TIMELINESS OF DIAGNOSIS OF HIV:
A QUANTITATIVE AND QUALITATIVE STUDY

by © Sarah Elizabeth Boyd, BSc

A thesis submitted to the

School of Graduate Studies

In partial fulfillment of the requirements for the degree of

Master of Science in Medicine

Clinical Epidemiology

Memorial University of Newfoundland

October 2017

St. John's Newfoundland and Labrador

Abstract

Introduction: A CD4 count <200 at diagnosis results in negative health outcomes and suggests delays in HIV testing.

Objectives: To describe the timeliness of HIV diagnosis in Newfoundland and Labrador (NL) and explore the reasons for delay.

Methods: Demographic and clinical information from new HIV diagnoses in NL between 2006-2016 were collected (n=58). Subjects were invited to interviews regarding testing barriers.

Results: At diagnosis the mean age was 40.6, 53/58 (91.4%) were male, 33/58 (56.9%) were men who have sex with men, and 21/58 (36.2%) had a CD4 count <200. For 39/58 (67.2%), their first test was positive, though 55/58 (94.8%) had previous healthcare contact. Heterosexuals were more likely to present late (p=0.049). Barriers to testing were negative healthcare interactions, stigma, being unaware of their risk, and fear of the diagnosis.

Conclusions: We defined missed opportunities for testing. Heterosexual men are more likely to test late. Late diagnosis may be prevented if testing is normalized.

Acknowledgements

First of all I would like to thank my supervisor Dr. Peter Daley for his support and encouragement. Dr. Daley pushed me to work hard while still helping me however he could.

I would also like to thank Dr. Jill Allison for being a great mentor for qualitative research, coding themes and helping edit this thesis.

Next I would like to thank my other committee members Dr. Brendan Barrett and Dr. Kathy Hodgkinson for helping edit this thesis.

Thank you to Carla Penney for coding the interviews and helping however she could.

Thank you Kim Burt for contacting the patients and helping out with the study however she could.

Thank you Dr. Zhiwei Gao for help with the quantitative data analysis.

Thank you to everyone on the research team who helped in any way or simply encouraged me throughout the whole process. Thank you David, Lucy, Laura and Amanda.

Thank you to my family and friends for their unwavering support.

Finally, thank you Chris for your unwavering support and encouragement in everything that I do.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

AIC – AIDS-Indicator Condition

AIDS – Acquired Immune Deficiency Syndrome

CD4 - Cluster of Differentiation 4

CDC – Center for Disease Control

ER – Emergency Room

HCP – Healthcare Provider

HIV – Human Immunodeficiency Virus

IVDU - Intravenous Drug Use

MSM – Men Who Have Sex with Men

NL – Newfoundland and Labrador

PCP - Pneumocystis Pneumonia

PHAC – The Public Health Agency of Canada

POC – Point of Care

STI – Sexually Transmitted Infection

List of Appendices

1.0 – Introduction

1.1 – The Problem with a Late HIV Diagnosis

According to the Public Health Agency of Canada, as of 2014 there are 75,500 people living in Canada that are HIV-positive. Of these, it is estimated that 21% are not aware of their HIV status [1]. HIV results in the destruction of CD4+ T lymphocytes which are crucial to the normal function of the human immune system. A CD4 count is used to measure how many of these lymphocyte cells are remaining and thus indicate impaired immune function [2]. Early diagnosis and entry into care are essential for positive outcomes. A late diagnosis is associated with a lower CD4 count and thus a higher rate of opportunistic infections, lower quality of life [3] and higher mortality rate [3][4]. In particular, a low CD4 count is associated with a higher mortality due to AIDS, infection, non-AIDS malignancy and renal failure among other causes of death [5]. The Association of Medical Microbiology and Infectious Diseases Canada recommends initiating antiretroviral treatment at HIV diagnosis, regardless of CD4 count [6]. Treatment should be started as soon as an individual reaches a CD4 count <350 cells/mm^3, if possible, to avoid the previously mentioned negative outcomes [7]. Initiating antiretroviral treatment with a low CD4 count also carries an increased risk of treatment failure [8]. Furthermore, a late diagnosis increases the risk of HIV being transmitted unknowingly. It is estimated that an early diagnosis decreases the lifetime transmission rate by almost 50% [3]. In a meta-analysis by Marks et al., it was shown that unprotected anal or vaginal sex decreased by 68% in persons aware they were HIV-positive compared to those who were not aware they were HIV-positive, when their partners were HIV-negative [9], meaning that awareness of HIV diagnosis may change risk factors for transmission. A late diagnosis also has a high economic

impact. In Alberta, it was determined that people presenting with CD4 counts of <350 cells/mm^3 had significantly higher costs during the first year of accessing care and medical costs remained almost twice as high in subsequent years [10].

1.2 – Normalizing Testing

In the Public Health Agency of Canada's (PHAC) guidelines for HIV testing, it states "It is recommended that the consideration and discussion of HIV testing be made a component of periodic routine medical care**.** This recommendation is based upon the current body of good quality evidence demonstrating the individual and public health benefits associated with normalising HIV testing"[11]. The PHAC guidelines also state that testing should be discussed by *all* care providers involved in HIV testing including primary care providers, nurses, counsellors, social workers, community health workers, midwives and community-based service providers. PHAC lists those who they recommend should be offered HIV testing which includes anyone sexually active who has never been tested before, anyone who had unprotected sex, and anyone asking for a test, among many other individuals [11]. It is recommended that individuals involved in high risk practices should be screened for HIV at least annually, while frequency for all populations should be decided on by the health care provider based on the individual's sexual history, the prevalence of HIV in the individual's demographic group and the prevalence of HIV in the geographical area [11]. Normalising HIV testing and making it a part of routine testing will reduce the prevalence of late diagnosis (LD) of HIV. In Canada, opt-out testing (testing which is included automatically as a routine test in which the individual has the right to refuse) is confined to prenatal screening and only in some provinces [12]. Opt-out testing has been shown to increase testing uptake. In Scotland, for example, routine opt-out HIV testing in genitourinary

medicine clinics was introduced in 2005 whereby all patients were offered an HIV test. This resulted in a significant ($p<0.001$) increase in HIV testing [13]. Furthermore, in an HIV testing campaign in London called "TestMeEast", HIV testing was offered to individuals having a routine blood test with 2402 (55.6%) of individuals getting tested [14]. This resulted in three new HIV diagnoses. The campaign used the hashtag #TestMeEast on twitter which reached 238,860 people [14]. In a 2014/2015 Australian point of care HIV campaign called "RAPID", 1,199 people received a free HIV test, 17.1% of which were first-time testers [15]. All of these efforts may have helped to normalize HIV testing and resulted in an increased uptake in HIV testing.

1.3 – Definition of Late HIV Diagnosis

The definition of a late HIV diagnosis has changed over time and still there is no consensus worldwide [4][10]. In Europe, a late presentation was defined as a CD4 count <350 cells/mm^3 or an AIDS-defining event, and advanced HIV was defined as a CD4 count <200 cells/mm^3 or an AIDS-defining event [16]. AIDS-defining events are illnesses listed by the Center for Disease Control (CDC) that are associated with severely immunocompromised individuals (Eg. Cytomegalovirus, Kaposi sarcoma, Lymphoma, *Pneumocystis jirovecii* pneumonia, etc.) [17]. Another study in China elaborated on this definition to include that the individuals must have met the <350 cells/mm^3 or <200 cells/mm^3 criteria within one month of HIV diagnosis, which would include those who are delayed in acquiring CD4 testing after HIV diagnosis [4]. Even with these two consensus definitions being suggested, many articles still use terms like "late diagnosis", "delayed diagnosis" and "late presentation" interchangeably, with various CD4 criteria.

1.4 – Late Diagnosis Prevalence

It is difficult to compare the prevalence of late HIV diagnosis in other provinces due to variations in definition, years, and data available. Table 1.1 summarizes information regarding late diagnosis of HIV in five previous surveillance reports. From these reports, the prevalence of late HIV diagnosis ranged from 8.8% in five provinces to 30% in Manitoba[18]–[22].

Table 1.1: The Prevalence of late diagnosi of HIV in Other Canadian Provinces

	Definition of LD	Year	Prevalence of LD
British Columbia [18]	AIDS diagnosis before or up to 12 months after the date of the first positive HIV test, or CD4 count <200 cells/mm^3	2010-2014	26.6%
Manitoba [19]	<200 cells/mm^3 when entering care	2015	30%
Nova Scotia [22]	Initial CD4 count of <200 cells/mm^3 within 6 months of HIV diagnosis	2001-2010	24.7%
Ontario [20]	CD4 count <200 cells/mm^3 at diagnosis	1997-2009	29%
Nationwide* [21]	CD4 count of <200 cells/mm^3 or presence of an opportunistic illness within 3 months of diagnosis.	2010	8.8%

* Data from five provinces in which AIDS cases were reported systematically and consistently. May not be nationally representative.

