-nominal reporting as the testing/reporting procedure of choice. Nominal testing is acceptable but anonymous testing is not permitted" (Document E3, p. 2). It required the provider to obtain the following personal identifying information in a non-nominal test,

first and last name and date of birth **AND at least one of** [emphasis in original] the following, Mother's/Father's Name, Address, MCP #, Photo ID, Referral Documentation) from the client to be recorded in the clinic record. An alphanumeric code will be assigned to the record (Document E3, p.3).

According to the policy, the client's chart should contain, at a minimum, the first and last name, date of birth, and one other piece of personal information. At a client's first visit, participants reported emphasizing that the most important piece of information to collect was contact information. During pre-test counselling, the nurse would get a sense of the client's level of comfort to provide information. Typically, the client's name and phone number were also requested. An MCP number was not required but could be provided if the client wished. Participants discussed the importance of other aspects of pre-test counselling, such as explaining the meaning of the non-nominal system and that, if they tested positive for HIV, that the client would be required to notify his or her sexual partners or provide their names and contact information to community health for the communicable disease nurses to contact them. The client was always advised of their responsibility to come back to the clinic to retrieve their test results. Participants noted

that the points that were emphasized during pre-test counselling depended on the needs of the client.

Document E3 stated that non-nominal reporting would ensure the confidentiality of any “information recorded on laboratory and epidemiological reports” (p. 2). It stated that “the client record will contain sufficient information to facilitate timely treatment and follow-up of the individual and contacts” (p. 2). Personal information collected was used to start a chart on each client after the first visit. Charts were stored in a locked filing cabinet or room and organized by chart number. The policy stated that an alphanumeric code was to be assigned to each client record and used to send the blood sample to the laboratory. Participants reported that no record of an HIV test was ordered through a community health testing site was entered in Meditech. When returned from the laboratory, tests for reportable conditions ordered by public health testing sites (including #3 and #4) were first sent to the Medical Officer of Health before being returned to the provider who had ordered the testing.

At testing site #3, the client charts could be accessed by two or three employees. At times, participants referred to this system of paper records as the Communicable Disease Database or the “CD system” because it housed information for all reports of HIV, Hepatitis C, Salmonella, Norwalk virus, and any other communicable diseases in the region. Keeping a complete record meant this paper record system tracked instances of communicable diseases that had been confirmed through tests that had been ordered by

other community health sites or an external source, such as a family physician.⁴ If a test result came back negative, confirmation of the negative test result was stored in the paper record of the client's chart at the site the client had visited for the test. Though all laboratory tests results ordered by testing site #4 were first sent to testing site #3, they were only recorded in the Communicable Disease Database, which was located at testing site #3, if the result was positive. If negative, the laboratory results were forwarded to testing site #4 where the chart would be updated accordingly.

There were specific procedures to follow for reporting and partner notification of positive results. In the event of a positive result, document E3 stated that "individuals testing positive will be reported to the Department of Health and Community Services through the Communicable Disease Reporting System using the assigned code" (p. 5). This meant reporting was done to the Provincial Government's Department of Health on a nameless basis. Participants confirmed that positive results for reportable communicable diseases (including HIV) were reported to the Department of Community

⁴ If the test had been performed at a location other than a community health testing site, the same procedures for non-nominal coding, reporting, and no direct entry into Meditech may not apply. Negative tests returned to family physicians are neither transmitted to the community health staff at testing site #3 nor stored in the Communicable Disease Database. Positive results returned to family physicians, required that the reporting physician complete a form providing basic information for the Communicable Disease Database. The timing or input procedure used by family physicians to record infectious diseases in Meditech is beyond the scope of this inquiry.

Health using a Communicable Disease Reporting form. The form had space requesting the following information on positive reports - name, age, MCP number, and home town. The form was completed by the data entry clerk at testing site #3 and sent to the provincial epidemiologist. The only way that information from the database was released to anyone other than for these reporting purposes was with the consent of the individual whose information it is or on court order.

According to document E3, staff conducting the tests were to record the “names of contacts and contact information” (p. 5) for contact tracing. It described how clients were encouraged to advise their partners to come forward for testing, but also acknowledged that detailed information about contacts may not be easily obtained at the first or subsequent visits. If partners failed to come forward through the partner notification process, only then would public health staff undertake contact tracing. With contact tracing, public health staff initiated contact with the partners identified by the client instead of leaving the responsibility to the client. With regards to names and contact information for past partners the policy stated,

Names of contacts and contact information will be recorded in confidence for contact tracing by [regional health authority] staff. Clients will be encouraged to advise their partners to come forward for testing (Partner Notification) at the initial visit. Detailed information about contacts may not be easily obtained at the first or subsequent visits, but every effort should be made to document contact information. The client will be advised that active contact tracing by public health staff will be initiated

after a negotiated time frame only if partners fail to come forward through the partner notification process. (Document E3, p. 5)

With regards to post-test counselling, document E3 stated that post-test counselling would not be done over the telephone. "No test results will be given over the telephone to ensure confidentiality and to ensure that counselling occurs" (p. 2).

Participants from testing site #3 reported that at the time of their first visit, clients were always scheduled for return appointments approximately two weeks after the date of their first test. This was done to ensure that post-test counselling was delivered in person regardless of whether the result was negative or positive. At the second appointment, results were released to the client only when he or she could confirm the identifying information provided at the first appointment.

Document E1 and E2, the Communicable Diseases Act and the Health and Community Services Act, also influenced the regional health authority's policy. The Communicable Diseases Act (Document E1) was the statutory basis for the control of communicable diseases in NL. Under the Health and Community Services Act (Document E2), the Minister of Health and Community Services has the ultimate responsibility for the Act; however, this authority may be delegated to the Chief Medical Officer of Health and the Regional Medical Officers of Health.

Document E2 defined communicable disease as "a disease mentioned in the Schedule, and includes other diseases that may be added to the Schedule by the minister". The Schedule listed HIV and AIDS as reportable conditions. The Act had been passed in 1970; sections pertaining to the reporting of communicable diseases and, therefore, most

relevant to HIV testing and reporting had not been updated since it was first passed and are stated below,

Notice by physician,

4. (1) When a physician knows, or has reason to believe, that a person is infected with a communicable disease he or she shall within 24 hours give notice to the deputy minister, or to the health officer in whose jurisdiction the person is, and to the hotel-keeper, keeper of a boarding house or tenant within whose house or rooms the person lives.

(2) The notice to the deputy minister or to the health officer shall, where possible, state the name of the disease, the name, age and sex of the person, and the name of the physician giving the notice, and shall by street and number or otherwise, sufficiently designate the house or room in which the person is living.

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Cases in which people were unwilling to provide any information whatsoever were rare, but they did happen. In such cases, clients were allowed to provide a pseudonym or alternate pieces of identifying information. When this did occur, pre-test counselling and follow-up was adjusted to emphasize the importance of returning for the results. One participant recalled a situation in which one person did not want to provide any information,

I think it was one person who did not want any identifying... didn't want a phone call, like a phone number or an address, didn't feel comfortable

with that. So, you know, I talked about some other identifying information for him like his mother's name and that sort of thing...I did take his mother's name as the other – you know, as the third part of the identifier; and I said, you know, you have to make sure that you come back for your appointment.

Challenging cases like this emphasized the special skill set required of communicable disease nurses and any healthcare provider who engaged in HIV testing and counselling. One of the many specialized skills they need to possess is the ability to build rapport when people feel uncomfortable and the ability to tailor information needs for individuals who continuously engaged in risky activities.

4.4.2 Past Testing Procedures

Document F2, *Partner Notification and follow-up/counselling guidelines for sexually transmitted diseases*, was classified as a historical, policy-related document. It had been issued by a legacy boards prior to regionalization. It became effective in February 1996 and applied to the entire communicable disease and epidemiology program. Due to the age of the document, participants could provide little information about the document itself; such as how it carried it out in practice, who was responsible for it, or what had replaced it. Similar to the draft policy that was in effect at the time of this study, document F2 also specified that all specimens were coded and the clients' names were not included on "either the specimen or the laboratory requisition" to ensure confidentiality.

Since document F2 was the last record of any official policy that stated finalized and formal procedures for issues relating to sexually transmitted infections, I assumed that this was the most recent version. Participants also suspected that this was the case. In cases where policies had not been finalized, policies from legacy organizations apply (J.D., Personal Communication, July 2009). Since the draft organizational policy that had not yet received official approval, document F2 would be the last official policy under any legacy organization and, therefore, would be discretionally applied. While it did state that community health nurses were to carry out reporting, it did not specify how information was to be transmitted when reporting.

Without making any specific reference to this historical policy document, participants recalled aspects of past testing practices such as the location of availability, personnel who performed the tests, and information storage. One participant recalled a time when testing site #3 was the only place in the small urban centre in which testing was available. The participant recalled how at that time, the health authority had often allowed people to be tested without providing accurate information, "I think to a certain extent we had pushed the limits in terms of allowing people to come and be tested using false names or identification".

Another participant was likely referring to the same time period when testing had been offered at this centralized location. The participant recalled how past testing services had been offered more frequently by many public nurses. To do this, nurses were periodically pulled from their job sites to come to a central location to offer testing services. A participant described how this capacity was lost as those nurses retired,

I think historically – and this... I’m going back probably ten, 12 years ago – I think it (the STI clinic) was run more often; but then as nurses... and what they used to use was they used public health nurses out in the district. I think there were a couple that were trained to do clinics. So they’d be pulled from their districts for that half day a week or whatever; but as those nurses retired, they were never replaced.

Finally, participants noted that at one time, files had been stored in an electronic Communicable Disease Database; however, the electronic database had not been working for over a year and they had reverted back to a paper filing system.

4.4.3 Participants’ Concerns: “...we have to define our parameters...”

Participants from testing site #3 expressed concerns related to low availability of the service, the importance and shortage of qualified communicable disease nurses, the inadequacy of testing and counselling services provided by some family physicians, confusion of terminology used by staff, organizational complexity, lengthy bureaucratic processes, political agendas and misleading documentation from PHAC. Despite referrals from other testing sites, testing site #3 was not “over-run with requests”. Nonetheless, at least one participant felt that there should probably be an STI clinic four days a week. This participant reported having advocated to her manager for the resources required to do this.

All participants from this site emphasized the importance building rapport with clients to deliver the most effective education and information during pre- and post-test counselling. At least one participant expressed concerns about the quality of HIV testing

and counselling services provided by family physicians. These concerns were related to reports that family physicians had provided inaccurate information during post-test counselling, inadequate follow-up on individuals who had been tested, lack of ordering of HIV tests for patients, and avoidance of addressing issues about sexuality or uncomfortable with STIs.

Participants reported to having historically referred to the service they provide as anonymous testing, but upon closer examination of the definitions and the processes realized that the processes were actually non-nominal. This was demonstrated by the following statement,

they realized that what they were doing was in fact non-nominal testing. They might have been talking about anonymous; but when we sat down and looked at the definitions where anonymous means that you have no recorded information about the individual, no way of contacting and no way of whatever, then they realized that, in fact, our practice has been non-nominal.

When speaking about how document E3 had been in draft format for over a year, a participant pointed out the length and process required when operating in large organizations. The participant explained that before policies were finalized, they were required to pass through numerous internal and external consultations, multiple layers of approval, and be presented to a committee. Changes to legislation required shared understanding and support from a large group of people and a political appetite for the issue. The participant called on community-based organizations to advocate for change,

...Legislation is complex. It requires a large number of people understanding the issue and deciding to move on it. Legislation is passed by the House of Assembly, and I think we would need that support in order to move towards anonymous testing capacity. Now I would say the government is not going to act on our request at the moment. If anonymous testing truly is something that is useful and desirable, it's going to have to be a matter of public debate, and outside agencies are going to have to bring it up to government independent of whether you're... we're discussing it or not because that... unless that information, or unless the discussion is occurring, it's not going to be... recognized as an issue that needs to be dealt with.

As it attempted to expand HIV testing services, participants acknowledged that after the legacy organizations merged to form the larger integrated health authority it was necessary to be more consistent with clinical directives and, in particular, its approach to testing. Participants described the past efforts to create standardized protocols and a shared understanding of the practical aspects of testing. They attributed the draft policy as evidence of this effort, but admitted that creating policy was a lengthy process within the large, bureaucratic organizational structure. One participant recalled that prior to regionalization, testing site #3 was the only place where testing had been offered, which allowed informal procedures to be more accepted,

But the problem that arises now is that more people are... more locations are looking for testing, so we have to define our parameters. We can't operate as a quiet little operation working under the radar. We're part of a

much larger organization. If we want to make sure that things are done comparably; and so, in fact, the demand for more testing availability, particularly in relation to outside agencies, has meant that we've had to write down our policy instead of operating under the radar. That has meant that we've had to think about the issue of non-nominal versus anonymous, and acknowledge that in fact anonymous testing is not covered by legislation, and therefore was probably not something we should be actively pursuing.

Finally, at least one participant felt that document E4, the PHAC (2007a) epidemiology update which stated that anonymous testing is available in NL, was "misleading" or irrelevant. The participant believed that the explanations provided in the footnotes to the tables regarding the delivery of anonymous testing were "splitting hairs" and would rather that the tables did not state that anonymous testing was available here because technically test sites offer only nominal and non-nominal.

the statement here (gestures to document E4) is that if you're positive through anonymous testing, then you have to be reported by name. It's splitting hairs. I think ... I mean, it's true, although I don't think there's any written documentation other than... that states government policy. I think the testing itself doesn't need to have a name attached to the test, but the law requires name-based reporting... If anybody is suspecting they're positive, they need to understand the fact that basically it's not anonymous.

4.5 Testing Site #4

Since it was also operated by the regional health authority, testing site #4 was following the same draft non-nominal testing policy as testing site #3. As such, it was reported that non-nominal testing was the *preferred* testing procedure when it was possible to obtain a test seeker's personal identifying and contact information. If necessary, participants would carry out a test without contact information. For the most part, testing at this site followed the same procedures that were described for testing site #3 as defined by documents E1 to E5 and F1 to F4. Several exceptions discussed here include the target population, time of operation, appointment making procedures, number of staff, circulation of test results, and the perceived risk tolerance of test seekers at this site. To demonstrate the limited public profile of this site, it is important to note that I was unaware of this particular site prior to the study and it was not identified in the scan for testing services to include in the list of participants. It was discovered through information provided by participants.

4.5.1 Current Testing Procedures

Testing site #4 was situated in a downtown residential area and targeted youth. This site first started to offer STI testing in 2007, after which there was a short hiatus due to personnel issue. At the time of the study STI, testing had resumed for approximately one year. The clinic was situated on the ground floor of a small building that was shared with another community-based organization, which was also dedicated to the needs of at-risk youth.