1.5 – Demographic Factors as a Predictor for Late Diagnosis

Demographic factors have also been suggested to predict whether an individual that is HIV-positive will present with an early or late diagnosis. In Nova Scotia, older age was the only demographic factor that significantly predicted a late diagnosis [22]. In British Columbia, heterosexual individuals were more likely to have a late diagnosis compared to men who have sex with men (MSM) [18].

In a study involving 34 European countries from 2010-2013, late presentation (defined as a CD4 count of <350 cells/mm^3 or an AIDS-defining event) occurred in 62.4% of heterosexual men, 52.2% of heterosexual women and 39.0% of MSM, suggesting heterosexual men may be less likely to get tested for HIV than MSM. The median age of individuals that were late presenters was 39 years (IQR=31-48) compared to 36 years (IQR=29-45) for all HIV diagnoses. [23].

In a comprehensive inter-country comparison, Hall et al. described patient demographics associated with a late diagnosis from surveillance reports in Australia, Canada, France, Italy and the United States in 2009 and 2010 [21]. A late diagnosis was defined as an AIDS diagnosis within 3 months of HIV diagnosis. Table 1.2 summarizes the prevalence of a late diagnosis in various demographic groups. In the majority of countries, older age, heterosexuality and IVDU were all predictors of a late HIV diagnosis. Canada has the lowest prevalence of late diagnosis, and the United States has the highest prevalence of late diagnosis.

Table 1.2: The prevalence of late diagnosis in various demographic groups in five countries

	Age	Sex	Transmission Category
Australia	0-9: 0.0% 10-19: 6.3% 20-29: 9.0% 30-39: 17.1% 40-49: 24.1% 50+: 32.3%	Male: 18.4% Female: 21.3% Transgender: 20.0%	MSM: 13.3% IVDU: 26.1% MSM-IVDU: 27.3% Heterosexual: 29.5%
Canada	0-9: 0.0% 10-19: 0.0% 20-29: 2.6% 30-39: 6.8% 40-49: 13.8% 50+: 13.7%	Male: 9.5% Female: 5.9% Transgender: No data	MSM: 7.4% IVDU: 8.7% MSM-IVDU: 7.7% Heterosexual: 8.7%
France	0-9: 17.1% 10-19: 6.8% 20-29: 7.6% 30-39: 13.1% 40-49: 18.4% 50+: 26.3%	Male: 16.5% Female: 12.8% Transgender: No data	MSM: 11.8% IVDU: 27.0% MSM-IVDU: -- Heterosexual: 17.4%
Italy	0-9: 0.0% 10-19: 2.9% 20-29: 6.9% 30-39: 11.5% 40-49: 17.5% 50+: 25.9%	Male: 14.3% Female: 15.3% Transgender: 0.0%	MSM: 11.5% IVDU: 16.1% MSM-IVDU: -- Heterosexual: 18.1%
United States	0-9: 7.3% 10-19: 12.8% 20-29: 16.8% 30-39: 29.9% 40-49: 37.3% 50+: 42.1%	Male: 29.1% Female: 27.4% Transgender: No data	MSM: 26.7% IVDU: 39.1% MSM-IVDU: 28.0% Heterosexual: 30.4%

1.6 – Missed Opportunities to Test for HIV

Numerous studies worldwide suggest that health care workers miss opportunities to test for HIV, thus resulting in a later diagnosis. In a British study involving 1,112 HIV-positive patients, 25.2% were found to have visited a health care provider (HCP) with an HIV-indicator condition, but had not been tested [24]. In another study in Spain, 99,426 patients were diagnosed with a total of 102,647 HIV-indicator conditions, of which only 18.5% of cases were tested for HIV within 4 months [25]. In Denmark, out of a cohort of 1,051 HIV-positive individuals diagnosed with a CD4 count <200 cells/mm^3, 40.0% had attended a hospital 1-3 years prior to diagnosis [26]. In New York, in a cohort of 253 patients diagnosed with HIV, 60.1% had accessed the health care system within 3 years prior to diagnosis indicating potential missed opportunities for an earlier diagnosis [27]. Major reasons for missed opportunities by healthcare workers included fear of making their patient feel uncomfortable [28]–[32], time and financial constraints [21][22][24][25] and inadequate HIV training and education [30]–[33].

1.7 – Barriers to HIV Testing

There are also numerous barriers to HIV testing that have been observed in previous Canadian studies. In a nationwide study involving young Aboriginals, the main reasons for not getting tested for HIV were the perception of not being at risk, perception that they had not been exposed to HIV, not experiencing any symptoms, their HCP not recommending testing, and not wanting to know their HIV status [34]. In a study on transgender people in Ontario, the main reasons to not get tested for HIV were the fear of a positive result, difficulty accessing

healthcare, their HCP believing they are low risk and having low knowledge about HIV, and various issues relating to being transgender [35].

In a study in Ottawa, attitudes towards HIV regarding HIV-serostatus disclosure, nondisclosure prosecutions and public health were examined in the MSM population. Both HIV-positive and HIV-negative individuals were interviewed. The men reported a stigma associated with being HIV-positive and concern about the legality and confidentiality of disclosure of HIV status [36]. These may also be barriers that would prevent MSM from getting tested for HIV. A British Columbia study involving MSM found that 35% of individuals had not told their HCP that they were homosexual and thus they may have been perceived as being lower risk for HIV and therefore not offered a test [37].

In a comprehensive review of studies involving barriers to HIV testing in Canada, the United Kingdom and Australia from 2003-2013, barriers were described at the intrapersonal level, interpersonal level, and extra-personal level [38]. Barriers in the intrapersonal level included fear of a positive diagnosis, internalized stigma about HIV, low perception of risk, low awareness of public services and poor knowledge of HIV. At the interpersonal level, barriers included not being offered a test by a HCP, negative experiences with HCPs, stigma of testing and HIV, fear of confidentiality breaches, fear of a HIV diagnosis affecting employment and insurance, and nondisclosure of sexual orientation to a HCP thus being perceived at low risk. At the extra-personal level, barriers to testing included policies surrounding HIV testing, accessibility of testing, the need to return for results, and laws surrounding sex workers and intravenous drug users discouraging them from getting tested [38]. The barriers that were mentioned in at least two of these studies were the perception of not being at risk for contracting

HIV, a HCP not recommending testing, fear of a positive HIV diagnosis and the stigma associated with HIV.

1.8 - HIV Testing in Newfoundland and Labrador

In NL HIV testing is offered nominally (the test includes the individuals name), non-nominally (the HCP knows the patient but the test is ordered using a code or the initials of the person being tested) and anonymously (the HCP does not know the name of the individual) [39]. However, if an individual tests positive for HIV through anonymous testing, follow-up care and HIV data reporting are all done nominally. While anonymous testing is available upon request, it is not part of the official guidelines for the province [39]. HIV testing in NL requires a blood test but there is an ongoing study currently offering point of care finger prick HIV screening in two locations in the province until July 2017 [40].

1.9 – Study Objectives

The main objectives of this study were:

1. To investigate the prevalence of delayed HIV diagnosis in Newfoundland and Labrador

2. To determine demographic factors associated with a delayed diagnosis

3. To determine if there are missed opportunities for diagnosis

4. To examine potential barriers to HIV testing

The secondary objective of this study was:

1. To determine how provincial/national HIV testing policy might be modified to reduce late diagnosis.

While previous research has been done on these study objectives, there is little research in Canada and none in Newfoundland and Labrador.

The role of Sarah Boyd was data collection, analysis, and primary author of this thesis.

2.0 - Methods

This study was conducted in two parts. In part 1, a quantitative study was performed using a retrospective chart review. In part 2, a qualitative study was conducted using semi-structured interviews with persons living with HIV.

2.1 – Ethics Statement

Ethics approval was given by the Health Research Ethics Board (HREB) of Newfoundland and Labrador for both parts of the study (Approved 18/08/2016, reference HREB 2016.181). The Research Proposals Approval Committee of Eastern Health also approved the study.

Informed Consent was not obtained for the retrospective chart review, but was obtained prior to conducting interviews. For the qualitative study, a nurse from the St. John's HIV clinic contacted potential participants and if they agreed to an interview, the names and phone numbers were then given to the research team. The voice recordings of the interviews were deleted after transcription and the transcribed interviews were stored on a password protected, encrypted hard drive. Consent forms, case report forms, and all other study material were stored in a locked file in Dr. Peter Daley's office. Names were removed from transcripts and a numerical code was created and stored in a different file to ensure confidentiality.

2.2 - Quantitative Study

2.2.1 – Study Design

The quantitative portion of the current study involved a retrospective chart review of individuals aged 18 years and older that were diagnosed with HIV in Newfoundland and Labrador (NL) between January 2006 and June 2016. A list of all individuals diagnosed HIV-positive in NL in this timeframe was received from the HIV Clinic in St. John's. Even if an individual had never been to the clinic, their name was still included on this list as the names of all individuals diagnosed with HIV in NL are sent to the clinic by the CDC. Individuals were then screened for eligibility. Patient information was acquired from paper charts and an electronic medical file by a research student. When individuals were first seen at the HIV clinic, the nurse would ask many questions regarding their risk factors and symptoms which would be uploaded to their electronic medical file. This was the main source of data for this study. If this history could not be found in the electronic file, other sections of the file were searched for relevant information, paper charts were searched and any remaining questions were asked to the nurse in person. Most of the information was readily available through the electronic charts.