Testing site #4 attempted to tailor its services to the needs of youth. Posters were used to advertise when “No-names” STI testing was available. Youth could call to make an appointment or come to the drop-in STI clinic hours. The drop-in schedule had been decided upon by collaborating with a community-based organization about how to best attract neighbourhood youth.

The healthcare professional at the site was responsible for taking the phone calls to book appointments as well as all testing and reporting requirements. As such, specific instructions about arriving in waiting room set-ups like testing site #3 were not required. At testing site #4, client charts were accessed by only one employee. Similar to testing site #3, participants reported scheduling the client’s return appointment for approximately two weeks after the date of their first test. This was done to ensure that post-test counselling was delivered in person regardless of whether the result was negative or positive.

Though targeted towards youth, testing site #4 also offered services to clients, including some adults when requested. It was reported that this clientele had very different needs than those typically seen at testing site #3. This comparison was possible because at least one participant had spent time at both testing sites #3 and #4 and in doing so had observed that more clients who led “high-risk lifestyles” accessed services at testing site #4. Many of the clients at testing site #4 regularly engaged in risky activities such as unprotected sex, sex for money, injection drug use, sharing of drug paraphernalia. Pregnant women and youth were reported as regularly frequenting the clinic to access services. When speaking about the differences in the needs of the clientele at testing sites #3 and #4, one participant said,

If I had somebody who is, you know, on the street and in the sex trade business or using I.V. drugs, I'll say you should be tested every couple of months because like at [testing site #3], the counselling goes in-depth with the window period and, you know, it (the testing) is probably a one-time thing, whereas here...they should just keep getting tested. I had one person in here who had STIs in the past, and was really afraid (because) she had symptoms and stuff; but then when I asked about the last time she had unprotected sex, she had had it that day. So it's like ongoing... you're trying to educate them and you're trying to say every time you have unprotected sex, really, you need to be tested again, you know, but that's... like that could be the norm for some of the people here, so they need to be treated... they need to be tested like every two months, not so much like... you know, "Come back in six weeks" and then "Come back in six months." These people need to be tested regularly, or if they're I.V. drug using or if they're snorting or using equipment...on a regular basis, they're putting themselves at risk. They need to be tested on a regular basis, so there are some differences like that. It depends on your population....you have to respond to their needs differently.

Laboratory results of ordered from testing site #4 were first sent to testing site #3 where, if positive, they would be recorded in the Communicable Disease Database before being forwarded to testing site #4. If negative, the laboratory results were forwarded to testing site #4 without any data entry or follow-up and the client chart, which was kept and maintained at testing site #4, was updated accordingly.

4.5.2 Past Testing Procedures

Testing sited #4 had begun offering testing around 2004. The first year after the service was offered, there was a short hiatus due to personnel issue. At the time of this study, STI testing had resumed for approximately one year. A general description of the regional health authority's past testing practices are the same as those described for testing site #3 since the health authority also over saw testing site #4.

4.5.3 Participants' Concerns: "...I'm not getting a lot of people down here..."

Participants' from testing site #4 expressed similar concerns as testing site #3 about low turnout, the importance of qualified communicable disease nurses and the inability of family physicians to provide adequate testing and counselling services, confusion of terminology used by staff, organizational complexity, lengthy bureaucratic processes, political agendas and misleading documentation from PHAC.

A participant from testing site #4 reported a desire to see an increase in the volume of people reasoning that the low volume at this site could be related to staff turnover,

The volume hasn't been great. We're trying to increase it and things but I'm not getting a lot of people down here, so I don't know why. I mean, it's something, I guess, in time we'll look at; and if the numbers don't... I think some of it is the inconsistencies of the nurses.

When staff turnover occurred, the participant felt that rapport was lost and it took time to create an environment in which trust could be re-established. Participants considered provider-client rapport to be extremely important at testing site #4 since

clients often reported being involved with risky activities, such as sex trade, injection drug use, sharing drug paraphernalia, and unprotected sex.

4.6 Areas of Incongruence: "...It's not mandatory ..."

It was evident that community-based organizations had a history and current practice of referring people to formalized settings for testing despite the concerns that were reported about doing so. These concerns included a lack of understanding the formal processes for testing, reporting, and the procedures for third party access to information and test results. Other areas of concern included the location of testing site #3 including the look of the building and the multiple services offered within it. This section examines key areas of incongruence, such as the past practices of offering anonymous testing by each of the three organizations. Similarly, incongruence was noted between the various definitions of testing, between legislation and official policies at testing sites, between reports from participants about procedures used in practice, and between the policies and procedures outlined in the documents and reports from participants.

The three organizations operating the four testing sites reported having a record of offering anonymous HIV testing as part of a research study or as part of a partnership with a private organization. Participants reported that the ability to offer anonymous testing in the past had been beneficial. After describing the complexity of process required to change legislation and influence policy and the range of external forces at play, one participant commented,

...I think there's a place for anonymous testing. You know, I think it can be set up. We don't have it, I don't think that we should pretend that we have it, and I don't think we should be pretending we have it through research studies because I don't think that's... Well, it's... you know, it's either doing research or it's doing testing... I think we're actually providing a service. If the environment changes to allow us to provide it, I would encourage it...

One key area of incongruence was between document E1 (the Communicable Diseases Act) and E3 (the draft policy entitled *Testing, Treatment and Reporting of STIs, HIV and bloodborne infections*). Document E1 was a piece of legislation stating all reports of communicable diseases transmitted from the health authority to the provincial government should state "the name of the disease, the name, age and sex of the person, and the name of the physician giving the notice" (p. 3). This is commonly referred to as name-based reporting. Document E3 was the health authority's draft policy addressing HIV testing. Section 15 of document E3 stated that "individuals testing positive will be reported to the Department of Health and Community Services through the Communicable Disease Reporting System using the assigned code" (p. 5). The meaning and definition of "assigned code" (p. 3) was clarified in document E3 as the "alphanumeric code" (p. 5) that is assigned to the record. This is the same code used to de-identify the sample when sent to the laboratory for testing. It does not identify the individual or provide his or her name, age and sex as outlined in the legislation. There was no explicit definition in the policy for generating this alphanumeric code. Several statements from participants demonstrated wide acceptance of the idea that alphanumeric

codes were some combination of initials, chart number, or age and did not contain the information requested in document E1. To summarize this key area of incongruence: the legislation outlined detailed personal information requirements for reporting to the provincial government when a test result confirms an individual is HIV positive; however, the health authority's policy suggests a non-identifying alphanumeric code is used to report positive cases to the provincial government.

The definitions of non-nominal provided by community-based organization #2 and the regional health authority had a notable area of difference. Specifically, the regional health authority's definition of non-nominal clearly stated that a client's true identity and contact information are included in the client's record. Community-based organization #2, however, used less forceful language, "identity of individual may be known by the testing clinic". This demonstrates the uncertainty about the differences in procedures expressed by community-based organizations.

Participants reported current practices of advertising the service as no-names, performing tests knowing that the information that they have recorded about the person being tested may not be accurate, allowing clients to provide fake names or no names, and reporting to the province with less information than required by official reporting standards. Participants viewed these practices as being within the scope of non-nominal testing. Upon closer examination and comparison, however, these practices were incongruous with non-nominal testing standards according to the definitions and policy guidelines outlined by the regional health authority in document E3. The health authority's definition of non-nominal suggests the test seeker's personal information (including name and contact information) was collected and on file. As such, these

practices fit more closely with the definitions of anonymous testing provided by both the regional health authority and community-based organization #2, which states “there is no address or contact information recorded that could lead to the identification or location of the individual presenting for testing” (Document E3, p. 6-7). Clearly, a situation in which testing is carried out with no name could create an anonymous situation. In addition to the incongruence between non-nominal policy and practice standards, there was incongruence between these practices and the legislative requirements for name-based reporting previously described. Interestingly, participants’ consistently expressed the view that anonymous testing was not legally permitted. Since the above practices were described as non-nominal, however, they were permitted within the scope of allowable practices according to participants’ interpretations of the legislation.

The term I used to describe the above practices was “discreetly anonymous”. I will now explain the rationale for this. It seemed that anonymous testing could be made available on certain occasions under some circumstances. For example, participants were okay with limiting or waiving information requirements for test seekers who were uncomfortable providing the information required for the non-nominal test, or to those who declined to respond to providers’ requests for information at intake, or to a test seeker who simply insisted on receiving the service in this way. Even if they had not encountered the situation personally, many participants indicated how they would respond if placed in one of these circumstances. Their responses indicated that participants shared the view that it was better to proceed to test with limited personal information than to have the test seeker leave the site without being tested at all. Despite delivering the service in this way, all participants were uncomfortable referring to any

aspect of their service as anonymous because of their perceptions of what was permitted by the legislation. A participant who described the service at their site as non-nominal described how testing services were advertised "...it's written on the sign that you don't have to use your name because when I was orientated to this position we were told that you didn't have to ask for a name". The participant explained that even in situations where a name was obtained it could still be advertised as "no-names" because no names were sent to the laboratory. Another participant from a non-nominal site stated,

Well, we don't do anonymous testing, number one, and I guess it's also for reporting. They can still be reported as - because we just take initials....We use initials and a code that goes on a lab slip and on the specimen. The chart that I have is... I do like to have a name because of positive patient identification. I do take a name. I ask for a name. If a person doesn't feel comfortable giving me a name, it's not mandatory, but I do need to have, you know, some way so that I know that this is, you know, John Brown in front of me. If a person wants to give me a false name, they can. Some people do. They might give me their first name and their middle name, or their middle name and their last name. I use a chart number. I do use a date of birth, and I do like contact information, and the contact information is only if they have a positive test result and they don't come back to clinic for some reason. To get their results, they must come back to clinic.

As alluded to in this quotation, policy document E3 permitted reporting by an "assigned code" (p.3) despite the fact that document E1 (the legislation) requested name-

based reporting and other identifying information. There were also inconsistencies with the way the reports were completed. The forms used for the Provincial Government's Communicable Disease Reporting System were reportedly completed in a manner that was inconsistent with legislation and protocol. Specifically, the forms used for the Communicable Disease Reporting System had a box where the participants' addresses and MCP numbers were requested. Participants from more than one testing site reported that a certain city was always written down as the address when reporting positive cases regardless of the test seeker's reported address. Similarly, '99' was always written down for the MCP number. Participants reported that provincial government officials, at times, requested patient MCP numbers; however, since they were not routinely collected nor requested at these testing site(s), they could not be provided on the forms used for the Provincial Government's Communicable Disease Reporting System. It may also be worth pointing out that at times, participants from the same testing site had conflicting reports of how reporting process was carried out; for example, one participant reported that the reports were transmitted by name and another participant reported that they were transmitted using initials. This demonstrates inconsistencies within practice between employees in a situation where there is incongruence between policies and practices and variation in the interpretation of certain legislation and terminology.

5.0 Discussion and Recommendations

This chapter discusses the meaning of the term anonymous as it is used in public health and clarifies other potentially confusing terminology. It explains my theory behind the areas of incongruence noted in chapter four. The discussion is divided into three main sections – the role of the Communicable Diseases Act in the incongruence, the need to increase clear communication about HIV testing policies and procedures, and the need for explicitly anonymous HIV testing. The discussion is presented and recommendations were made based on social justice principles within a social determinants of health inequality framework. In this small urban centre, providers who discreetly deliver anonymous testing or have done so openly in the past contribute to overall population health by providing test seekers an opportunity to reduce health inequities. Eighteen recommendations are made for consideration with regards to required clarification and updates to provincial legislation, increasing communication of policies and procedures in formalized and community-based settings, disseminating information to the public and changes to federal documents. Finally, this chapter describes how this research will be disseminated and suggests areas that merit further inquiry in future research.

5.1 Summary of Key Findings

My original objective was to evaluate the congruence between HIV testing policies and everyday testing practices in community-based organizations and public health clinics. In addition to identifying areas of incongruence, I have expanded on the

analysis of various systemic issues to offer possible explanations for the key areas of incongruence.

5.1.1 What is Anonymous?

I have spent a significant amount of time in this small urban centre and am intimately familiar with its small social circles. I was not surprised that some academic literature that suggested it is a place where there is a perception that “everyone knows their neighbour’s business” (Gustafson et al., 2008, p. 190). I doubted the possibility of anonymity and struggled with its meaning. To me, anonymity represented the opportunity to receive a service without anyone knowing you had sought the service in the first place. It was interesting to explore and compare the usage of various definitions of *anonymous* as provided by the participants, the policy documents, and in other preventative health services contexts.

I determined that it was possible to offer truly anonymous HIV testing both *explicitly* and *discreetly*. The successful operation of past HIV testing studies in this small urban centre demonstrated the success of explicit testing, and variations of current reported procedures used for non-nominal testing demonstrated the possibility of discreet testing. Once again, this is with the understanding that the distinguishing factor between anonymous and non-nominal testing is the absence of a request for or recording of any contact information on the client, or any other information that could lead to the identification of the test seeker. This fits with the use of the term *anonymous* in other widely accepted and beneficial health promotion programs across Canada that use this term, such as alcoholics anonymous (Mann, Zalcman, Smart, Rush & Suurvali, 2006). It

also fits with anonymous HIV testing guidelines in provinces with established anonymous testing programs in Ontario (Ontario Ministry of Health and Long-Term Care, 2008). Further references to *truly anonymous testing* in this document describe a testing situation in which contact information is not requested or recorded. All participants demonstrated acceptance of and support for the need for human contact at various points during anonymous HIV testing. This is also a standard of practice suggested by PHAC (2006b) guidelines.

5.1.2 Explaining the Incongruence

This section focuses on the circumstances and contextual factors that explain dual role that the Communicable Diseases Act and conceptual confusion played in creating the inconsistencies that first inspired me to do this study. At the outset of the inquiry, there were several conflicting messages pertaining to the availability of anonymous HIV testing in this small urban centre. PHAC (2007a) Epidemiology update and the advertisements for anonymous testing in local student newspapers had indicated that anonymous testing was available (Muse, 2008). The Communicable Diseases Act, however, required name-based reporting. To add to the uncertainty, members of the community were unsure about whether or not anonymous testing was, in fact, available and what personal information was required to be tested for HIV as defined by the three different types of tests.

The most likely explanation of these events is related to a temporary offering of anonymous testing that became available through a research study, which finished before my data collection began in January 2009. Participants verified the anonymous testing

study had been underway prior to 2007 at both community-based organizations that participated in this inquiry. The document review confirmed that various community-based organizations in the city had offered anonymous testing through the study. A participant who had been closely involved with this study confirmed that it had received ethical approval from two separate boards and granted organizational participants the ability to conduct testing anonymously free of any legislative restrictions. The document review analysis also confirmed that if anonymous testing was not available on-site at the community-based organization through the study, referrals were made to anonymous testing services elsewhere in the city. In a literature review of harm reduction strategies directed at controlling the spread of HIV, Hilton, Thompson, Moore-Dempsey, and Janzen (2001) note that harm reduction programs are often are frequently run as pilot projects, under-funded, and insufficiently coordinated. Vancouver's safe injection site, InSite, is evidence of a similar temporary program that also received ethical exemptions. InSite "operates under a waiver of Federal rules that allow it to provide services as a research project" (Drucker, 2006, p. 1). Despite having positive outcomes for users of the site as measured by Wood et al. (2004) it has not achieved long-term, sustainable operations.

The temporary offering of anonymous testing through a study was likely reported to PHAC at the time the 2007 Epidemiology Update was being prepared for publication. Knowing about the research study helped me make sense of the initially perplexing footnote in the PHAC (2007a) Epidemiology update that read "Anonymous testing is available upon request but is not part of the official guidelines for the province" (p. 16). The availability of this service was referring to past offerings of anonymous testing

through the study, whereby “not part of the official guidelines” meant it was available through a temporary research study. In this way, it was excluded from legislative violations.

5.1.3 Other Potential Pitfalls in Testing Terminology

Kodner and Spreeuwenberg (2002) demonstrate the importance of terminology in determining how providers “think about, shape, deliver, manage, regulate, finance, and evaluate health care” (p. 1). Throughout this inquiry, I noticed loose understandings of certain key concepts and became concerned about the potential for confusion of linked and unlinked information, as well as technicalities in the definitions of privacy, confidentiality, and security in the context of anonymous testing.

Phrases that suggested variations of the concept of link that were used in the organizational definitions of anonymous included “lead to the identification of” (Document E3) and “connect to the individual’s identity” (Document C9). Participants made multiple references to the word *link* when describing anonymous testing in their own words. For example, one participant described his perception about anonymous testing with statements such as “it should be impossible to link the test result to the individual”. I suspected that a likely deduction of this participant’s statement could result in a layperson equating *anonymous* as a type of *unlinked* testing. This is an important distinction that is discussed here.

The Council for International Organizations of Medical Sciences (2002) states that personal information collected for health purposes can be stored and classified as *linked* or *unlinked*. Unlinked information “cannot be linked, associated or connected

(even by deduction) with the person to whom it refers" (p. A). Linked information can be linked, associated or connected with the person to whom it refers. There are three categories of linked information including anonymous, non-nominal, or nominal. Within this linked category, anonymous information means that "the information cannot be linked to the person to whom it refers except by a code or other means known only to that person, and the investigator cannot know the identity of the person" (p. A). Non-nominal, on the other hand, is when the personal information *can* be linked to the person by a code known to the person and the investigator in which the code does not include personal information. Finally, nominal is when the information can be linked to the person by means of personal identification, usually the person's name. According to these definitions, anonymous testing is still considered to be *linked* to an individual; however, only the individual to whom it is linked knows his or her code and is, therefore, the only individual who can identify this information. In this way, it is considered anonymous. This fits with the explanation provided in the previous section.

On a related note, much work has been done surrounding the concept and practice of *unlinked* anonymous testing in the field of HIV/AIDS (Johnston et al., 1992; Kessel, Watts & Weiss, 2000; Rennie, Turner, Mupenda, & Behets, 2009). While an in-depth discussion about unlinked anonymous testing is beyond the scope of this analysis, I draw it to the attention of the reader here as something that could potentially lead to further confusion in the field. Unlinked anonymous HIV testing refers to screening of blood that has been de-identified and, therefore, cannot be traced back to an individual. Unlinked anonymous testing is a controversial screening practice that is done without an individual's explicit consent and is considered to be a surveillance technique.

Many references to broad concepts of *privacy*, *confidentiality*, and *security* were made, but participants lacked a demonstrated understanding of the distinctions between them. This paragraph differentiates between these terms to make this information accessible for providers. According to the Newfoundland and Labrador Centre for Health Information (NLCHI) (2004), confidentiality refers to “the obligation to protect, respect and maintain the confidentiality of personal information from unauthorized persons, processes, or devices” (p. 7). The NL Department of Justice (2009) describes confidentiality as the right of a person to withhold information from others. Privacy, on the other hand, is referred to as the “protection of personal information” (Department of Justice, 2009) or “the right of an individual to control the collection, use, and disclosure of personal information about himself or herself” (NLCHI, 2004, p.8). Finally, the concept of security has a narrower focus. It refers to the “establishment and maintenance of safeguards to protect personal information from unauthorized access, use, disclosure, modification, loss or theft” (Department of Justice, 2009). It focuses on the means used to protect data and/or information from “accidental or malicious disclosure, modification, removal or destruction” (NLCHI, 2004, p. 8). In general, people expect that in situations involving medical and financial services that their personal information will only be shared with people they intend to share it with.

5.2 Communicable Diseases Act: “...because you can get in big trouble...”, or can you?

Laws to provide powers necessary to counter public health threats have existed since early times (Coker & Martin, 2006). All participants interpreted the Communicable Diseases Act in the same way: it was believed that anonymous testing has always been

illegal and will be illegal until there is some change in the legislation that absolves responsibilities around mandatory name-based reporting. Since this interpretation was widely accepted by the study participants and other community members, I presumed this was an accurate interpretation and conducted the study on this premise. For instance, some participants from community-based organizations feared that offering anonymous testing would result in prosecution and/or eventual shut-down of their clinic. Similarly, participants from the regional health authority recognized their close connection to the provincial government and the need to abide by provincial laws. During the interviews, participants were quick to point out that anonymous testing had been offered as part of a study and it was no longer available to illustrate that they were now complying with legislation. I eventually speculated that participants were hesitant to discuss their organization's practice of offering anonymous testing because they perceived that doing so was illegal.

In the final stages of the write-up, I corresponded with two provincial government representatives who dealt with communicable diseases within the Department of Health and Community Services and the Department of Justice. The representative from the Department of Health confirmed that while there were some legal complexities to the interpretation of the Act, it was "safe to assume" that the widely accepted interpretation that had been expressed by the participants was correct (G.B., Personal Communication, March 4, 2010). This confirmed the Department of Health and Community Services supported the widely accepted interpretation that an Act requiring mandatory reporting prohibits anonymous testing. My inquiry was then forwarded to a solicitor with the Department of Justice who pointed out that Section 4 outlines mandatory reporting

provisions and Section 34 sets out the offences section where a person wilfully commits a breach of the Act. The solicitor was unsure if Section 4 has ever been enforced and that there were at the time of the correspondence, no Regulations adopted under this Act. Finally, the Solicitor noted that the Act is dated and may be in need of updating (G.S., Personal Communication, March 8, 2010).

This section examines this interpretation of the Communicable Diseases Act and explains my suspicion that legislation is the root cause of much policy-practice incongruence and the biggest barrier to transparent communication and conceptual clarity. I address whether or not the interpretation of anonymous testing as an illegal practice is a correct interpretation of the Communicable Diseases Act 4(3) on the following grounds - absence of historical prosecution, silence about testing, ethical issues surrounding reporting requirements, and antiquated legislation. I conclude by examining reasons why this could be an incorrect and outdated interpretation based on a comparison to legislation in provinces where anonymous testing is available. These reasons offer possible explanations for key areas of incongruence and provide further rationale for excerpts from key documents.

Coker and Martin (2006) examine the role of law in the protection of public health. Not only does law have direct consequences, such as providing reason for penalty in the event of a breach, it also has a wider role to play by helping shape socio-cultural norms. Laws create expectations of standards of health and safety and public perceptions that certain behaviours or actions represent the minimum standards of health protection that are accepted by society. The findings of this inquiry have led me to question both the enforceability of the Communicable Diseases Act given the accepted standards of

practice observed in this study. It seems that providers from formal and informal settings unequivocally see the need for HIV testing that does not require collection of personal information or other modifications of service delivery that would increase the likelihood of a person receiving preventative treatment or education. The law has failed to keep pace with the changing needs and demographics of the clients seeking services and the changes to clinical environments required to suit them. Valdiserri (2004) points out that this has significant negative impact on program and policy development.

I question how reasonable it is for us to consider the act of offering anonymous testing as an illegal activity for which a service provider will be prosecuted. For example, at no point during the history of confusion about testing terminology where non-nominal testing was referred to as anonymous was there ever any mention of illegality or prosecution. This was also the case for widespread advertising of anonymous testing, and the offering of anonymous testing through the specialized research studies. Coker and Martin (2006) explain that a lack of penalizing action creates a precedent that this practice is acceptable.

The Communicable Diseases Act is very specific about reporting requirements, but it is silent with respect to testing for communicable diseases. It does not explicitly describe procedures permitted for preventative testing and screening programs. Within a public health context, Coker and Martin (2006) point out that the absence of law sends a message about acceptable behaviour through implication. Specifically, if the law is silent it implies that the action is okay even if it is not in the interest of public good. High fat food is a good example. In the absence of a law to prevent the advertising of junk food to children, it is implied that there is nothing unacceptable about targeting children in such

advertisements. If this rationale is applied to the Communicable Diseases Act, which is silent about anonymous HIV testing, it would be implied that the provision of anonymous testing is okay. As such, I question my participants' and the widespread interpretation of anonymous testing as an illegal practice. If this practice is, indeed, legal, it still begs important questions about the feasibility and ethical appropriateness of offering anonymous testing when there are name-based reporting requirements.

Walsh (2007) describes this ethical tension as a "legal-regulatory limbo". To explain this conundrum, it is helpful to separate the testing and reporting processes. Any jurisdiction that permits anonymous testing, but also requires name-based reporting is asking people to think of testing and reporting as mutually exclusive processes. Specifically, you can be tested anonymously, but positive cases are reported and followed up on using names. Therefore, once a positive result is confirmed, the anonymity of the test that was initially offered quickly dissipates.

While it does have specific procedures for the reporting process, the wording of the Communicable Diseases Act as it pertains to reporting are open to interpretation. The relevant section of the Communicable Diseases Act reads as follows,

(2) The notice to the deputy minister or to the health officer shall, where possible, state the name of the disease, the name, age and sex of the person, and the name of the physician giving the notice, and shall by street and number or otherwise, sufficiently designate the house or room in which the person is living.

This definition raises questions about a definition for *possible*. Would situations where individuals seeking testing refused to provide personal information for a variety of

personal reasons merit a situation in which it was “impossible” to record and report the personal information stated in the Act? If a healthcare provider deemed it inappropriate or insensitive to request or insist on this information due to an individual’s personal circumstance, would it be “impossible” to report the personal information stated in the Act? I discovered that Quebec, New Brunswick, and Nova Scotia, three of the provinces that officially and publicly offer anonymous testing without fear of prosecution for engaging in an illegal activity, use similar wording to describe the requirements for transmitting personal information in their applicable legislation. Terms such as “if it is available” (Quebec), “if known” (New Brunswick), and “to the extent possible” (Nova Scotia) seem to leave flex room for the reporting provider to omit personally identifying details, or possibly never make an effort to collect them at all.

This argument is strengthened by the fact that the last update to this section of the Act was in 1970. Coker and Martin (2006) note that a fundamental shift has occurred in public health overtime in the balance between common good and individual rights protection. Kodner (2009) points out the increased need to reduce the gap in health systems’ ability to service the complex and growing needs of vulnerable populations, instead of continuing to enlarge their “overwhelming and increasingly anachronistic acute, episodic medical orientation”. Coker and Martin suggest an environment in which biomedical values permeate the attitudes and beliefs of providers poses an increased risk for human rights breaches. For example, in situations where the authorities who are responsible for exercising public health powers without regard for the impacts on the population have the potential to apply certain public health measures with little consideration for individual rights. They emphasize the importance for such interference

measures to occur under certain conditions. Specifically, when and if it is necessary to protect public health, where the interference it is proportionate to the public health threat, and where the relationship of power of a public health provider over an individual is known and regulated by law.

A need for a shift away from biomedicine towards public health measures that service the needs of vulnerable populations has been acutely pronounced throughout the HIV/AIDS movement. In 1996, a new class of antiretroviral agents was introduced and resulted in a marked decrease in HIV-related mortality. Valdiserri (2003) concludes that since the availability of highly active antiretroviral therapy, the real and perceived public health risk of HIV/AIDS has decreased. Real risk is demonstrated by measureable decreases in key indicators, such as mortality. For example, after one year of availability of treatment it was estimated that there was between 15 to 20% fewer HIV-related deaths in the United States and Canada. Valdiserri explains that perceived risk is related to public perception of the unknown. When perceived risk is high, a layperson will have more negative feelings towards and react more strongly to a risk this is perceived to be dreadful, unknown, new, and unobservable. It is of fundamental importance to point out that law and policy-makers in 1970 when the Communicable Diseases Act was last updated may have had far higher levels of real and perceived risk about HIV/AIDS than present-day law and policy-makers.

Outdated provincial legislation that no longer reflects practice and a decrease in alarmist attitudes towards HIV/AIDS offers a possible explanation for the inconsistencies that were observed in this inquiry. Most notably, the regional health authority's draft policy outlined non-nominal reporting, where cases were reported to the Department of

Health and Community Services using an “assigned code” (p. 5) as a matter of routine practice; however, the Communicable Diseases Act requests detailed personally identifying information (“name of the disease, the name, age and sex of the person, and the name of the physician giving the notice, and shall by street and number or otherwise, sufficiently designate the house or room in which the person is living”). A participant from the health authority noted that the intention of the draft policy was to reflect the changing needs of health service delivery for HIV testing and the current practices of the providers who do testing, counselling, and reporting. Similarly, participants reported that when the HIV Clinic in the acute care setting was open, clients had been referred to it using a non-nominal code, chart number, or initials. While no one from the acute care setting was interviewed to confirm this, it suggests healthcare providers in acute care settings also provided anonymous care when necessary to the extent possible despite the reporting requirements outlined in the Communicable Diseases Act. This suggests further and longstanding incongruence between the Communicable Diseases Act and practice in the acute care setting. Taken together, these areas of incongruence suggest the Communicable Disease Act is prohibitive and has failed to keep up with changing nature of this highly stigmatized disease in which psycho-social factors play an important role in accessing preventative services and treatment.

5.2.1 Legislation in Other Provinces

To inform my recommendations on the legislative aspect of the inquiry, I looked at the applicable legislation of those provinces that PHAC (2007a) had identified as offering anonymous HIV testing that did not have footnotes indicating that positive tests

became part of the nominal system. Provisions in provincial legislation that making anonymous testing legal included recent updates to allow anonymous HIV testing (Saskatchewan), unique reporting forms for HIV/AIDS (SK), exclusion of HIV from the list of reportable conditions with inclusion of AIDS (Ontario), and the use of careful wording.