2.2.2 – Main Outcome

The main outcome for the quantitative portion of the study was the CD4 count at diagnosis to determine if any demographic factors or other variables could predict late HIV diagnosis.

2.2.3 – Variables Collected

Demographic information such as age at diagnosis, gender, residence and employment were collected as well as risk factor information such as sexual orientation, intravenous drug use, maternal to child transmission, intravenous drug use, and whether an individual originated from an HIV-endemic country. Furthermore, the following information regarding HIV testing was collected: number of previous HIV tests, the date of last HIV test, date of positive test, who initiated testing, where the test was performed and CD4 count at diagnosis. The following disease information was collected: other STIs, AIDS-indicator conditions and symptoms experienced at diagnosis. Information regarding previous healthcare contact was recorded including the number of clinic visits, emergency room (ER) visits and hospital admissions within five years prior to HIV diagnosis. The number of visits with a patient's family doctor was unavailable. Finally, smoking status, alcohol use and drug use were recorded.

2.2.4 – Data Analysis

All data was entered into SPSS Version 22 and a statistical analysis was performed. As the distribution of CD4 at diagnosis (see Figure 1) was not normal, nonparametric tests were used to compare the mean CD4 count of different variable categories to determine if certain demographics or characteristics were associated with a later diagnosis. A Mann-Whitney U test was used for variables with two categories and a Kruskal-Wallis test was used for variables with three or more categories. Mean CD4 count with standard deviation was also determined for each variable.

2.3 – Qualitative Study

2.3.1 – Study Design

All individuals who met inclusion criteria for the quantitative study were invited to participate in semi-structured interviews regarding HIV testing. The nurse at the HIV clinic contacted each patient to determine if they were interested in participating in an interview. A list of individuals who were interested was given to the research assistant who then called the patients to further discuss the study and set-up interview times if they were still interested. All interviews took place between November 2016 and January 2017. Interviews were conducted via telephone or in person and informed consent was obtained prior to the commencement of interviews. Interviews were recorded, transcribed and coded for important issues and themes regarding HIV in NL.

2.3.2 – Main Outcome

The main outcome for the qualitative portion of the study was factors influencing HIV testing. Secondary outcomes included all other information regarding HIV testing and living with HIV.

2.3.3 – Variables Collected

The questions were open-ended and invited a narrative response. Participants were asked the following questions specifically: whether the individual thought they were at risk for acquiring HIV, if they knew the risk factors for HIV prior to their diagnosis, what led them to decide to get tested, whether they requested testing or if their doctor suggested it, information they were given about HIV before and after their positive diagnosis, barriers to HIV testing, how their life has changed since their diagnosis and other information regarding testing in their community. The interview guide can be found in appendix D.

2.3.4 - Data Analysis

Validity was ensured through inter-rater coder agreement, member checking and qualitative data software analysis. Three different people on the research team independently read through the interview transcripts after names were removed and identified key themes from the data. These themes were compared for consistency between the three researchers. The qualitative analysis software NVivo was also used to ensure no important themes were missed by scanning the text for keywords and sorting coded information for further thematic analysis. When final themes had been developed and agreed upon by the researchers, two individuals who participated in the interviews were shown their transcribed interview with themes and asked if they agreed with the researchers' analysis.

3.0 - Results

3.1 - Quantitative Study

A total of 66 individuals were diagnosed with HIV in NL between January 2006 and June 2016. After reviewing their medical charts, it was found that 8 had been previously diagnosed HIV-positive outside the province and were therefore excluded from the study. Of the 58 people diagnosed with HIV, 21 (36.2%) were diagnosed with a CD4 count < 200 cells/mm^3 and thus had a late diagnosis. Ten (17.2%) had a CD4 count of 30 cells/mm^3 or less. Figure 1 shows a flow chart of the participants.

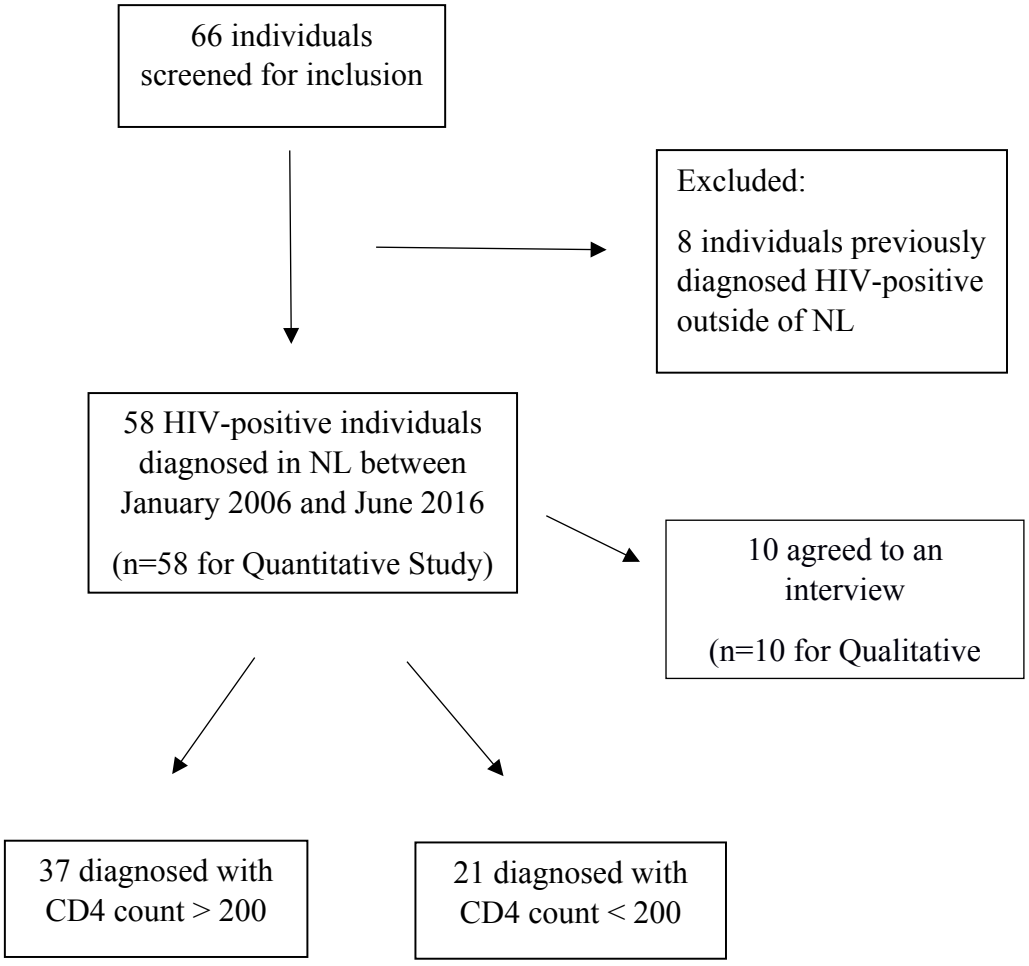

Figure 3.1: Flow chart showing individuals included in the study with an early and late diagnosis

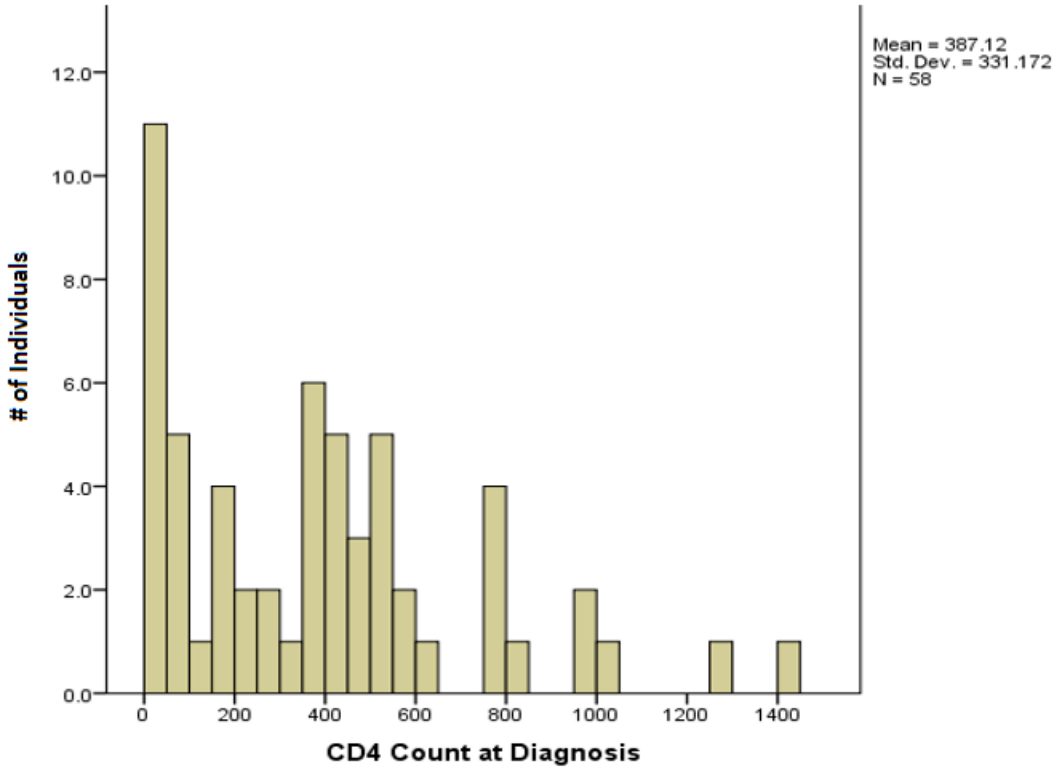

Figure 3.2: Histogram Showing the CD4 Count at HIV Diagnosis

Figure 3.2 shows the distribution of CD4 counts at diagnosis. The highest category of CD4 count is 0-50 cells/mm^3 with 11 individuals. The data is not normally distributed.