In Saskatchewan, the legislation was updated in 2003 to allow a unique reporting format for HIV/AIDS that was different from other communicable diseases (Government of Saskatchewan, 2003). Under the Public Health Act, Saskatchewan's Disease Control Regulations defined anonymous test sites as a "a place where a person may have a specimen collected for the purpose of testing for human immunodeficiency virus infection without the person's name being disclosed" (p.3). As of 2003, anonymous testing sites had been permitted with the approval of the minister under the condition that the operators provide "a monthly report of information to the co-coordinator in the format approved by the department" (p.5).

In Ontario, the Health Protection and Promotion Act Section 31(1) specifies that "every medical officer of health shall report to the Ministry in respect of reportable diseases and in respect of deaths from such diseases that occur" (Ontario Ministry of Health, 1990). However, HIV is not included on the reportable communicable diseases list, but AIDS is (Regulation 559(91), Health Protection and Promotion Act).

In Quebec, the Minister's Regulation under the Public Health Act states that when there is a confirmed case of HIV, the "name and permit number of the health professional who requested the analysis" and "if it is available, the patient's health insurance number" must be transmitted to the national public health director (Government of Quebec, 2003).

There are stricter reporting parameters if the transmission is in a “person who has received blood, blood products, organs or tissues” (Section 3(4)).

The Government of Nova Scotia’s Health Protection Act (2005) refers to the Reporting of Notifiable Disease and Conditions Regulations to outline all reporting procedures. Under these regulations, HIV is considered a notifiable condition (Schedule A, Part I). The Regulations stipulate that occurrences of notifiable conditions are to be reported and “to the extent possible” the report must include the following information about the individual with the condition “the name, age, address, ethnicity and sex of the person who is the subject of the report; the name of the notifiable disease or condition or the illness that is being reported; and all clinical and epidemiological details pertinent to the diagnosis and follow-up of the person who is the subject of the report”. These regulations came into effect in 2005.

Under the New Brunswick Health Act, Section 94 outlines public health and communicable disease legislation. “AIDS related complex, and any confirmed HLTIV-III virus antibody reactive status” (Section 94(1) p. 24) are listed as notifiable diseases. The notification procedure requires the district medical health officer or the nearest public health inspector to immediately notify the district medical health officer (Section 94(3), p. 24). The report “shall contain the name of the person infected or suspected to be infected, the place of residence and the name of the disease, if known” (Section 94(3)).

5.3 The Need to Increase Communication between Service Providers

Three areas of concern expressed by participants who worked in a community-based organization were different than those expressed by participants who worked for

the regional health authority. Firstly, participants from both community-based organizations voiced concerns about the regional health authority's lack of communication about the official HIV testing policies and procedures. This concern is referred to as 'lack of communication of official policies and procedures'. Secondly, participants from both community-based organizations felt there was an urgent need for access to anonymous testing services, while participants from the regional health authority demonstrated varying levels of support for anonymous testing depending on their personal understanding of anonymous testing. This concern is referred to as 'sense of urgency for desired changes to testing services'. Finally, aside from recognizing the need to scale up the availability of testing service delivery and improve volume at testing sites, participants from the regional health authority were more likely to express satisfaction that current testing procedures were highly confidential and provided specialized services when needed. Participants from community-based organizations, on the other hand, displayed lower levels of trust in the security of data provided during the HIV testing process and were more suspicious about its intended and potential usages due to their damaging effects. This concern is referred to as 'community distrust in the current system'. Based on Valdiserri's (2003) theory that perceived risk is related to public perception of the unknown, this section discusses why there is a need for increased communication between community-based organizations and the regional health authority using the dimensions of risk, trust and accountability. Increasing communication could play a role in bridging the gap between levels of trust displayed by employees of community-based organizations, which are more likely to reflect the views of the general population, and healthcare workers.

5.3.1 Exploring the Differences in Service Providers' Concerns

The concerns expressed by participants from both community-based organizations and the regional health authority support those of previous studies that have demonstrated the importance of and need for increased collaboration between community-based organizations and formalized medical settings (Rutledge & Robinson, 2009). To provide “seamless, high-quality psychosocial care” (p. 29) required to prevent chronic illnesses, it is best to utilize community-based organizations that exist to provide support for people with diverse needs. Literature concerning the conditions necessary to prevent HIV deems effective information exchange a vital component of collaboration between community-based organizations, researchers, and policy-makers (Roussel, Fan & Fulmer, 2004).

Participants from community-based organizations listed a number of concerns with the HIV testing system in place at the time of the study, through which anonymous testing was *not officially* available. They described the benefits of anonymous testing based on their experiences of having been able to offer it in the past and the gap in service delivery that was created by losing it. What participants from community-based organizations did not realize was that discreet anonymous testing was available under certain circumstances, but this was not widely communicated or even realized by the people offering the service.

Based on Gilson and Erasmus' (2006) finding that communication is a foundational principle of the accountability required to build trust in health service delivery, the lack of understanding the “official” process is likely a main factor in all concerns identified by participants from community-based organizations. Participants from community-based organizations expressed a sense of urgency about the need to

establish anonymous HIV testing services in the small urban centre far more than participants from the regional health authority did. This is because participants from community-based organizations associated the current system with a higher degree of risk. Most importantly, there was much uncertainty about what it means to be “in the system”. Knowledge deficits displayed by participants from community-based organizations included the belief that there was a fee associated with HIV testing at any site that was operated by the regional health authority, and the belief that during a non-nominal test the MCP number was recorded in the file making test results accessible for third party information requests from family physicians and insurance companies.

Along with the complexity of language and ambiguous history of HIV testing services, uncertainty is a key dimension of perceived risk (Morgan et al., 2001) that was observed in this study. Participants of community-based organizations believed that there were too many unknowns about HIV testing in this small urban centre. Community-based organizations had unanswered questions about specific aspects of the testing procedure (personal information requirements, costs, waiting room set-up, quality of service delivery, and other aspects of the testing services to which they are referring their clients). This was a sharp contrast with their past experiences of offering on-site truly anonymous testing through a study, which was a process they were physically close to, which allowed them a high degree of control and the opportunity to gain a sophisticated understanding of the process.

Participants from the regional health authority, on the other hand, were more content with current HIV testing services from a security perspective and felt there was no need for drastic or urgent change. This could be because they enjoyed implicit

knowledge that the participants from community-based organizations lacked, which could only be acquired through in a formalized setting. For example, they were aware of the security measures taken to protect the identity of those who have been tested for HIV, such as the absence of MCP numbers on reporting forms that are sent to the provincial government, the number of people who accesses the files, the ability to be tested without providing one's true name or contact information, how Meditech operated, and the processes surrounding random code generation. Furthermore, they were confident in their own and other members' of their professions' abilities to keep clients' information confidential despite local privacy breeches that had recently occurred. Finally, this inquiry demonstrated that the regional health authority permits only experienced public health nurses who have undergone extensive training to be communicable disease nurses. This finding is consistent with previous harm reduction studies such as Gustafson et al.'s (2008) finding that registered nurses are well-positioned to play a role in harm reduction efforts and could benefit from transparent communication on specific harm reduction practices.

5.4 Social Justice and an Expanded Social Determinants of Health Inequality Framework to Support Explicit Anonymous HIV Testing in Small Urban Centres in NL

Public health is based on social justice and human rights, which aim to reduce factors that perpetuate vulnerability (Burris, 2004) and is often analysed using the social determinants approach. Graham (2004) highlights the need for researchers to place increased emphasis on the social processes that drive health inequalities to develop policies that address health inequalities. Most importantly, when addressing a "policy

audience” (p.118), Graham emphasizes the importance of differentiating between the *social determinants of health* and *social determinants of health inequalities*.

To help with differentiating between these two things, it is helpful to review Braveman and Gruskin’s (2003) distinction between equality and equity. Equal means the same opportunity to access a service, but does not address the variety differences that exist within the broader social context. Equity refers to the fair opportunity for all population groups to be healthy and focuses on the distribution of resources that drive different health outcomes. Equal opportunities to be healthy are fundamental to the concept of health equity. While it is possible to assess equality with respect to specified measurable outcomes, there are more considerations and interpretations when judging whether a process is equitable or not. A health disparity is inequitable if it is systematically associated with social disadvantage that puts a previously disadvantaged group at a further disadvantage. Resource allocation, policy and program development, and decisions about those directives shaping systemic factors should be distributed and designed in ways that are most likely to improve the health outcomes of disadvantaged social groups with the outcomes of their more advantaged counterparts. In this way, governments and systems strive to be non-discriminatory. This section reviews regionally-specific academic research, demographic trends and statistical information that demonstrate health inequality in NL by focusing on three determinants (education and literacy, personal health practices, and health services) that were relevant to the findings.

5.4.1 Literacy Rates and Discreet Testing

NL has one of the lowest health literacy rates in Canada, where health literacy is defined as “the ability of individuals to access and use health information to make appropriate health decisions and maintain basic health” (Canadian Council on Learning, 2007, p.3). Health literacy encompasses one’s ability to obtain, understand and act upon health information and services and to make appropriate health decisions for his or her own health. In general, health literacy decreases with one’s social position and resulting access to education, labour, property, wealth, and political influence (PHAC, 1999). Literacy rates are particularly relevant to this study because of the requirement for a test seeker to understand and act upon words used to describe testing services, such as *anonymous*, *nominal*, and *non-nominal*. Participants’ attributed the interchangeable use of testing terminology to the belief that most test seekers do not understand the technical differences between the terms non-nominal and anonymous. They suspected that people, providers and test seekers alike, preferred the term anonymous because they knew what it meant. The assertion that familiar terms are preferred seems likely given these statistics on health literacy levels. Embedding complex language and terminology into public services creates a systemic barrier. The current delivery of testing, as well as the Communicable Diseases Act and the regional health authority’s policy exemplify how policy can propagate power imbalance and health inequity.

A key barrier to accessing STI testing in Canada identified by Goldenberg et al. (2007) was limited access to information. Aside from the controversial poster campaign launched by testing site #2, there was no evidence of efforts to communicate the availability of testing services, the type of testing services, or the procedures used in each

type of test and setting. Absence of such communication places the general public, especially people with low literacy levels, at a disadvantage when it comes to accessing information about testing services. Obermeyer and Osborn (2007) confirmed that providers and test seekers have different notions of what constitutes confidentiality and anonymity and suspect that this unclear understanding is related to the uneven application of practices intended to protect confidentiality. When providers and clients do not share an understanding about the differences between confidential and anonymous testing, the negotiation of potential tensions between testing policy guidelines and individual clients' preferences is left to providers and test seekers at the point of service delivery (Obermeyer & Osborn, 2007).

Combining this observed lack of communication with the finding that test seekers are more conservative in their definitions of confidentiality (Awad et al., 2004), suggests that a power imbalance between provider and test seeker becomes evident at the very early stages of the testing process. The likelihood for test seekers who demonstrate a more conservative definition of confidentiality to receive the service in the manner they would like decreases with literacy rates as does their ability to negotiate. The highly technical nature of HIV testing language takes away one's ability to enjoy the advantage offered by health literacy – "to obtain, understand and act upon health information to make appropriate decisions for his or her own health" (Canadian Council on Learning, 2007, p.3).

Effective education for children and lifelong learning for adults are key contributors to individual and population health (PHAC, 2003). With literacy levels as an indicator, education contributes to health and prosperity by equipping people with

knowledge and skills for problem solving, and helps provide a sense of control over life circumstances. Graham (2004) has cautioned against “blurring the distinction between the social factors that influence health and the social processes that determine their unequal distribution” (p. 109). We must treat low health literacy as a driver of health inequality in NL. To incorporate Graham’s (2004) work, I urge increasing the emphasis placed on inequality: low health literacy limits people’s ability to access HIV testing services due to lost negotiation power and a lack of communication of understandable material that explains HIV testing. Policies that have provisions that account for the likelihood of a test seeker to display low health literacy should become central to the delivery of HIV testing services.

5.4.2 Perceived Irresponsibility

In addition to having different understanding of confidentiality, providers may not view requests from test seekers for enhanced confidentiality in a positive light especially if it is seen as an accommodation for an individual who is perceived as irresponsible (Obermeyer & Osborn, 2007). Goldenberg et al.’s (2007) work on barriers to testing to make the connection with irresponsibility; real and perceived judgmental behaviour by healthcare providers is a barrier to testing. This could create feelings of stigma, shame, and social discomfort could deter people from seeking testing as well as related concerns about anonymity and confidentiality. Yang et al. (2005) describe how HIV stigma is often coupled with multiple layers of co-stigmas that can be directly or indirectly related to both the cause and consequences of the infection including injection drug use, sex work, sexual behaviour, ethnicity, poverty and disability. Instead of examining all of the

characteristics that result in multiple layers of stigma described by Yang et al., I focus on the risk factors that participants said were present within their client populations that could be related to irresponsibility, including injection drug use, sex for money unprotected sex, and sharing of drug paraphernalia.

There is a strong presence of injection drug use in NL (HRU & ACNL, 2007; Oxycontin Task Force, 2004). Patten (2006) has demonstrated the link between injection drug use and the risk of transmission of HIV and other sexually transmitted infections. Individuals involved in injection drug use are considered to be at-risk of HIV and shown to be more likely to access anonymous testing services than nominal or non-nominal testing (Hoxworth et al., 1994; Kegeles et al., 1990). On the topic of injection drugs, it is necessary to point out that 53% of new HIV infections among Aboriginal Canadians are attributed to injection drug use, which is much higher than the 14% of new infections within the general population that are attributed to injection drug use (PHAC, 2007a). Since this is a Canadian statistic, it is impossible to conclude whether it is indicative of HIV infection within NL's Aboriginal population. According to Statistics Canada Census data (2006a), NL's self-identified Aboriginal population represents 5% of the provincial population, which is higher than the national average. Given the strong presence of this population in NL and the challenges of delivering culturally appropriate HIV testing services presented by Bucharski et al. (2006) and Tseng (1996), it is necessary to draw attention to the increasing number of infections attributed to injection drug use on a national scale to highlight the need for further investigation of HIV testing service delivery to NL's Aboriginal populations.

Another area of intersection between social exclusion, injection drug use and stigma is the MSM category. Of the 18,560 adult male AIDS cases reported in Canada, 76.1% were attributed to men who have sex with men and an additional 4.7% were attributed to the men who have sex with men who also reported being injecting drug users (PHAC, 2007a). In NL, 51% of infections are attributed to men who have sex with men (Department of Health and Community Services, 2008). There was a dearth of academic literature on lesbian, gay, bisexual, and transgendered populations in small urban centres in NL, so I consulted a Canadian study that recruited its sample of lesbian, gay and bisexual youth from rural communities in British Columbia. Poon and Saewyc (2009) revealed that this population experienced feelings of victimization, had experimented with substances, and had special needs to consider when accessing preventative health services. I suspect lesbian, gay, bisexual and transgendered populations in this small urban centre face similar challenges.