Table 3.1: Patient Demographics

	Total	Mean CD4 at Diagnosis	P-value
Total	58 (100%)	387	----------
Sex:			
Male	53 (91.4%)	390	0.957[a]
Female	5 (8.6%)	355	
Residence:			
Urban	50 (86.2%)	364	0.392[a]
Rural	8 (13.8%)	533	
Age:			
20-29	12 (20.7%)	495	
30-39	11 (19.0%)	324	0.812[b]
40-49	24 (41.4%)	388	
50+	11 (19.0%)	329	
Employment:			
Unemployed	13 (22.4%)	366	
Part-time	5 (8.6%)	289	
Full-time	33 (56.9%)	392	0.881[b]
Retired	2 (3.4%)	258	
Disabled	1 (1.7%)	396	
Student	4 (6.9%)	602	

[a] = Mann-Whitney U Test

[b] = Kruskal-Wallis Test

As seen in Table 3.1, most individuals diagnosed with HIV were middle-aged men living in urban NL that work full-time. There was no significant difference of CD4 count at diagnosis between sex, residence, age or employment.

Table 3.2: HIV Risk Factors

	Total	Mean CD4 at Diagnosis	P-value
Sexual Orientation:			
MSM	33 (56.9%)	449	0.049[a]
Heterosexual	21 (36.2%)	262	
Unknown	4 (6.9%)	----	
IVDU:			
Yes	2 (3.4%)	387	0.818[a]
No	56 (96.6%)	387	
From HIV-endemic country:			
Yes	3 (5.2%)	140	0.207[a]
No	49 (84.5%)	410	
Unknown	6 (10.3%)	----	
Blood Transfusion:			0.690[a]
Yes	1 (1.7%)	174	
No	57 (98.3%)	391	
Maternal Transmission:		----------	----------
Yes	0 (0%)		
No	58 (100%)		

[a] = Mann-Whitney U Test

Table 3.2 describes the risk factors of individuals diagnosed with HIV. The highest number of people were MSM, with very few IVDUs and people from HIV-endemic countries. There was only one patient that had had a blood transfusion, and no patients contracted HIV through maternal transmission. There was a significant difference of CD4 count between MSM and heterosexual individuals with MSM having a higher CD4 count. There was no significant differences for categories of IVDU, originating from an HIV-endemic country of blood transfusion though there are few individuals in these groups. Furthermore, MSM had significantly more HIV tests than heterosexual individuals (p=0.036).

Table 3.3: Testing history

	Total	Mean CD4 at Diagnosis	P-value
Who Initiated Testing:			
HCP	35 (60.3%)	369	
Patient	15 (25.9%)	457	0.292[b]
Insurance	4 (6.9%)	378	
Immigration	2 (3.4%)	124	
Unknown	2 (3.4%)	----	
Site of Diagnosis:			
Hospital	10 (17.2%)	89	
Primary Care	22 (37.9%)	358	0.001[b]
ER	1 (1.7%)	3	(p=0.001 when
STI Clinic	19 (32.8%)	579	comparing
HIV Clinic	6 (10.3%)	448	Hospital to STI Clinic)
Number of Previous HIV Tests:			
0	39 (67.2%)	308	0.021[b]
1-2	12 (20.7%)	604	
3+	7 (12.1%)	456	(p = 0.031 when comparing 0 to 1-2 visits)
Tested Within a Year Before Diagnosis:			0.004[a]
Yes	9 (15.5%)	683	
No	49 (84.5%)	333	

[a] = Mann-Whitney U Test

[b] = Kruskal-Wallis Test

As seen in Table 3.3, HIV testing was initiated by healthcare workers most of the time, with the patient asking for the test approximately a quarter of the time. Four individuals were tested for HIV for insurance purposes. Regarding the site of diagnosis, most individuals were diagnosed in primary care or at a STI clinic. For 67.2% of patients, the first time they were tested for HIV was when they were diagnosed HIV-positive, and 84.5% had not been tested within a year prior to their diagnosis. There was no significant difference in CD4 count based on who

initiated the HIV test. There was however, a significant difference in CD4 count based on where the individual was diagnosed (lower in the hospital and ER), the number of previous HIV tests, and whether the individual was tested for HIV a year before they were diagnosed.

Table 3.4: Previous Healthcare Contact

	Total	Mean CD4 at Diagnosis	P-value
Clinic Visits:			
0	8 (13.8%)	469	
1-9	33 (56.9%)	383	0.910[b]
10-19	9 (15.5%)	330	
20+	8 (13.8%)	387	
ER Visits:			
0	15 (25.9%)	402	
1-4	28 (48.3%)	415	0.652[b]
5-9	9 (15.5%)	364	
10+	6 (10.3%)	256	
Hospital Admissions:			
0	48 (82.8%)	405	
1	8 (13.8%)	307	0.374[b]
2	1 (1.7%)	528	
3	1 (1.7%)	16	

[b] = Kruskal-Wallis Test

Table 3.4 shows previous healthcare contact within 5 years prior to HIV diagnosis . 86.2% of individuals had attended a clinic, 74.1% had been to the ER, and 17.2% had been admitted to hospital. Overall, 94.8% of individuals had at least one contact within the healthcare system. Clinic visits ranged from 0-61, ER visits ranged from 0-18, and hospital admissions ranged from 0-3. The mean number of all healthcare contact visits was 13.7. There was no significant difference between categories of clinic visits, ER visits and hospital admissions. For ER visits, it appears that there is a trend that the more visits, the lower the CD4 count at

diagnosis. Reasons for ER visits were recorded and many were issues regarding feeling generally unwell, fatigue and shortness of breath. However, it should be noted that there were visits that are irrelevant to HIV, for example, trauma. During these visits it is unlikely that an ER physician would consider HIV testing, however, if opt-out testing was put in place, HIV cases would not be missed.

Table 3.5: Substance Use

	Total	Mean CD4 at Diagnosis	P-value
Smoker:			
Yes	30 (51.7%)	403	0.236[a]
No	24 (41.4%)	336	
Unknown	4 (6.9%)	----	
Alcohol user:			
Yes	34 (58.6%)	417	0.053[a]
No	18 (31.0%)	263	
Unknown	6 (10.3%)	----	
Illicit Drug user:			
Yes	21 (36.2%)	445	0.429[a]
No	32 (55.2%)	350	
Unknown	5 (8.6%)	----	

[a] = Mann-Whitney U Test

Table 3.5 shows that most of the individuals were smokers and alcohol users while over a third were drug users. Marijuana was the most common drug used. There was no statistically significant difference between CD4 count at diagnosis for the different categories of substance use. Notably, patients who denied alcohol use trend to a later diagnosis.

Table 3.6: Sexually Transmitted Infections Present at HIV Diagnosis

Syphilis:	
Yes	9 (15.5%)
No	38 (65.5%)
Test Not Done	11 (19.0%)
Hepatitis C:	
Yes	3 (5.2%)
No	49 (84.5%)
Test Not Done	6 (10.3%)
Chlamydia	
Yes	3 (5.2%)
No	16 (27.6%)
Test Not Done	39 (67.2%)
Gonorrhea:	
Yes	1 (1.7%)
No	18 (31.0%)
Test Not Done	39 (67.2%)

Table 3.6 lists other sexually transmitted infections (STIs) that were concurrently diagnosed with HIV. The most common STI was syphilis which occurred in 15.5% of cases, followed by Hepatitis C and Chlamydia in 5.2% of cases and Gonorrhea in 1.7% of cases. Some individuals were not tested for STIs other than HIV, and over two-thirds of patients were not tested for Chlamydia or Gonorrhea.

Table 3.7: AIDS-Indicator Conditions Present at HIV diagnosis

Pneumocystis jiroveci Pneumonia	6 (10.3%)
Cytomegalovirus	4 (6.9%)
Lymphoma	2 (3.4%)

Table 3.7 lists AIDS-Indicator conditions (AIC) at the time of HIV diagnosis. Overall, 8 (13.8%) individuals had one or more AIC with the most common being Pneumocystis Pneumonia (6 cases) followed by Cytomegalovirus (4 cases) and Lymphoma (2 cases). For the 4 cases of Cytomegalovirus, 1 case was Cytomegalovirus retinitis and the other 3 cases were written only as "Cytomegalovirus" in the patient files, therefore the type is unknown.

Table 3.8: Symptoms at HIV Diagnosis

Asymptomatic	20 (34.5%)
Swollen Lymph Nodes	19 (32.8%)
Weight Loss	17 (29.3%)
Fatigue	16 (27.6%)
Thrush	13 (22.4%)
Short of Breath	8 (13.8%)
Night Sweats	6 (10.3%)
Cough	6 (10.3%)
Rash	6 (10.3%)
Oral Ulcers	6 (10.3%)
Fever	5 (8.6%)
Change in Vision	3 (5.2%)
Bleeding Gums	2 (3.4%)
Dizziness	2 (3.4%)

As seen in Table 3.8, a little over one-third of individuals were asymptomatic at diagnosis. The mean CD4 count for asymptomatic individuals was 511 cells/mm^3 compared to a mean CD4 of 316 cells/mm^3 for symptomatic individuals. Of those that were symptomatic, the most common symptoms were swollen lymph nodes, weight loss, fatigue, thrush and shortness of breath. Other symptoms included night sweats, cough, rash, oral ulcers, fever, change in vision, bleeding gums and dizziness. As 15.5% of individuals also had syphilis, some of these symptoms (eg. rash and oral ulcers) may be due to their syphilis infection rather than HIV alone.

Table 3.9: Disease Stage at HIV Diagnosis

A1 (asymptomatic, CD4 >500)	14 (24.1%)
A2 (asymptomatic, CD4 200-499)	12 (20.7%)
A3 (asymptomatic, CD4 <200)	3 (5.2%)
B1 (symptomatic, CD4 >500)	4 (6.9%)
B2 (symptomatic, CD4 200-499)	6 (10.3%)
B3 (symptomatic, CD4 <200)	10 (17.2%)
C3 (AIDS indicator conditions)	8 (13.8%)

Table 3.9 shows where the individuals fell in the CDC Disease Staging System [41] including whether or not they were asymptomatic, symptomatic, or had an AIDS-Indicator Condition. From Table 3.9 we can see that the most common categories were A1 (24.1%), A2 (20.7%) and B3 (17.2%).

3.2 – Qualitative Study

Of the 58 individuals diagnosed with HIV in NL between 2006 and 2016, 10 (17.2%) agreed to participate in an interview, all of which were MSM. While the sample size was fairly small, there were no more individuals we could ask who were eligible for an interview. However, data saturation is believed to have been met as each theme was mentioned in at least two interviews. All 10 were men who have sex with men. The mean CD4 count at diagnosis among the interviewees was 620 cells/mm^3 (range 56-1408). There was not a significant difference in CD4 count at diagnosis in the interview population compared to the whole population (p=0.086). The list of themes derived in this study can be found in table 3.10.

Table 3.10: Themes Derived from HIV Interviews

Themes from Interviews	Number of Interviews Where Theme was Discussed
Theme 1: Stigma Surrounding HIV and testing	8 (80%)
Theme 2: Interactions with the Healthcare System (Positive and Negative)	7 (70%) for positive and negative interactions each
Theme 3: “It Can’t Happen to Me”	7 (70%)
Theme 4: Fear of the Diagnosis	6 (60%)
Theme 5: The General NL Population is Uneducated about HIV	6 (60%)
Theme 6: NL Lacks Adequate Support for People with HIV	4 (40%)
Theme 7: NL Requires a Broader Range of HIV Testing	4 (40%)
Theme 8: Some People are no longer Afraid of HIV	4 (40%)
Theme 9: NL has a Drug Problem in the Gay Community	2 (20%)

Theme 1: There is a Stigma Surrounding HIV and Testing

The stigma surrounding HIV was brought up in almost all interviews. Stigma was mentioned in both the context of getting the HIV test and after the men had been diagnosed HIV-positive.

"But I know when you're sitting in the waiting room and there's multiple clinics going on and you're waiting there…It goes through my mind sometimes when I'm sitting there and I think "Now am I going to run into anyone I know here now and they're going to be coming out when I'm going in?" (participant 5)

"You were almost wishing that it had been cancer because with cancer it's more accepted in society and with this diagnosis, it's so taboo and so looked down upon. You don't realize how badly you will be judged". (participant 3)

"Some guys it's no big deal, some guys will immediately stop talking to you, some guys will be rude and say "Oh god, I'm not…" you know, so I guess people associate the HIV and the STI with, I don't know, just dirty or whatever the word is". (participant 5)

Theme 2: Interactions with the Healthcare System

Many individuals mentioned having negative interactions with the healthcare system during testing and while receiving news of their HIV diagnosis.

"On three separate times while getting tested they asked "Are you an intravenous drug user?" and of course I said no, and there was twice on two different encounters where actually one guy picked my arm up and he was going all over it and my knuckles and said to the other guy "I can't find any puncture marks". And I was like "Okay, you're being a complete shithead … From the front counter to the doctors the attitude is very, very poor. I keep telling people don't go to that clinic". (participant 2)

"I went to go get tested and my doctor said "nah, you don't need to get tested for that you look fine". (participant 10)

"Because what the doctor told me was "you have AIDS" he didn't say HIV-positive. I don't have AIDS. I've never had AIDS. I have HIV. My CD4 count was never low enough for AIDS." (participant 1)

Another individual stated that he believed he had been tested by his health care provider for years which may also show a lack of communication between HCPs and patients.

"It came as a really big surprise and shock because I was under the understanding that my family doctor who I had been seeing for the past 15-17 years, when I would go for prostate exams or just a physical every year that he would be doing the HIV testing". (participant 7)

Individuals also discussed positive interactions with the healthcare system, and in particular positive interactions with the HIV clinic in St. John's. Participants noted that the clinic was privacy oriented, never judgemental, caring and organized.

"I'm impressed because they're very, very privacy oriented and very, very thorough, that's the one thing about them". (participant 2)

"I talk to (the HIV nurse) on a daily basis because she's the best. I love her. She's very good, very thorough, very inviting, very sweet person and she doesn't make you feel uncomfortable". (participant 10)

"But even from the being diagnosed to the follow-up it was seamless for me, it was almost like it was all taken care of and I just had to show up which made it really, really easy, I didn't have to think about "Okay, what's the next step?" They had all that information…". (participant 5)

Theme 3: "It Can't Happen to Me"

When asked if they believed they were at risk for HIV, almost all participants said they did not think they were at risk despite being in the high risk category of MSM. Most were aware about the risks associated with unprotected anal sex but believed it just could not happen to them.

"I was aware because I work in health care, so you are aware but you never think it will happen to you…I guess I never thought it would happen to me, and I guess a lot of people do think that "Oh that will never happen", but it do. It's out there. You just don't think about it, right? So you just go on with life". (participant 3)

"Because I've been (tested) before, I knew how easy it was to access, and maybe just after going so many times, it's like "Well I've gone so many times before and it's always been negative". Why would I bother to keep going?" (participant 5)

Theme 4: Fear of the Diagnosis

Over half the participants noted that the fear of the HIV diagnosis itself was a barrier to getting tested as it is believed to still be a death sentence. The fear of criminalization which was previously reported in another Canadian study [36] was not brought up as an issue in this population. No participants described the fear of diagnosis as being a barrier for themselves, but described this as something they were aware of among their friends in the local community.

"And anyone I talk to, and I've talked to guys that I've known for years and say, you know, "Do you ever go get tested?" and they say "Nah, I haven't been there in a couple of years" "You need to go" "I just don't wanna go, I don't want to know" (participant 5)

"No one really wants to go get tested, you know? I think it's because they're nervous, they're scared and they just don't want to know. That's it. They just don't want to know. Their nerves go to the sky and they're like "No, okay I'm not going to go get tested" and they're the ones who got it" (participant 10)

Theme 5: The General NL Population is Uneducated about HIV

Over half of the participants recounted their own misinformation about HIV and the lack of education and awareness among the general population.

"When I was dealing with it I was going through a hard time and didn't know if I could wash my clothes with someone else's clothes because that's how much information I was lacking" (participant 10)

"I think more education out and about would help people through it more. For the public, even. Sometimes I listen to my family members when they're talking and the subject comes up and they don't know. They're so uneducated about it, and the comments they make, I just sit there and look at them and say "Are you for real?" (participant 3)

Theme 6: NL Lacks Adequate Support for People with HIV

In 40% of interviews, participants complained that NL does not have adequate support for people living with HIV in the province. A couple of participants noted they get their support from other provinces.