In an examination of community-based HIV prevention research, Shannon et al. (2007) note that women who exchange sex for money, drugs, shelter, or other commodities as a means of basic subsistence face an elevated risk of HIV transmission. While there was a lack of academic literature on the sex trade in NL, local grey literature suggests that there is a growing presence of female prostitutes in the downtown area who face similar challenges (Walsh, 2008). Part of the increase in local prostitution was attributed to the economic gains that have resulted from the recent economic prosperity related to the oil industry. As a result of increased oil-related traffic to the region, the demand to trade sex for money had increased, as well as the price people were willing to pay.

Prior to recent oil-related economic prosperity, increased exposure to STIs was previously observed in other areas related to industry and employment. Due to interprovincial migration, NL temporarily loses youth who seek temporary employment in other provinces, often in industry-related jobs such as oil and gas, and later return to the province (Statistics Canada, 2006c). Research demonstrates the growing trend for youth involved in industry-based interprovincial migration have a propensity to binge on alcohol and drugs and access the sex trade (Goldenberg et al., 2007). This places them at a higher risk for infection in a stigmatized environment where access to health services for sexually transmitted infections is low. This creates a need for specialized prevention and screening services and an elevated risk of bringing the infection home to their home communities.

In summary, people who use injection drugs, participate in the sex trade, and engage in unsafe sexual practices experience feelings of stigma or shame about the activities in which they engage. Goldenberg et al. note that perceived judgmental behaviour by healthcare providers on an individual's personal choices can result in stigma, shame, and social discomfort. This stigma could deter people from seeking testing and related concerns about anonymity and confidentiality. These individuals may need additional services and support when seeking testing. Under a social determinants model, we might try and fit these activities into the "personal health practices" box. This is defined as those actions by which individuals can prevent diseases and promote self-care, cope with challenges, and solve problems that prevent sickness and enhance health and well-being (PHAC, 2003). As Graham suggests, these practices have damaging health effects and are by no means evenly distributed throughout the population. Their

presence suggests an examination of a broader psycho-social context of inequality, rather than focusing on the individual making the health decision.

5.4.3 Health Services as a Deterrent to Testing

Goldenberg et al. (2007) state that characteristics of health service delivery systems that can prevent people from accessing STI testing services include inconvenient hours of operation, wait times, and clinic location. There was evidence of this with participants' concerns about testing in formalized environments such as the location and accessibility of testing site #3, under-awareness of the services available at testing site #3, and concerns about the quality of STI services provided by family physicians. There were specific concerns about the numerous services offered at testing site #3. I made the assumption that many community-based organizations focused on testing site #3 because it had been established for a longer period of time than testing site #4. Additionally, testing site #4 was focused on youth and since opening has maintained a relatively low public profile so participants may not have been aware of this service. One participant described a situation in which a person who injected drugs was afraid to be tested at testing site #3 because of the possibility of bumping into a child protection social worker. The person thought the social worker would find out that he or she was there for an HIV test. This would indicate that we was an unfit mother and she would lose her children.

While healthcare professionals have a duty to prevent this from happening, I believe this supports the conclusion of Awad et al. (2004) that the public's "fear of health providers breaking confidentiality is exacerbated when reports of specific instances of breaches are made public" (p. 123). I remind the reader about the November 2007

incident described in Chapter 1 in which a healthcare provider installed a file sharing program on her laptop while working from home and unknowingly transmitted confidential medical files over the Internet (Office of the Information and Privacy Commissioner, 2008). PHAC (2003) refers to health services as those services that are designed to improve the health of individuals and populations by maintaining and promoting health, preventing disease, and restoring health. This inquiry has demonstrated how HIV testing is a health services that is situated within a broader structural inequality as described by Young (2006). Certain aspects of the current service delivery, in fact, deter individuals from accessing preventative health services. This drives health inequality, denies the individuals their fundamental human right to health, and demonstrates social injustice.

5.5 Implications and Recommendations

Thus far this chapter has outlined a number of theoretical and practical implications of the research findings. This discussion has highlighted systemic inequities within the current testing system, such as the expectation that people with low literacy levels will be able to understand the nuances between non-nominal and anonymous. Such expectations and requirements demonstrate how, through policy mechanisms, the system can favour basic human needs and the rights of some more than others. Despite differences in individual understanding of the definition of anonymous testing, all participants supported the need for specialized services to some extent. Community-based organizations supported this enthusiastically, while support from participants at the

regional health authority was on an as-needed basis, and fluctuated with their individual understandings of anonymous.

Based on these findings, I believe that explicit anonymous testing should be made available through a province-wide policy in a transparent manner and supported at all levels of government, healthcare, and community in NL. Risk behaviours that could have a negative health outcome for which specialized services are provided are typically viewed as a harm reduction approach, which traditionally centre around substance use and the sex trade (Shannon et al., 2007). Anonymous testing, as a specialized service, should be made available *not* as a harm reduction effort for drug users and sex trade workers, rather for the general population of test-seekers. I refer here to individuals who may not be affiliated with any risk group or engage in any health damaging activity, but who may want more confidentiality than offered by non-nominal testing. This section provides recommendations for change at various levels of responsibility (federal, provincial, and organizational). It identifies areas in which future research would be beneficial, reviews the dissemination plan, and offers concluding remarks. The recommendations that follow take into consideration that official anonymous testing may not be supported by all stakeholders and recognizes the time required for legislative change. I have attempted to make pragmatic suggestions that could lead to realizable change.

5.5.1 Recommendations to the Provincial Government: Clarify and Update Legislation

Knowing that other provinces offer anonymous testing despite wording of their respective provincial legislation that closely resembles that of NL's Communicable

Diseases Act, questions about its interpretation and application must be addressed. The provincial government Departments of Justice in partnership with Health and Community Services should take the following steps to alleviate uncertainty for providers in testing situations.

1. Issue a statement that clarifies whether or not the Communicable Diseases Act prohibits or permit anonymous testing;
2. If anonymous testing is prohibited, provide justification given that
 - a. positive outcomes were noted when explicit anonymous testing was made available during a previous research study;
 - b. discreet offerings of anonymous testing occur in practice environments; and
 - c. research participants unanimously support the provision of specialized services and the presence of at-risk populations.
3. If anonymous testing is permitted, the Department of Justice and the Department of Health and Community Services should coordinate a forum in which all regional health authorities and other service providers of STI prevention services are given a chance to clarify the language in the current legislation and discuss its challenges.
 - a. This forum should provide clarification for all parts of section 4(3) of the Communicable Disease Act including “where possible”
4. Examine the possibility of updating this legislation as many other Canadian provinces have by looking at changes that have been made to other provinces’ communicable diseases legislation to reflect the changing

nature of HIV as a communicable disease. Regardless of how NL's legislation is interpreted at present and whether or not stakeholders support anonymous testing, this legislation should be updated to reflect changes in accepted standards of practice for HIV testing, the decrease in alarmist attitudes of HIV-related risk and dread that have resulted from advances in treatment. Interference with individual information is required only to an extent that is proportionate posed by the public health risk it poses.

5.5.2 Recommendations to the Regional Health Authority: Reduce the Unknowns

Due to a lack of communication about the HIV testing procedures at the formalized testing sites operated by the regional health authority, employees of community-based organizations were uncertain about various aspects of HIV testing procedures. This precluded them from being able to help their clients by answering questions or volunteering information that would reduce the unknowns about an already stressful situation, HIV testing. Limited understanding of this process takes away community-based organizations' ability to provide current and detailed information. This is significant when the critical role the community-based movement has had in responding to HIV/AIDS in Canada is examined. Initial efforts to respond to HIV/AIDS originated within communities and expanded to their present fortitude of being available in all Canadian provinces and territories (CIHR, 2009). The services provided by community-based organizations in British Columbia were described as being "flexible, timely, innovative and creative, often with minimal financial resources" (Pacific AIDS

Network, 2009, p. 7). While there are many contextual factors that differentiate the response of NL's community-based organizations from that of British Columbia's, it is safe to say that it is challenging to provide information about HIV testing services in the absence of a clear definition of anonymous testing and without a complete description of testing procedures. The fact that a policy directing employees to use non-nominal reporting has been in draft format for over a year was evidence of the slow-moving policy process in the large organizational structure. Action to communicate an organizational policy internally or externally cannot occur until the policy is approved.

In the absence of policy guidelines on which to develop clinical directives, public health providers rely on their professional training and experience or view their personal moral foundations as sufficient to solve an ethically challenging clinical decision (Baum et al., 2007). Without an intricate knowledge of the details of the process, it is impossible for providers to understand the process themselves, which precludes them delivering this knowledge to an inquiring client. Clear communication of the procedures followed during the three types of HIV tests at the regional health authority's testing sites is required. After finalizing the policy, details of procedures used at public health settings should be communicated to the community-based organizations. This will require revisions to the current policy document. Messages should be disseminated using knowledge translation principles outlined by Graham et al. (2006), which include techniques such as tailoring the message to the needs of the audience. The regional health authority should take the following steps:

5. the draft HIV testing policy should be revised to address the question of what to do when a test seeker withholds personal information required for

non-nominal testing. Examine the possibility of including a clause that states “in a special circumstance or any other event in which there a client is hesitant to provide personal information, anonymous testing may be performed”;

6. When the policy is finalized, create descriptions for all staff providers involved with providing testing services;
7. the regional health authority’s Community Services division should take leadership of defining the various types of testing and their availability in a formalized public health setting. Plain language definitions should be proactively communicated to all community-based organizations. This communication must include a list of the sites where testing is available and the type of test that is offered at that location.
8. Any formal public health site that offers HIV testing must have access to a clear, non-technical description of the testing procedures followed at that site. This description should aim to eliminate all the unknowns about the testing process. For each type of test (nominal, non-nominal, and anonymous), this detailed description should include:
 - a. the address and phone number of the testing sites,
 - b. the type of testing available (which type and if it is on-site or off)
 - c. a description of the clinical set-up
 - d. the procedure for making an appointment,
 - e. a description of the waiting room and call in process

- f. (in bold letters) the personal information required to be tested for HIV with a specific mention of what contact information is required and acceptable
- g. (in bold letters) the procedure that will be followed if a test-seeker is unwilling to provide personal information
- h. (in bold letters) state that there is no charge for the HIV test,
- i. (in bold letters) a description of if, how, and when a client's MCP number is used and stored in the testing process
- j. a description of the process used to send specimen to laboratory
- k. what happens with positive tests results – how are they stored, where are they stored, who can access them, how (paper or electronic, what steps are taken to keep them secure)
- l. what happens with negative tests results – how are they stored, where are they stored, who can access them, how (paper or electronic, what steps are taken to keep them secure)
- m. a description of how third party requests, including but not limited to family physicians and insurance companies, for information are handled
- n. a description of the reporting process including when is it reported, why is it reported, and how is it reported
- o. a description of the partner notification requirements
- p. a description of how having an HIV test will impact future interactions with the healthcare system if the result is negative

- q. how having an HIV test will impact future interactions with the healthcare system if the result is positive
9. Full and detailed version of this information should be made available to community-based organizations on the regional health authority's website and upon request.

5.5.3 Recommendations to Community-based Organizations: Two-way Communication and Advocacy

Once the preceding steps are complete and community-based organizations have received clarification about both the Communicable Diseases Act and official HIV testing policies and procedures, there is an onus on community-based organizations to communicate their own policies and procedures to the regional health authority.

10. Any community-based organization that offers on-site HIV testing or has a clinic that refers test seekers off-site, there must be a clear, non-technical description of the testing procedures followed at that site. This description should aim to eliminate all the unknowns about the testing process. This detailed description should include all the information outlined in items *a* to *q* under recommendation #8 above for each type of test (nominal, non-nominal, and anonymous). This information should be provided to the regional health authority's Community Services Division.
11. For a community-based organization that refers testing inquiries off-site, providers must be familiar with the details of the HIV testing process at that site; and

12. Community-based organizations must make it possible for Community Services staff and other staff from the regional health authority to easily access information about services provided by their organization. If staff working in formalized environments were aware of the services that are available in community-based settings, they could better communicate this to clients upon request or when it could be otherwise beneficial to access services through a community setting.
13. Community-based organizations should publicly and cooperatively advocate for systemic changes that will better service their needs.

5.5.4 Recommendations to Stakeholders when Communicating to the Public

After communicating this information about their respective services to each other, community-based organizations involved with HIV testing and referrals and the regional health authority Community Services Division should communicate information to the public. Chiarelli (2006) suggests using a grade six level when communicating messages to the Canadian public about preventing chronic disease. Random testing of institutional documents describing the difference between anonymous, non-nominal, and nominal testing using were as high as 13.3. Although these documents are circulated among providers, it may indicate one reason for the confusion that persists among providers who could be expected to have literacy proficiency above a grade six level. It also gives an idea of the complexity of the subject matter and the extreme changes required to reduce the technicality of the language for a public audience.

Other techniques Chiarelli (2006) suggested included use of images and visual aids whenever possible. It should be noted that information from “disease-specific charities” (p. 10) has historically been at too high a reading level to benefit the groups to which it is targeted. Reported current problems with messaging to be irrelevant content, overuse of posters and brochures, and uselessness of standalone leaflets.

14. the regional health authority’s Community Services division should communicate the availability of testing services using a variety of mediums grounded in formalized settings. This includes posters at the testing sites, posting information on the website, health promotion fairs, to family physicians and pharmacies.
15. Community-based organizations should take the lead on special measures that will ensure this information reaches at-risk populations and other test seekers who require a higher degree of confidentiality. Basic information about service availability can be verbally delivered at the following locations - street reach, food banks, mobile vans, harm reduction sites.

5.5.5 Recommendations to PHAC and F/P/T AIDS

This inquiry has demonstrated that federal guidelines, such as the Canadian Guidelines on Sexually Transmitted Infections (PHAC, 2006b), do not address what to do in the event that a client does not wish to provide personal identifying information. It has also revealed the participants viewed the PHAC (2007a) Epidemiology update as misleading or irrelevant. The Federal/Provincial/Territorial Advisory Committee on AIDS (2007) “is a liaison committee that facilitates strong federal/provincial/territorial

intergovernmental collaboration in addressing a pan-Canadian approach to HIV/AIDS in Canada, while respecting jurisdictional responsibilities/activities” (p. 26). It has been “proactive and responsive” (p.1) in addressing HIV/AIDS issues and informing policy and program development for over eighteen years.