"There's not a lot of resources around here to talk to someone about it at a certain time. Everyone goes home at 5 o'clock time frame and it's kind of like where to get your information and how to get your information… I had to call AIDS Vancouver and talk to one of the representatives there about everything that was going on and I made a friend within that center that I talked to pretty much on a daily basis. So I don't talk to anyone around here, I speak to someone outside of Newfoundland". (participant 10)

"When I first found out I was looking for support, and when it comes to this city it's very hard to find group support. There's none. Zero." (participant 2)

Theme 7: NL Requires a Broader Range of HIV Testing

In just under half of the interviews, participants stated how they wish there had been a point of care test or how they have friends that could benefit from this test. The idea of waiting for the result and fear of needles were two issues brought up.

"And here they don't have quick testing. I went on holiday and while I was there, we were out having lunch at a restaurant, and across the parking lot they were doing HIV testing in an ambulance vehicle for people. And I was like: Oh my god, if they only had that in Canada". (participant 3)

"If there was another way of getting people to test without needles. A swab or something like that. If that was in place…I know a lot of grown men who are afraid of needles. Something easy like pee in a bottle. Something along those lines. It's the needle that keeps a lot of people away. I've seen people faint. Very fearful" (participant 1)

Theme 8: Some People are not Afraid of HIV

In a complete contrast to the theme of "Fear of the Diagnosis", in a little less than half of the interviews, participants noted how some people no longer fear HIV and therefore delay testing or continue to have unprotected sex. Interestingly, one participant recounted how his friend purposely became infected with HIV.

"Everybody knows that most STIs are curable anyway and HIV now is manageable so like I really don't think many people care that much. A lot of my friends who are HIV-positive have sex parties and will tell people beforehand their …and everybody goes" (participant 8)

"I think people are thinking well that's not a death sentence anymore so I don't have to be careful" (participant 1)

"…he said he got intentionally infected. I've come across individuals who are like this. Who said they want to get it out of the way because they're very, very sexual, which is what he is… He told me that he was very happy that he had become infected. He said "…I'm so sexual in nature and so involved in the drugs and everything else". He just wanted to get it out of the way" (participant 2)

Theme 9: NL has a Drug Problem in the Gay Community

Two participants (20%) noted how the gay community in St. John's has been using more drugs over the last few years and believe this may result in riskier behavior.

"Within the gay world, you will find there has been a lot of drug use and it has gotten worse. The younger ones are very involved with drugs. They'll use that term "party and play". Crystal meth and molly are big ones…the drug thing is phenomenal. It's getting worse. It's getting really, really worse" (participant 2)

"Probably the drugs too are a big deal. A lot of gay guys are using drugs. It's really big now. Crystal meth, molly, coke, anything like that. So at night everyone is looking for sex and don't care about using condoms. There's a lot of drugs and alcohol on the go, I guess, too" (participant 8)

4.0 - Discussion

4.1 – Quantitative Findings and Implications

Overall, 36.2% of our patients received a late diagnosis (CD4 count < 200 cells/mm^3), and 17.2% had a CD4 count of 30 cells/mm^3 or less. Of the Canadian studies available, NL has a higher prevalence of late diagnosis despite using a stricter definition of a late diagnosis (<200 cells/mm^3 at diagnosis) compared to more lenient definitions such as "<200 cells/mm^3 at diagnosis or an AIC 12 months after diagnosis" which was used in other studies. Even with the stricter definition, our prevalence was 36.2% compared to the highest of 30% in Manitoba using the criteria of <200 cells/mm^3 when entering into care [20]. More studies are needed, however, to determine the prevalence in other provinces without published surveillance data.

The only statistically significant demographic factor that appears to predict late diagnosis was sexual orientation, with heterosexual individuals more likely to present later than MSM. One possible explanation for this could be that MSM may be tested more often, as their sexual orientation is a known risk factor. Support for this possibility is that MSM had significantly more HIV tests than heterosexual individuals (p=0.036). Furthermore, healthcare practitioners may be more inclined to suggest HIV testing for patients with this risk factor. More emphasis needs to be put on encouraging "never before tested" sexually active heterosexual individuals to get tested for HIV and normalizing testing so HIV will no longer be considered a "gay disease". While it would cost more money upfront to offer testing to these men, avoiding a late diagnoses could save money in the long run. There was no significant difference in gender, age, residence and employment. As the vast majority of individuals were male, however, it may be justified to recommend HIV testing in all sexually active middle-aged men who have never before been

tested. From our study, the most likely to present with a late diagnosis of HIV are heterosexual male individuals who are middle-age and live in urban NL. Frequent visits to the ER and never previously being tested for HIV would also be a good reason to suggest HIV testing.

The fact that for 67.2% of people their first HIV test was the one where they were diagnosed HIV-positive also implies Newfoundlanders are not accessing routine testing. The mean age of individuals at diagnosis was 40.6 years, which leaves many years of previous sexual activity during which no testing occurred. Furthermore, 84.5% of individuals had not been tested within a year prior to diagnosis, when frequent sexual activity and therefore HIV transmission may have occurred. For this reason HIV testing must be normalized and become part of a healthcare routine.

Over 60% of HIV tests were suggested by a healthcare practitioner (HCP), however, there may have been many opportunities to recommend testing sooner. The mean number of healthcare contact visits in the five years before diagnosis was 13.7. This number includes clinic visits, ER visits and hospital admissions. This does not include family physician visits, indicating that the mean number of visits may be higher than 13.7. Individuals with a late diagnosis were infected with HIV years before diagnosis, meaning there was a long period during which testing could have been performed.

Our study also suggests missed opportunities for other STI testing, as testing for *Chlamydia* and Gonorrhea at the same time as HIV testing only occurred in one-third of cases. It is important to note that over one-third of individuals were asymptomatic at the time of HIV diagnosis with CD4 counts as low as 85 cells/mm^3. This indicates HCPs should not just offer HIV testing to individuals presenting with HIV-specific symptoms alone, or they may miss HIV-positive asymptomatic individuals.

One heterosexual male was diagnosed with a CD4 count of 16 cells/mm^3 with the AIDS-Indicator Condition of Pneumocystis Pneumonia (PCP). In the eight months prior to his diagnosis, he had been to the ER five times complaining of chest congestion, cough, shortness of breath, weakness, fatigue, inability to sleep, feeling generally unwell, sore throat and swollen tongue. There was no mention of HIV in the first four visits. On his fifth visit, five months before he was diagnosed, in the physician's notes it mentions how the symptoms could be due to HIV and how the patient had not been tested within the past seven years, however, no test was performed. The patient was sent home and was not diagnosed HIV-positive until five months later, when he presented to the ER again with PCP.

4.2 – Qualitative Findings and Implications

The only individuals who agreed to participate in an interview were MSM. This observation may demonstrate increased awareness and comfort in discussing HIV among the MSM population compared to the heterosexual population.

Theme 1: There is a Stigma Surrounding HIV and Testing

Stigma was the main discussion point during the interviews. Many individuals had only told select family and friends about the diagnosis, and were concerned about others finding out they were HIV-positive, due to the stigma attached. A common theme involving stigma was that individuals may feel uncomfortable in the waiting room of an STI clinic because others would think they were promiscuous. This stemmed from the idea that if someone had a low number of sexual partners, they would not need to get tested for STIs. This clearly demonstrates the fact that STI testing must be normalized. One solution to stigma as a barrier to HIV testing is to offer anonymous testing. Currently in NL anonymous testing is available upon request but is not part of the official guidelines for the province [39]. It is quite possible that many individuals are not aware that they can request anonymous HIV testing and instead choose not to get tested at all.

Furthermore, some individuals noted that since NL is a small province, everyone seems to know everyone, or at least knows someone who knows you, especially in small towns. The idea that everyone knows you or knows someone that knows you was part of this waiting room fear. The “everyone knows everyone” fear was also mentioned as a reason for reluctance to disclose HIV status. One participant from a small town stated how everyone in his town knows of him as the “guy with HIV” because of this gossiping. The idea that only “dirty” people contract HIV was also brought up in interviews, further amplifying the stigma. In a 2010 study in Paris, it was found that individuals determined to have a stigma towards people with HIV based

on their response to questions (eg. Would you have a meal at their home?) were significantly less likely to have ever been tested ($p<0.0001$ for men and $p=0.0002$ for women) [42]. Another study in the United States involving black MSM found that the men with a high internalized stigma towards HIV based on their agreement with statements like "I am concerned that if I go to an AIDS organization someone I know might see me", were less likely to get tested for HIV though this did not quite reach statistical significance ($p=0.06$) [43].

Theme 2: Interactions with the Healthcare System

The next major theme in the interviews was interactions with the healthcare system. One individual asked his HCP for a requisition for an HIV test and was denied because the doctor said he looked healthy. As many individuals are asymptomatic at diagnosis, screening using the presence of symptoms as an indicator is not an appropriate approach to testing. Furthermore, this man was homosexual and had had unprotected sex with various partners and knew he was at risk. In this case the physician could have explored the reasons why the test was requested or they may have been unaware of the fact that individuals can be HIV-positive and be asymptomatic. In a study looking at HIV testing among young MSM in Detroit, individuals whose HCP discussed HIV prevention with them were significantly more likely to have been tested for HIV compared to individuals who had never discussed HIV with their HCP ($p<0.001$) [44]. This indicates HCPs should openly discuss HIV prevention and HIV testing with their patients. Many other individuals said they went to get tested for HIV and felt they were judged or treated poorly by the person doing the testing. One man stated he left one clinic crying because of the way he was treated. If individuals believe they are being judged or otherwise treated badly by a HCP, they may be unlikely to return for another test. In a Los Angeles study, for example, approximately one fourth of the sample reported perceived stigma from a health care provider

regarding HIV and this stigma was found to be associated with a lower access to care (OR=3.29) [45]. To combat this, a HIV stigma scale for health care providers in North America has been developed and assessed using nursing and medical students across Canada [46]. The scale consists of questions used to measure stigma by healthcare providers (eg. HIV (+) patients make me uncomfortable) which can then be used to provide appropriate training to reduce the HCP's stigma [46]. Furthermore, they may tell their friends of the bad experience and deter them from going as well. One individual said during the interview that he tells all his friends to avoid a certain clinic for the way he was treated. An individual who is willing to get tested for HIV who is treated with respect may be more likely to get tested again in the future. Many participants also noted that their family doctor gave them no information about HIV once they were diagnosed and told them they were positive in a less than ideal way. One individual said the doctor simply passed him a paper with the words "HIV-reactive" circled in red pen. Another individual reported his family doctor was mad at him for being HIV-positive. Many participants also noted they were convinced they were dying until they met with the HIV clinic.

A more positive healthcare interaction was noted when the question "Who provides care for your HIV?" was asked during the interview. This led to 70% of individuals praising the team members and giving a narrative about how the clinic has positively impacted their life. While this would not affect HIV testing, it is nice to know there is a good resource for people that test positive for HIV.

Theme 3: "It Can't Happen to Me"

The next major theme was the idea that "it can't happen to me". Many individuals knew the risks involved with unprotected anal sex and knew about HIV but were under the impression

that they would not get it. Many participants noted how they would ask if their partner was "clean" and if they said yes then it was safe to not use a condom. Unfortunately, many individuals that are HIV-positive are unaware of their status. Furthermore, the idea that they haven't gotten any STIs over the years while having unprotected sex led to a false feeling of security. The number of sexual partners was also thought to be associated with HIV. One participant noted that he was shocked that he had gotten HIV because he had only had two sexual partners in the previous year. In a study in 2007 in the United states, 936 MSM who had never been tested for HIV indicated that they were not at risk for HIV as the number one reason for not having been tested [47]. Although MSM is a known risk factor for HIV, many individuals did not think they were at risk and this correlated with avoiding testing.

It is important that emphasis is placed on the idea that HIV can happen to anyone, and not getting STIs in the past does not mean it cannot happen in the future. Furthermore, it should be made clear that although an individual may only have a few sexual partners, those partners may have had numerous partners before them and may have exposed them to HIV and other STIs.

Theme 4: Fear of the Diagnosis

The next main theme and barrier to testing is the fear of the HIV diagnosis itself. The participants described this fear as something they were aware of among their friends in the local community instead of a barrier they faced themselves. It is possible that this sample was atypical of the general population or they were unwilling to admit that they experienced this fear themselves. Many individuals may be reluctant to get tested because they are afraid of finding out they are HIV-positive. This may be partially because of the stigma attached to HIV and due to the fear that HIV is a death sentence. In many interviews the participants said they believed HIV was a death sentence before they were diagnosed and many thought they were dying up

until when they met with the HIV clinic. More education is needed for these reasons. An Australian study in 2012 involving 1093 MSM further demonstrated how fear of an HIV diagnosis can impact testing [48]. In this study, 40.2% of people who had never been tested indicated fear of a positive result as a barrier to testing for them. This was significantly higher ($p<0.01$) than individuals who had been tested previously in which 26.0% indicated they were scared of receiving a positive diagnosis [48]. If the public is made aware about HIV and misconceptions about HIV are eliminated, the stigma may decline. Furthermore, if the public is educated about how HIV is no longer a death sentence and is classified as a chronic disease, perhaps more people would be willing to get tested as they know there are treatments available.

Theme 5: The General NL Population is Uneducated about HIV

The previous theme of fear of the diagnosis ties in perfectly with the next theme that the general population of Newfoundlanders are uneducated about HIV. For example, some individuals shared how they were uneducated about HIV transmission. One individual believed that only the receptive partner during intercourse could become HIV-positive, while another believed HIV could not be contracted through oral sex. While the risk is much lower for the penetrative partner and performing oral sex, it is still possible to contract HIV this way. Another participant believed he had been tested for HIV for years as he had been getting yearly bloodwork and assumed HIV was part of the annual checkup. Other individuals shared their own misconceptions about HIV after they had been diagnosed. One individual recounted his fear of being around small children after he was diagnosed as he was afraid that they would somehow contract HIV through casual contact. The misconception about HIV being transmitted through casual contact was also brought up by other participants referring to negative encounters with HIV-negative individuals. With more education to the general public regarding what it means to

be HIV-positive and how the virus is transmitted, there may be less stigma, STI testing may become more normalized, and individuals may be less afraid to be diagnosed HIV-positive.

Theme 6: NL Lacks Adequate Support for People with HIV

While the HIV clinic had excellent reviews, approximately half of the participants still said NL lacks adequate resources for people with HIV. Many participants noted how they felt completely alone and helpless from the time they were first diagnosed until they had their appointment with the HIV clinic. As there is a stigma attached to HIV, many felt they could not confide in family and friends and even talking to someone that deals with general mental health issues was too intimidating as they were too afraid to share their diagnosis. Even after meeting with the HIV clinic, some individuals still had many questions and felt that after 5pm there was no one they could talk to about their concerns. Perhaps an HIV or STI crisis line or other service would be helpful in addressing this issue.

Theme 7: NL Requires a Broader Range of HIV Testing

The next theme inferred from the interviews is that NL would benefit from other testing methods including a point of care (POC) test. A few reasons for why other testing options would be beneficial are that some individuals fear needles or do not like bloodwork, there is too much time between the test and the result which may make people worry, and the need to return for test result is inconvenient. Anonymity of results may also attract more individuals to test for HIV. In the 2012 Australian study looking at barriers to HIV testing in 1093 MSM, the individuals who had never been tested were significantly more likely to say having blood drawn was a barrier to testing than those who had been tested in the past ($p=0.02$) [48]. From this study it appears that a fear of bloodwork does impact likelihood of testing and a different method of

testing would be beneficial. Currently a POC HIV screening finger-prick blood test is being offered in two locations in NL as part of another research study so perhaps more individuals will take advantage of this service. Our data suggests there is value in a POC test and we support making this more widely available after the current research study concludes.

Theme 8: Some People are not Afraid of HIV

In a direct contrast to the theme involving the fear of testing positive for HIV, another theme brought up was that some individuals no longer fear HIV as it is quite treatable. For this reason, we must be careful how educational campaigns are marketed. On one hand, we want to reduce the fear that HIV is a death sentence, and on the other hand we must ensure that people are still concerned about HIV enough to get tested as one means of reducing transmission in the community. It must also be made clear that HIV can be fatal if not treated, but many treatment options are available.

Theme 9: NL has a Drug Problem in the Gay Community

Finally, one last theme was that there may be a drug problem in the gay community. While this was only brought up in 2 (20%) interviews, no question regarding drug use had been asked during the interview so for this to be brought up independently twice may indicate a real problem. Furthermore, both individuals listed the same drugs being used (i.e. crystal meth and "molly" – a form of MDMA). This could be an important issue for HIV transmission as many individuals under the influence of these drugs may be involved in riskier sexual behaviour or share drug equipment though this association is still unclear [49].

4.3 – Study Limitations

Limitations of this study include a retrospective chart review, a small sample size and possible recall bias. Our retrospective study design may have missed data or conclusions because these were not available in the medical record. Perhaps some individuals had more symptoms at diagnosis but they were not recorded, for example. Furthermore, some information relies on the honesty and recall of the individuals. When asked if they were alcohol users, for example, 31% said they did not use alcohol at all. It is possible that some individuals may not have been honest about their alcohol use. Furthermore, sexuality can be a complex subject, so some individuals may describe themselves as heterosexual but may have occasional sex with men thus putting them at higher risk. For the qualitative study, some individuals may have forgotten certain experiences as they had been diagnosed up to ten years prior to the interview. Over long periods of time it would be quite easy to forget exactly how the physician acted or what they said the day they were diagnosed. Furthermore, there was a selection bias for the interviews. All the individuals that agreed to participate in an interview were MSM and their responses may not generalize to everyone diagnosed with HIV. The mean CD4 count of those who agreed to an interview was also higher than those who did not, which may mean that these individuals faced less barriers to HIV testing.