16. The next PHAC Epidemiology update should contain a condensed version of the information identified in recommendation #8 with full transparency about the testing practices instead of the summary tables and footnotes that offer little opportunity to access follow-up information;
17. The Canadian Guidelines on Sexually Transmitted Infections (PHAC, 2006b) should be updated to address a situation in which a test seeker is unwilling to provide personally identifying information and there are legislative restrictions at play.
18. The F/P/T AIDS should review the findings of this inquiry and provide input about the development and implementation of a formal provincial anonymous HIV testing policy in NL and identify possibilities for inter-jurisdictional collaboration in this endeavour.

5.6 Future Research

My study revealed concerns about family physicians’ ability to provide adequate and effective HIV testing and counselling and the inability of family physicians to deal with sexual health issues, particularly those related to HIV. These concerns included loss of confidentiality especially among family members, feeling uncomfortable, wait times for appointments, and quality of service delivery. My study, however, was limited to

community-based organizations and public health clinics and I cannot draw conclusions about the degree that participants' concerns are reflected in practices of family physician service delivery. It would be useful to examine issues pertaining to prevention and treatment of STIs in a family physician setting in NL. Pertaining to HIV testing, it would be useful to know more about the procedures used by local family physicians when referring people to HIV testing. Areas that merit further inquiry are family physicians' practices for making referrals for HIV testing, their awareness about non-nominal services and the possibility of non-nominal blood requisitions, referrals to treatment and services for HIV positive people, and level of comfort with discussing issues related to sexual health.

A second area in which to consider future research is examining how the move toward electronic health records will impact people living with HIV/AIDS and HIV prevention strategies. At the time of the study, participants from community-based organizations had doubts about the confidentiality and privacy of health information within small circles of healthcare providers where there is a perception that information is inappropriately shared. They had questions about how this would worsen with the move toward electronic health records and the impact this would have on people who had been tested for or are living with HIV/AIDS. Just as offering anonymity in the face of name-based reporting, participants raised questions about confidentiality with electronic access to personal health information. They wanted to know where and who could see non-nominal test results that are recorded electronically. Similarly, there were questions about whether or not all staff of the regional health authority would be able to see a client's prescription for anti-retroviral medication or paramedic's ability to open the electronic file of anyone who boards an ambulance.

A third area for future research is the inconsistent and disjointed nature of HIV testing policy between Canadian provinces. This presents an opportunity to highlight testing programs and efforts in place, within Canada and internationally, that display positive outcomes and merit of application to a Canadian setting. This would create a best practices approach to HIV testing in high-income, low-prevalence countries. The needs of test seekers within Canada's diverse geography and inter-provincial differences should not prevent such an endeavour.

5.7 Plans for Dissemination

Lomas' (1993, 2000) definitions of diffusion and dissemination are integral to the logic I used to develop my dissemination plan. Diffusion describes passive efforts that result in uptake only where the audiences are highly motivated, and the latter entails a push approach designed to bring the research to a range of audiences. I chose qualitative description for its emphasis on plain language summaries that can be synthesized for policy audiences and communicated across disciplines. The diffusion efforts I am planning include presentation of these findings at two conferences - the Aldrich Interdisciplinary Graduate Student Research Conference in St. John's, NL, April 2010 and the Canadian Association of Health Services and Policy Research Conference in Toronto, Ontario, May 10 to 12, 2010. I also plan to submit an article about my findings in one academic journal, *AIDS and Behaviour*, and having my thesis on file at Memorial University of NL's library.

To disseminate my findings, I will synthesize the findings into one-page reports and provide them for the three organizations that participated in my study. I will tailor the

reports to highlight the findings and recommendations that are relevant to each organization. If the organizations wish to disseminate them further, I will meet with them to discuss their dissemination needs and move forward collaboratively. I will also highlight parts of the report that are relevant to the reporting process and Communicable Diseases Act and forward them to the Provincial Government's Department of Health and Community Services as well as the Department of Justice. At the time this document was printed, one dissemination interview had been completed. The participant agreed with all key themes and findings, and supported moving forward with the proposed recommendations.

5.8 Conclusion

In this thesis, I have argued that social justice principles should inform policy and situated the findings within an expanded social determinants of health framework (Graham, 2004; PHAC, 2003). Some Canadian provinces allow official anonymous testing; others do not (PHAC, 2007a). This demonstrates an uneven application of social justice principles across the country (Braveman & Gruskin, 2003; Gostin & Powers, 2006; Rawls, 1999). Based on this inquiry, I support a movement towards a legislative change that would allow a transparent policy that permits explicit anonymous testing in NL's urban centres. In this sense, the meaning of anonymous would resemble the definition of *truly anonymous testing* used in this document where contact information is not requested or recorded and pre and post-test counselling is delivered face-to-face. In addition to providing an opportunity for people in this small urban centre to access harm reduction measures, it will also be a specialized service available to anyone seeking a

higher degree of confidentiality than is offered by non-nominal testing procedures regardless of their involvement in health damaging, stigmatized activities. Providing this service supports the call to increase the visibility of social justice in Canadian public health policy (Baum et al., 2007; Edwards & Maclean Davison, 2007). It is an equitable way to honour the right to health provision outlined by the UN/WHO (1948, 2006a, 2009b). This will increase health equity by decreasing the gap in our community between test seekers who require a higher degree of confidentiality and the legislative restrictions that create fundamental tensions at the point of service delivery. These findings may also be considered relevant to other small urban centres in NL.

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Appendix A – Study Invitation

Dear _____

Insert name of organization is being invited to take part in a research study that aims to address the challenges of offering anonymous HIV testing in [small urban centre], NL. I have received approval from Memorial University of NL's Human Investigations Committee to conduct this research (REFER TO DOCUMENT PROVIDING PROOF OF CONSENT).

I would like to know about (insert name of organization)'s HIV testing policy. I am particularly interested in your anonymous testing procedures. I would like to do a document review of (insert name of organization)'s HIV testing policies. It is important to note that a policy need not be in a manual. The document review will be of all policy-related documents including meeting minutes, emails, briefing notes, or any other hard copies that have been or currently are used to direct testing procedures.

I understand that (insert name of organization) has its own research protocols with respect to providing access to historical and current policy documents. I would like to meet with you to explain the discuss how this can be completed in a manner that ensures minimum disruption to (insert name of organization)'s daily activities.

Please contact me at (709)680-8139 or r63ajh@mun.ca to discuss the details of this request.

Sincerely,

Amanda Hancock

Appendix B – Interview Consent Form

Consent to Take Part in Research

TITLE: HIV Testing in [small urban centre]: Are Policies and Practices Congruent?

INVESTIGATOR(S): Amanda J. Hancock

You have been invited to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:

- **discuss the study with you**
- **answer your questions**
- **keep confidential any information which could identify you personally**
- **be available during the study to deal with problems and answer questions**

If you decide not to take part or to leave the study this will not affect your professional status.

1. Introduction/Background:

This research project aims to address the challenges of providing HIV testing in a city that has a limited number of healthcare providers and stigma towards such conditions. The findings will not attempt to solve, rather shed light on, issues of public health ethics and privacy.

2. Purpose of study:

This is an exploratory study that aims to evaluate the congruence between HIV testing policies and practices in [small urban centre], NL.

3. Description of the study procedures and tests:

Participants will be asked to complete a confidential interview where they will be asked about their professional experiences with HIV testing.

3. Length of time:

The interview will occur in a single setting and could take anywhere from 30 – 90 minutes.

5. Possible risks and discomforts:

This is a low risk study. Participants will be asked to describe professional experiences from memory and speak in general terms about organizational policies.

6. Benefits:

Version date:

Initials: _____

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed in instances where legal violations are disclosed.

When you sign this consent form you give us permission to

- **Collect information from you**
- **Share information with the people supervising the study**
- **Share information with the people responsible for protecting your legality and safety**

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study

Information collected and used by the research team will be stored by the Principal Investigator in a locked office. Amanda Hancock is the person responsible for keeping it secure.

Your access to records

You may ask the researcher to see the information that has been collected about you.

9. Questions:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is:

**Amanda Hancock
Email: r63ajh@mun.ca
Phone: (709)437-6162**

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

**Office of the Human Investigation Committee (HIC) at 709-777-6974
Email: hic@mun.ca**

After signing this consent you will be given a copy.

Signature Page

Study title: HIV Testing in [small urban centre]: Are Policies and Practices Congruent?

Name of principal investigator: Amanda J. Hancock

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent form	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I have spoken to Amanda Hancock and she has answered my questions	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }
• at any time		
• without having to give a reason		
• without affecting my professional status		
 I understand that it is my choice to be in the study and that I may not benefit.	Yes { }	No { }
I agree to be audio taped	Yes { }	No { }
I agree to having a professional transcriber listen to this audio tape	Yes { }	No { }
 I agree to take part in this study.	Yes { }	No { }

Signature of participant

Date

Signature of witness (if applicable)

Date

To be signed by the investigator or person obtaining consent

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator/person obtaining consent

Date

Telephone number: _____

Appendix C – Generic Interview Guide

Anonymous HIV Testing in [small urban centre], NL: Are Policies and Practices
Congruent?

Student Name: Amanda Hancock

Interview Guide

- 1) Walk me through a typical HIV testing scenario at (fill in name of organization).

Probes

- let the individual describe a typical HIV testing experience *without* specifying which type of test (nominal, non-nominal, or anonymous)
- 'Who, what, where, how often' of testing

- 2) From your experience, what are the procedural differences that occur at (fill in name of organization) when the test is anonymous?

Probes

- Find out the interviewee's practical application of the characteristics that differentiate the three types of tests
- Determine if he or she knows that PHAC Epi reports state that anonymous testing is available in NL

- 3) What personal information is collected at the time of an anonymous HIV test? (name, fake name, contact information, etc)

- 4) Can you describe the contact, follow-up and counseling procedure for an anonymous HIV test for which the result is negative? Positive?

Probes

- How is news of a positive test delivered?
- How is someone who has had an anonymous test given pre and post-test counseling?

- 5) There are a limited number of places in the city that test for HIV and at each place there are a relatively small number of healthcare practitioners - did you ever have concerns that the identities of individuals who wanted to remain unidentified would become known. If so, how did you handle that?

Probes

- Describe the measures that are taken to safeguard the identities of these individuals.

- 6) Can you describe a situation when an individual came seeking testing but refused to provide any personal information? Or refused to make up a nameless code?

Probes

- Would an individual ever leave without being tested?
- What would you do if this person's test came back positive?

Anonymous HIV Testing in [small urban centre], NL: Are Policies and Practices
Congruent?

Student Name: Amanda Hancock

7) Is there a policy about HIV testing at your organization?

Probes

- If yes
 - How do the procedures you've just described fit with the policies at (fill in name of organization)?
 - If they don't fit, why did you do it?
 - When/how did you learn about this policy?
 - Formally: Orientation, training, etc.
 - Informally: what did co-workers and managers say about this policy, what impression did they give
 - When/how is it introduced to new staff?
 - What are new staff told about anonymous testing?
 - Do they get an orientation or training on HIV testing policy?
 - Do they get an orientation or training on HIV practice?
 - How often do you refer to it?
 - Can you describe a time when you did refer to it?
 - Circumstances
 - Outcomes
 - What format is it in?
 - Were you involved in writing the policy?
 - If not, who was involved? Why?
 - When was it last revised?
 - Were you involved in the latest policy review? Why/why not?
 - Do you have suggestions that could improve the policy?
 - What is the general attitude towards this policy at (fill in name of organization)?
 - In your opinion, is it effective?
- If no
 - Why isn't there a policy for HIV testing?
 - Would having a policy help you do your job better?

8) If you needed anonymous HIV testing, where would you go?

Probes

- Is it possible to get a truly anonymous HIV test in [small urban centre], NL?

9) What does anonymous testing in [small urban centre], NL mean to you?

Probes

- Some say anonymity is lost when one's face is exposed.

Appendix D – Document Trees

Community-based Organization #1
15 documents

Historical Documents
8 documents

Current Documents
7 documents

B1 - STIs and your Relationship

B2 - When and Where to get Tested for
STIs 2005

B3 - No Title, STI Research 2002

B4 - Poster Advertising HIV Testing

B5 - Services and Resources (2007)

B6 - Intake Sheet

B7 - Policies for HIV Testing (2004)

B8 - Clinic Policies and Procedures
(2003)

A1 - Clinic Information

A2 -The 5 W's of STI Testing

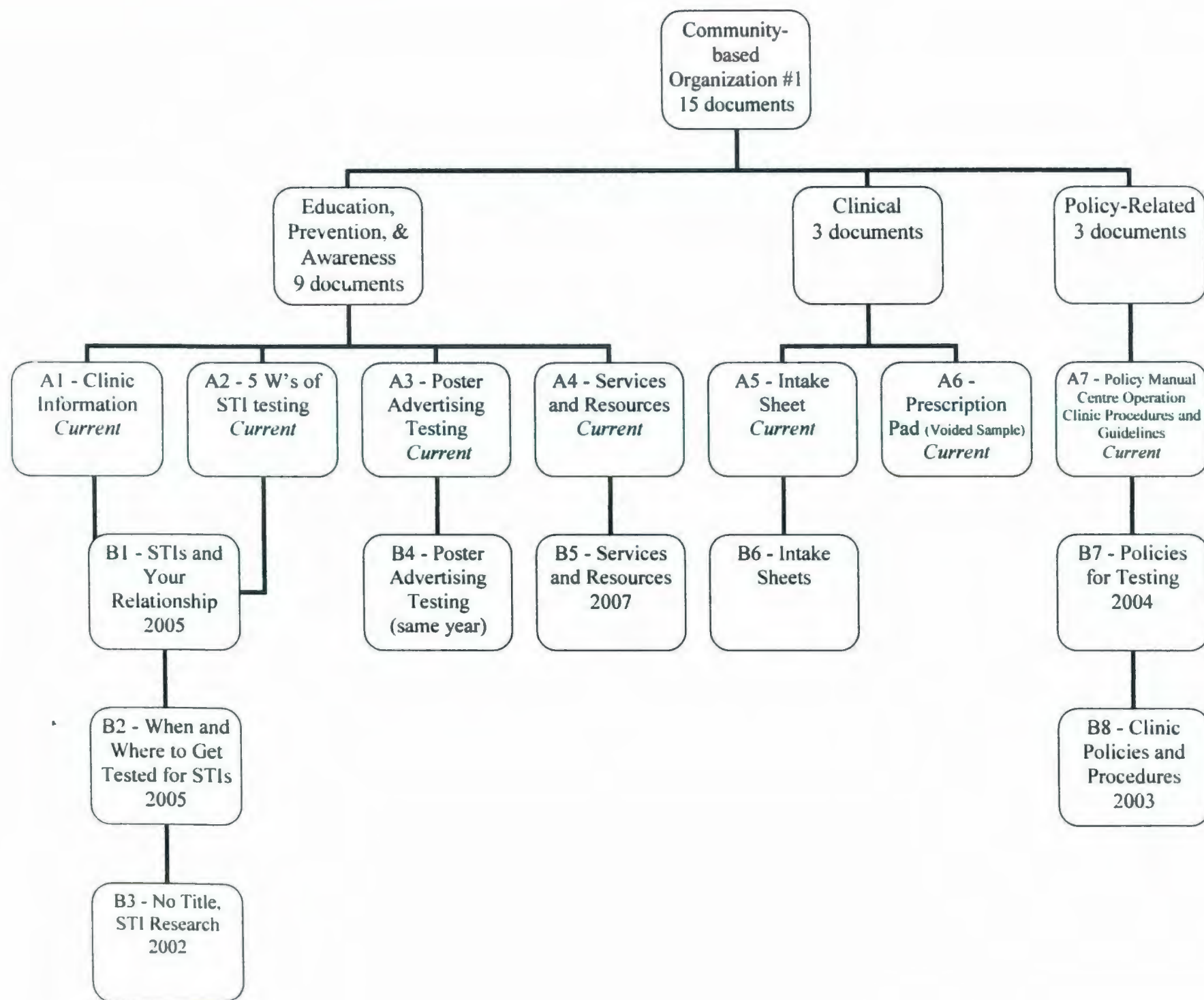
A3 - Poster Advertising HIV Testing

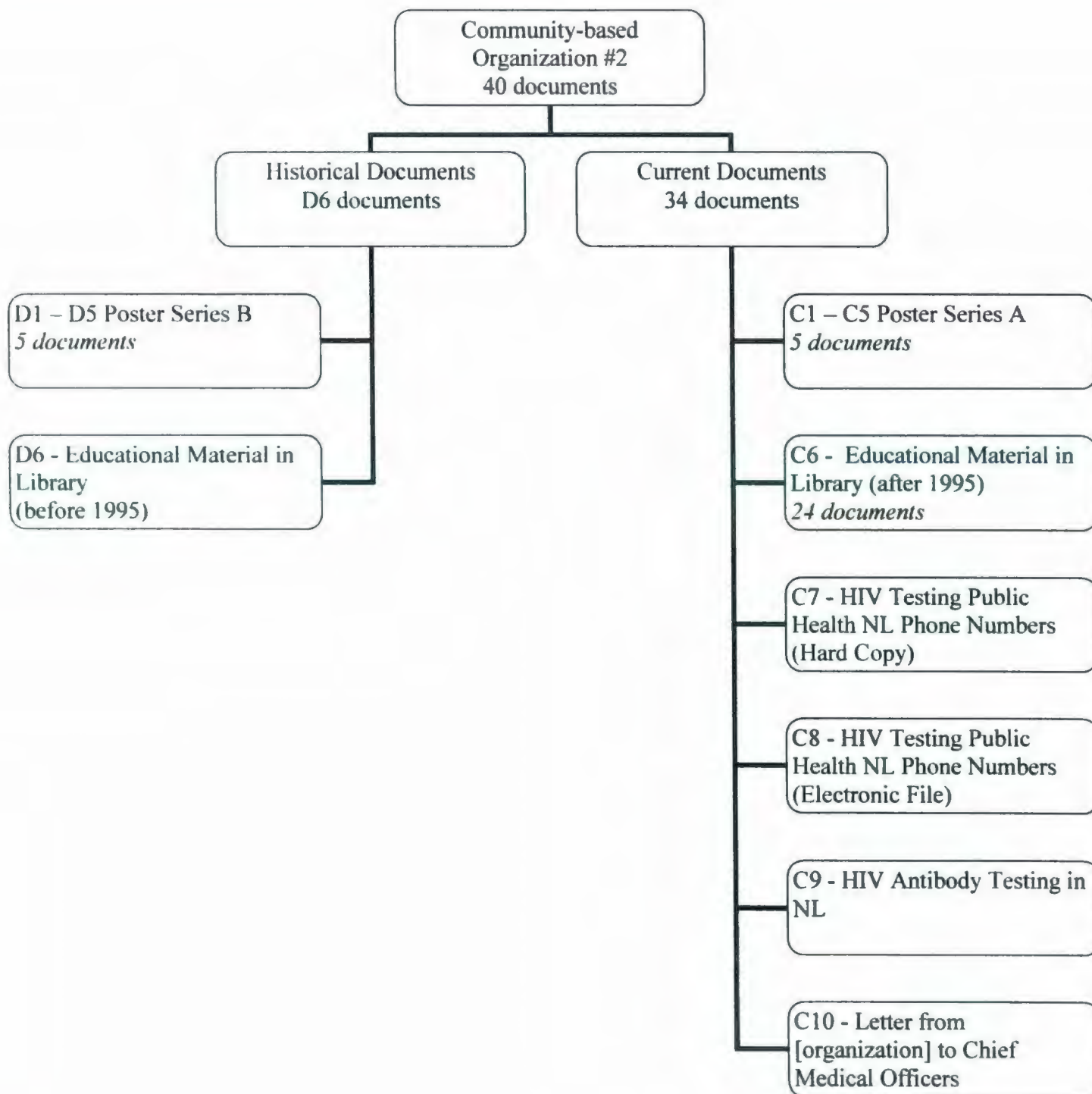
A4 - Services and Resources (2009)

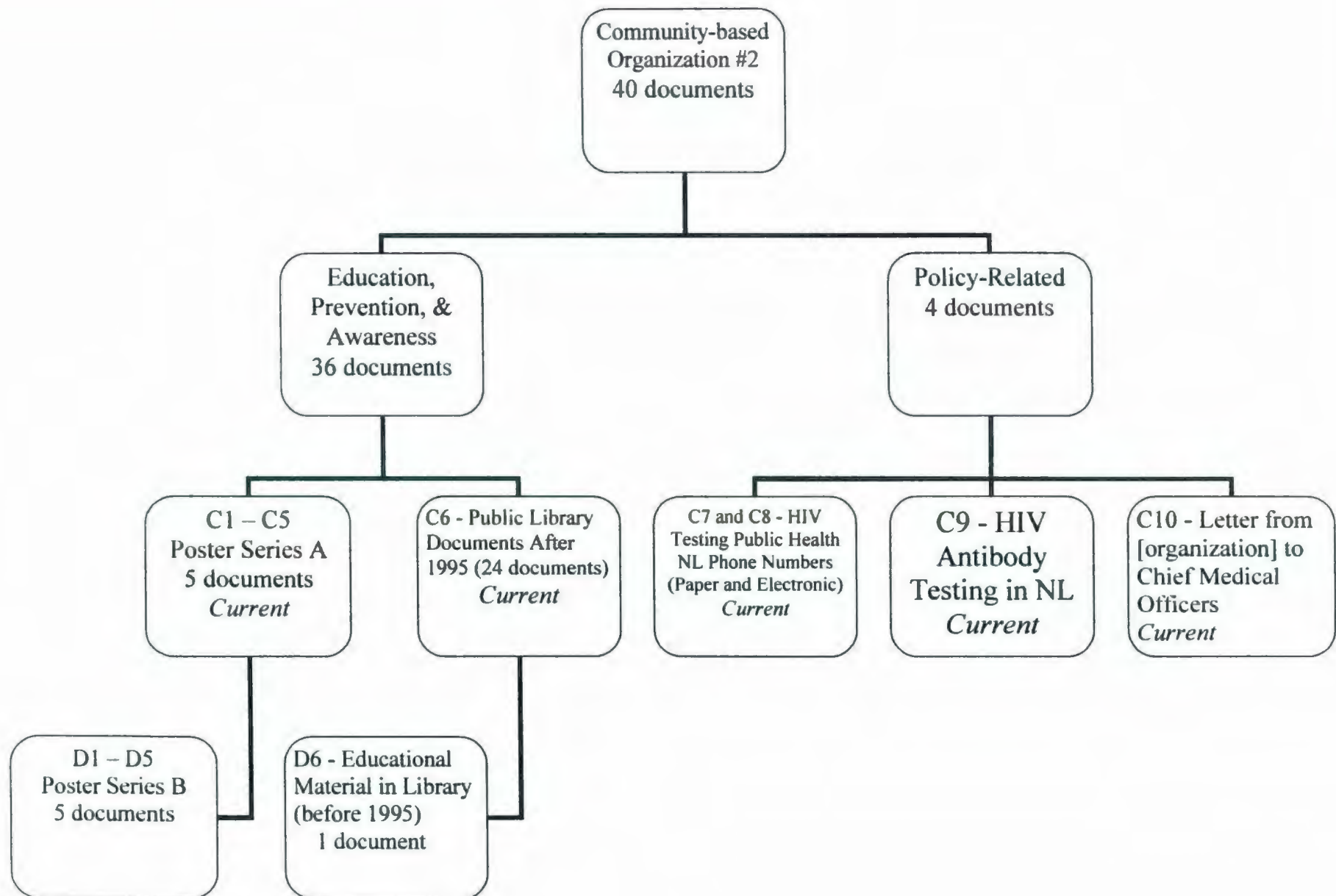
A5 - Intake Sheet

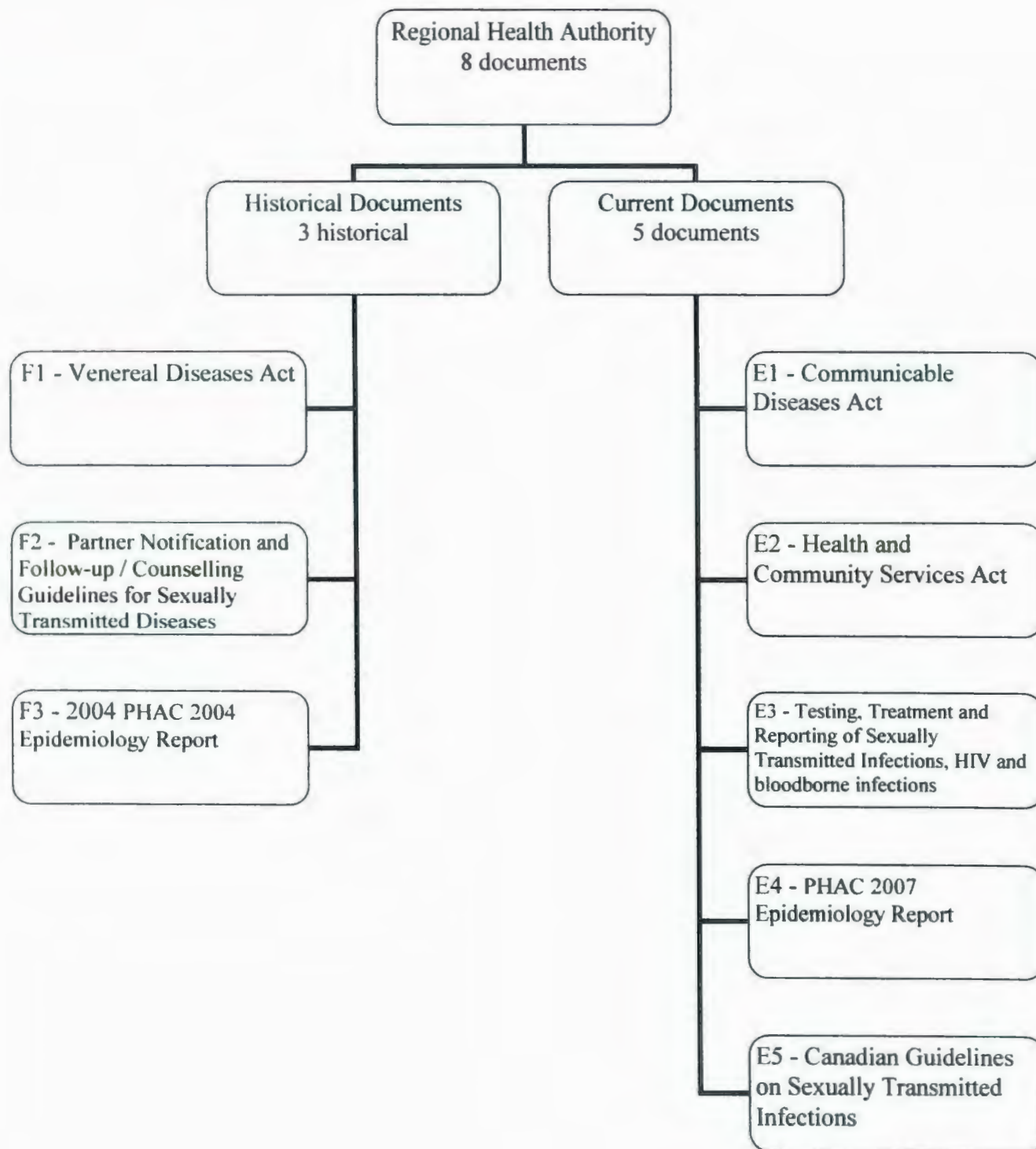
A6 - Prescription Pad (voided sample)

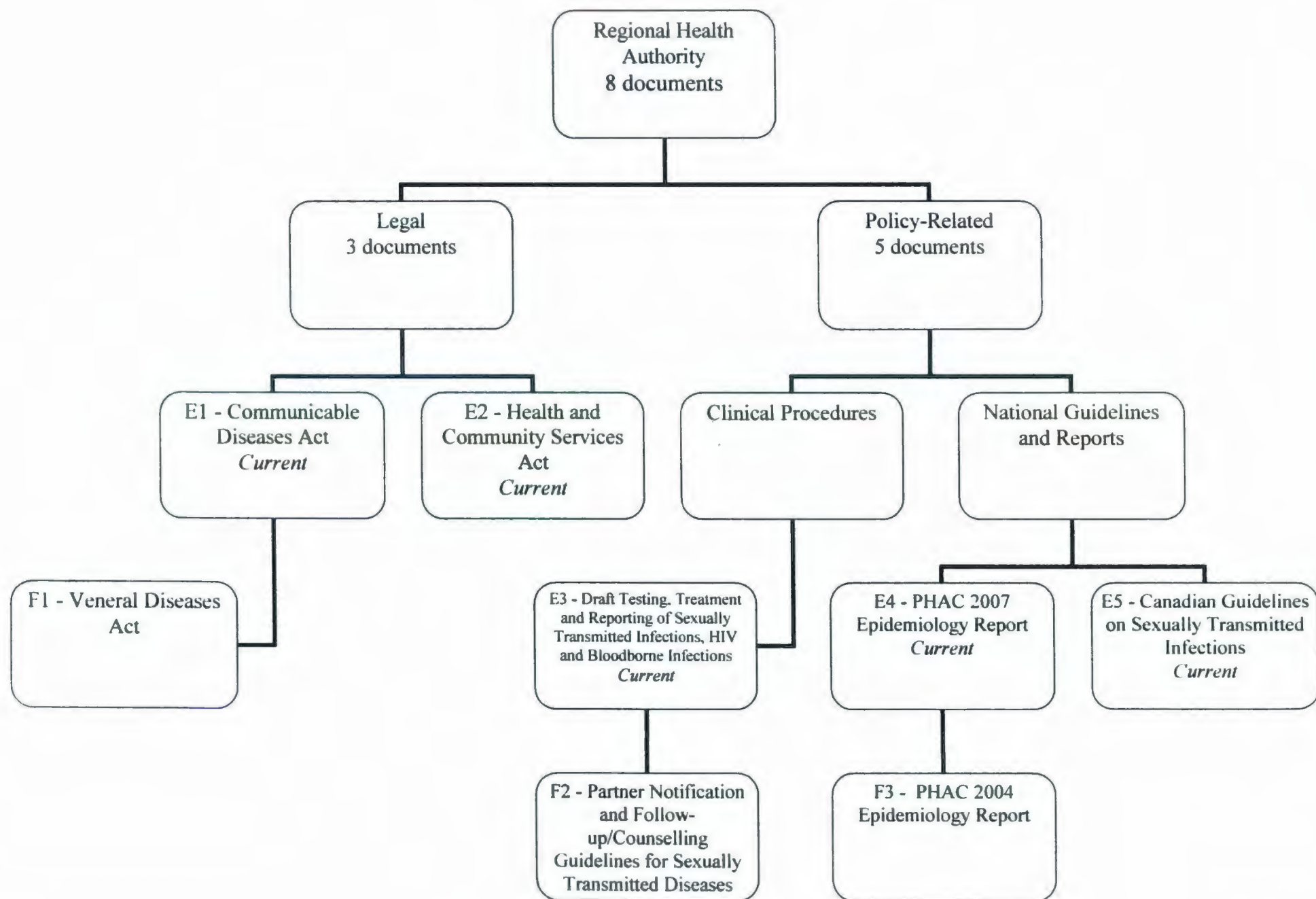
A7 - Policy Manual Centre Operation Clinic
Procedures and Guidelines











Appendix E – Interview Guide Revision

Interview Guide

- 1) Walk me through a typical HIV testing scenario at (fill in name of organization).

Probes

- let the individual describe a typical HIV testing experience *without* specifying which type of test (nominal, non-nominal, or anonymous)
- 'Who, what, where, how often' of testing

- 2) From your experience, what are the procedural differences that occur at (fill in name of organization) when the test is anonymous?

Probes

- Find out the interviewee's practical application of the characteristics that differentiate the three types of tests
- Determine if he or she knows that PHAC Epi reports state that anonymous testing is available in NL

- 3) What personal information is collected at the time of an anonymous HIV test? (name, fake name, contact information, etc)

- 4) Can you describe the contact, follow-up and counseling procedure for an anonymous HIV test for which the result is negative? Positive?

Probes

- How is news of a positive test delivered?
- How is someone who has had an anonymous test given pre and post-test counseling?

- 5) There are a limited number of places in the city that test for HIV and at each place there are a relatively small number of healthcare practitioners - did you ever have concerns that the identities of individuals who wanted to remain unidentified would become known. If so, how did you handle that?

Probes

- Describe the measures that are taken to safeguard the identities of these individuals.

- 6) Can you describe a situation when an individual came seeking testing but refused to provide any personal information? Or refused to make up a nameless code?

Probes

- Would an individual ever leave without being tested?
- What would you do if this person's test came back positive?

Comment [GS1]: Wouldn't this information come from the above question?

Might you say something like how do you go about collecting personal information at the time of an anonymous test?

Comment [GS2]: Wouldn't this question be better placed following question 3?

Anonymous HIV Testing in [small urban centre], NL: Are Policies and Practices
Congruent?

Student Name: Amanda Hancock

7) Is there a policy about HIV testing at your organization?

Probes

- If yes
 - How do the procedures you've just described fit with the policies at (fill in name of organization)?
 - If they don't fit, why did you do it?
 - When/how did you learn about this policy?
 - Formally: Orientation, training, etc.
 - Informally: what did co-workers and managers say about this policy, what impression did they give
 - When/how is it introduced to new staff?
 - What are new staff told about anonymous testing?
 - Do they get an orientation or training on HIV testing policy?
 - Do they get an orientation or training on HIV practice?
 - How often do you refer to it?
 - Can you describe a time when you did refer to it?
 - Circumstances
 - Outcomes
 - What format is it in?
 - Were you involved in writing the policy?
 - If not, who was involved? Why?
 - When was it last revised?
 - Were you involved in the latest policy review? Why/why not?
 - Do you have suggestions that could improve the policy?
 - What is the general attitude towards this policy at (fill in name of organization)?
 - In your opinion, is it effective?
- If no
 - Why isn't there a policy for HIV testing?
 - Would having a policy help you do your job better?

8) If you needed anonymous HIV testing, where would you go?

Probes

- Is it possible to get a truly anonymous HIV test in [small urban centre], NL?

9) What does anonymous testing in [small urban centre], NL mean to you?

Probes

- Some say anonymity is lost when one's face is exposed,

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Comment [GS3]: Asking a why question can be seen to be judgmental. I might say something like

if the procedures didn't fit, walk me through how you made the decision to adjust them?

Comment [GS4]: Another why question perhaps something like

Have there been any discussion about whether having a policy would be desirable?

(OR

Have there been any discussions about whether a policy is needed?

I think you'll get the why with these Without seeming so intrusive

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Appendix F – HIC Ethics Approval

MEMORIAL

January 30, 2009

Reference #08.166

Ms. A. Hancock
34 Quarry Road
Torbay, NL A1K 1A3

Dear Ms. Hancock

RE: Newfoundland and Labrador's anonymous HIV testing policy: Provider knowledge, attitudes and practices

This will acknowledge receipt of your correspondence, dated January 29, 2009

This correspondence has been reviewed by the co-chair under the direction of the Committee **Full approval** of this research study has been granted for one year effective November 6, 2008.

This is to confirm that the Human Investigation Committee reviewed and approved or acknowledged the following documents (as indicated):

- *Revised consent form, approved*
- *Interview guide, approved*

This approval will lapse on **November 6, 2009**. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HIC office prior to the renewal date. *The information provided in this form must be current to the time of submission and submitted to HIC not less than 30 nor more than 45 days of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HIC website <http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc>

The Human Investigation Committee advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:

- *Your ethics approval will lapse*
- *You will be required to stop research activity immediately*
- *You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again*

Lapse in ethics approval may result in interruption or termination of funding

For a hospital-based study, it is your responsibility to seek the necessary approval from Eastern Health and/or other hospital boards as appropriate.

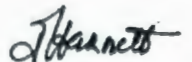
Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.

This research ethics board (the HIC) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as per these guidelines.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Fern Brunger, PhD
Co-Chair
Human Investigation Committee

C C Dr. C. Loomis, c/o Office of Research, MUN
Mr. W. Miller, c/o Patient Research Centre, Eastern Health
HIC meeting date: February 5, 2009

Appendix G – RPAC Application and Approval



Eastern Health

Process for Review and Approval of Clinical Research to be conducted within Eastern Health (city hospitals)

In keeping with the commitment to review and to approve research projects in a timely and efficient manner, we have a two step research approval process.

1. All projects to be conducted within this institution are required to have review and full approval of the Human Investigations Committee. This is a joint committee of Eastern Health and The Faculty of Medicine, MUN. Applications should be completed and forwarded to The Office of Research and Graduate Studies, Faculty of Medicine, Level I, HSC. Information on the Human investigations Committee application form and process are available from web site <http://www.med.mun.ca/hic/default.htm>
2. Once full approval has been granted by HIC, application for research to be conducted within our institution, must be made to the Research Proposal Approval Committee (RPAC). The primary mandate of this committee is to review resource utilization, impact to the organization and access to confidential information for any project to be conducted within the institution. In addition we catalogue all research activities within the institution. Review by RPAC requires submission of a short form, which provides a brief explanation of the project, associated costs and sources of funding. Applications are available at <http://www.med.mun.ca/prc/>
3. All projects are reviewed and approved by the appropriate Program Clinical Chair or Director before receiving final full approval from RPAC.
 - ♦ The committee meets monthly.
 - ♦ It is the responsibility of the Principal Investigator of research project to insure appropriate institutional and departmental approvals are in place prior to undertaking any research project

Two copies of this application form are required

1. Completed and signed RPAC Applications are to be sent to:

Donna Bruce RN
Manager Patient Research Centre
Room 1406, Level I, HSC
300 Prince Philip Drive
St. John's, NL, A1B 3V6

- ♦ Or can be faxed 709-777-6995

2. An electronic copy forwarded to Donna.Bruce@easternhealth.ca

Questions can be directed to Patient Research Centre at Phone 709-777-7283



Eastern Health

RESOURCE ALLOCATION REQUEST FOR CLINICAL RESEARCH PROPOSALS

To complete this application you will need:

1. A copy of your spending budget
2. A copy of any applicable Departmental Agreements
3. An electronic copy of this application is to be sent to Donna.Bruce@easternhealth.ca
4. HIC approvals are automatically forwarded to the Patient Research Centre

- **HIC Reference Number: #08.166**
- **Protocol Title: N/A**
- **Title of Study: Anonymous HIV Testing in [small urban centre], NL: Are Policies and Practices Congruent?**

Brief Description

Across Canada, HIV testing policies have evolved differently in each province since testing became available in the 80's. It is important to engage in regionally-specific research to fine out if NL's HIV testing policies are effective. The Public Health Agency of Canada's Epidemiology Report (2007) suggests that in Newfoundland and Labrador, "if someone tests positive for HIV through anonymous HIV testing, that individual then becomes part of the nominal/name-based system, in which counseling, follow-up care, and HIV data reporting are all done nominally" (p. 15). In other words, the names of individuals who test positive for HIV could eventually be disclosed. To date, there has been no attempt to determine if and how this anonymous HIV testing policy is followed in practice. Examining the policies of three settings that offer HIV testing in [small urban centre] and asking the persons involved in providing that service will inform academics, policy, and decision-makers for future policy debates on the matter. The findings will not attempt to solve, rather shed light on, issues of public health ethics and privacy.

Study objectives

1. To review the HIV testing policies in the three settings (four organizations) that offer voluntary HIV testing in [small urban centre], NL.

Setting	Organization
---------	--------------

1) Institutional	i. St. Claire's
2) Public Health	ii. Eastern Health Public Health Clinic(s)
3) Community	iii. NL Sexual Health Centre – Planned Parenthood iv. AIDS Committee of NL (ACNL)

2. To determine policy guidelines by performing a document review. Specifically, how is anonymity maintained if anonymous testing is offered?
3. To examine everyday HIV testing practices by speaking with the healthcare providers who have been or are presently involved in administering HIV testing and/or counseling.
4. To evaluate and interpret the congruence between established policy and everyday practices.
5. To address the policy challenges associated with offering anonymous testing in [small urban centre], NL.

Pharmacy

1. Does this proposal involve the use of medication (including placebos) other than those normally used for patients? Medications (Active or Placebo) will be dispensed by the Hospital Pharmacy?

YES () NO (x)

(A) If yes, Please specify

(B) Has this project been submitted to pharmacy for review

YES () NO (x)

Tests and Procedures

2. Does the proposal involve local laboratory tests, x-rays or other imaging techniques other than required for normal patient care? (If yes, attach a copy of your Departmental Agreement)

YES () NO (x)

Will samples be sent to Central Laboratory

YES () NO (x)

Does this project request use of archived biological samples

YES () NO (x)

Health Records or IMAT?

3. Does this project require access to Health Records or IMAT?

YES () NO (x)

If yes .. How many records _____

Paper

YES () NO (x)

Electronic

YES () NO (x)

When do you plan to do this review from _____ to _____

Other Hospital Supports

4. Does the proposal require assistance of nurses or hospital staff other than the research personnel

YES (x) NO ()

If yes, please describe

This study will be completed in two stages: a document review and key informant interviews. The document review of each organization's HIV testing policy must be completed before the key informant interviews. I do not anticipate needing the assistance of any staff other than the research personnel to complete the first stage (the document review), but I will not rule it out because it may be required for clarification depending on how developed the policy documents are. The purpose of the second stage is to find out about everyday practice issues of HIV testing; therefore, I will need the assistance of healthcare providers who have been or are presently involved in administering HIV testing and/or counselling or responding to public inquiries about the same. This assistance will be required at a later date at which time I will request key informant interviews with a maximum of 12 key informants: three from each of the aforementioned organizations (see 'Study Objectives').

5. Does the proposal involve admission of subjects to the hospital or the clinical investigation unit?

YES () NO (x)

Please describe _____

The approval of this proposal is contingent upon

- ◆ Adequate funding being available to support the project
- ◆ The researcher providing upon request an update on the progress of the research.

**Your signature on this form gives approval to list your project in our annual report.
For contracts please check any contractual limitations related to publishing the title**

SIGNED: _____
Principal Investigator

_____ Date

Program Clinical Chief/ Director

_____ Date

Version : June 08/06



**Eastern
Health**

**Department of Research
Corporate Strategy & Research
Rutter Building, 22 Pearl Place
P.O. Box 13122
St. John's, NL A1B 1A3
Tel: (709) 752-1636
Fax: (709) 752-1733**

April 14, 2009

Ms. Amanda Hancock
34 Quarry Rd
Torbay, NL
A1K 1A3

Dear Ms. Hancock :

Your research proposal HIC # 08.166 – "Anonymous HIV testing in [REDACTED] NL: Are policies and practices congruent?" was reviewed by the Research Proposals Approval Committee (RPAC) of Eastern Health at its meeting on April 14, 2009 and we are pleased to inform you that the proposal has been approved.

The approval of this project is subject to the following conditions:

- The project is conducted as outlined in the HIC approved protocol;
- Adequate funding is secured to support the project;
- In the case of Health Records, efforts will be made to accommodate requests based upon available resources. If you require access to records that cannot be accommodated, then additional fees may be levied to cover the cost;
- A progress report being provided upon request.

If you have any questions or comments, please contact Donna Bruce, Manager of the Patient Research Centre at 777-7283.

Sincerely,

Mike Doyle, PhD
Director of Research
Corporate Strategy & Research
Chair, RPAC

cc: Ms. Donna Bruce, Manager Patient Research Centre