4.4 – Future Studies

Further research that would add to the knowledge around uptake of HIV testing would include interviewing different groups of individuals or handing out surveys regarding testing. Our study population included only 2 IVD users and 5 women so it would be important to determine if there really are very few cases of IVDU and women with HIV or if they are not being tested. A study that would be interesting to conduct in NL would be asking people who have never been tested for HIV the reasons why they have never been tested. Perhaps specific age groups and risk groups could be targeted in this study. Another study would be to interview people that have tested negative for HIV and ask them the reasons why they chose to get tested and ask them to discuss their testing experience. These studies may also suggest ways to increase HIV testing. Currently there is a study ongoing in NL involving a POC test which will be interesting to see if more individuals chose to get tested through this method, and may be grounds to introduce POC testing permanently. Further studies could also analyze the impact of drug use in the gay community and offer education or an intervention to address this potential problem. A study surrounding an educational intervention addressing the issue that some individuals no longer fear HIV could also be implemented.

4.5 - Possible Testing Interventions

Based on the results of our study, new policy to promote HIV testing may reduce the incidence of late diagnosis. Universal testing at each healthcare contact is expensive and the pre-test probability among the general population is extremely low. However, testing based on local risk factors may be more efficient. ER patients automatically selected based on demographics such as age, sex, urban address, or absence of previous HIV test results could be notified to the

attending physician as at risk of late diagnosis of HIV. This automated notification could inform the physician that the test will be performed unless the lab is notified that the patient refuses. Opt-out testing in the ER has been successfully implemented in other jurisdictions as patients are diagnosed earlier and linked to care [50,51]. With opt-out testing, more individuals are willing to accept an HIV test [52]. Healthcare providers should also talk openly to their patients about the risks involved with unprotected sex and normalize the discussion of HIV and testing. If an individual asks for an HIV test, they should not be denied a test. Furthermore, it may be useful for HCPs to offer testing to middle-aged sexually active heterosexual men who have never before been tested.

5.0 - Conclusion

Many individuals are getting tested late for HIV and presenting with low CD4 counts. While there are few studies in which to compare, it appears that NL has a higher prevalence of late diagnosis than other Canadian provinces. There was frequent healthcare contact prior to diagnosis which may represent missed opportunities for HIV testing. This may have been prevented if HIV testing was a more routine testing procedure. Furthermore, education of physicians may reduce delayed HIV diagnosis. Physicians must recognize that HIV occurs in heterosexual individuals as well as MSM, and that many individuals with HIV may be asymptomatic. As well, stigma is a problem in NL and this must be addressed through educational campaigns normalizing HIV testing and what it means to be HIV-positive. Individuals must be made aware that HIV is no longer a "death sentence" if treated but can be fatal if left untreated. However, educational campaigns should not downplay the severity of HIV as some individuals were noted to no longer fear HIV and avoid testing for this reason. Educational campaigns may also be beneficial in encouraging heterosexual men to get tested for HIV.

6.0 – References

[1] Public Health Agency of Canada, "Summary: Estimates of HIV Incidence, Prevalence and Proportion Undiagnosed in Canada, 2014," 2014.

[2] Public Health Agency of Canada, "Canadian Guidelines on Sexually Transmitted Infections". Retrieved July 7, 2017 from http://www.phac-aspc.gc.ca/std-mts/sti-its/cgsti-ldcits/section-5-8-eng.php. 2016.

[3] P. G. Farnham, C. Gopalappa, S.L. Sansom, A.B. Hutchinson, J.T. Brooks, P.J. Weidle, V.C. Marconi, and D. Rimland. "Updates of Lifetime Costs of Care and Quality-of-Life Estimates for HIV-Infected Persons in the United States," *JAIDS Journal of Acquired Immune Deficiency Syndrome*, vol. 64, no. 2, pp. 183–189, 2013.

[4] H. Jiang, N. Xie, J. Liu, Z. Zhang, L. Liu, Z. Yao, X. Wang, and S. Nie. "Late HIV Diagnosis:Proposed Common Definitions and Associations With Short-Term Mortality," *Medicine (Baltimore).*, vol. 94, no. 36, p. e1511, 2015.

[5] The Antiretroviral Therapy Cohort Collaboration, "Causes of Death in HIV-1-Infected Patients Treated with Antiretroviral Therapy, 1996-2006: Collaborative Analysis of 13 HIV Cohort Studies," *Clinical Infectious Diseases.*, vol. 50, pp. 1387–1396, 2010.

[6] Association of Medical Microbiology and Infectious Diseases Canada, "The Use of Early Antiretroviral Therapy in HIV-infected Persons," pp. 1–21, 2016.

[7] J. A. C. Sterne, M. May, D. Costagliola, F. de Wolf, A.N. Phillips, R. Harris, M. J. Funk , R. B. Geskus, J. Gill, F. Dabis, J. M. Miró, A. C. Justic, B. Ledergerber, G. Fätkenheuer, R. S. Hogg, A. D. Monforte, M. Saag, C. Smith, S. Staszewski, and M. Egger. "Timing of initiation of antiretroviral therapy in AIDS-free HIV-1-infected patients: a collaborative analysis of 18 HIV cohort studies". Lancet. Apr 18; 373(9672): 1352–1363, 2009

[8] A. Hänsel, H. C. Bucher, R. Nüesch, M. Battegay. "Reasons for Discontinuation of First Highly Active Antiretroviral Therapy in a Cohort of Proteinase Inhibitor - Naive HIV-Infected Patients," *Journal for Acquired Immune Deficiency Syndrome,26:191-197, 2001.*

[9] G. Marks, N. Crepaz, J. W. Senterfitt, and R. S. Janssen, "Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States - Implications for HIV prevention programs," *Journal of Acquired Immune Defiiency Syndrome*, vol. 39, no. 4, pp. 446–453, 2005.

[10] H. B. Krentz and M. J. Gill, "The Direct Medical Costs of Late Presentation (<350/mm) of HIV Infection over a 15-Year Period," *AIDS Research & Treatment*, vol. 2012, p. 757135, 2012.

[11] Public Health Agency of Canada, “Human Immunodeficiency Virus - HIV Screening and Testing Guide.” 2014.

[12] S. Wertheimer, “Women and HIV Testing in Canada : Barriers and Recommendations as Identified by Service Providers,” Canadian AIDS Society pp. 1–19, 2011.

[13] L. M. Williamson, P. Flowers, C. Knussen, and G. J. Hart, “HIV testing trends among gay men in Scotland, UK (1996-2005): implications for HIV testing policies and prevention,” *Sexual Transmission and Infection*, vol. 85, no. 7, pp. 550–554, 2009.

[14] R. Bath, R. O’Connell, M. Lascar, R. Ferrand, S. Strachan, N. Matin, I Bassnet, C Orkin, “TestMeEast: a campaign to increase HIV testing in hospitals and to reduce late diagnosis,” *AIDS Care*, vol. 28, no. 5, 2016.

[15] A. J. Mutch, C. Lui, J. Dean, L. Mao, J. Lemoire, J. Debattista, C. Howard, A. Whittaker and L. Fitzgerald, “Increasing HIV testing among hard-to-reach groups: examination of RAPID, a community-based testing service in Queensland, Australia,” *BMC Health Service Research*, vol. 17, no. 1, p. 310, 2017.

[16] A. Antinori, T. Coenen, D. Costagiola, N. Dedes, M. Ellefson, J. Gatell, E. Girardi, M. Johnson, O. Kirk, J. Lundgren, A. Mocroft, A. d’Arminio Monforte, A. Phillips, D. Raben, J.K. Rockstroh, C. Sabin, A. Sonnerborg and F. de Wolf . “Late presentation of HIV infection: A consensus definition,” *HIV Medicine*, vol. 12, no. 1, pp. 61–64, 2011.

[17] Center for Disease Control, “AIDS-Defining Conditions” MMWR 57(RR10);9, 2008.

[18] British Columbia Centre for Disease Control, “HIV in British Columbia: Annual Surveillance Report 2014,” *BC Center for Disease Control*, pp. 1–45, 2015.

[19] Manitoba HIV Program, “Manitoba HIV Report 2015,” 2015.

[20] D. Jaworsky, L. Monette, J. Raboud, D. O’Brien-Teengs, C. Diong, S. Blitz, S. B. Rourke, M. R. Loutfy. “Comparison of late HIV diagnosis as a marker of care for Aboriginal versus non-Aboriginal people living with HIV in Ontario,” *Canadian Journal of Infectious Disease & Medical Microbioly*, vol. 23, no. 4, pp. 96–102, 2012.

[21] H. I. Hall, J. Halverson, D. P.Wilson, B. Suligoi, M. Diez, S.Le Vu, T. Tang, A. McDonald, L. Camoni, C. Semaille, C. Archibald. “Late diagnosis and entry to care after diagnosis of human immunodeficiency virus infection: A country comparison,” *PLoS One*, vol. 8, no. 11, 2013.

[22] NSHW, “Surveillance Report on HIV/AIDS in Nova Scotia: 1983 to 2011,” 2012.

[23] A. Mocroft *et al.*, "Late presentation for HIV care across Europe: Update from the collaboration of observational HIV epidemiological research europe (COHERE) study, 2010 to 2013," *Eurosurveillance*, vol. 20, no. 47, 2015.

[24] S. Ellis, H. Curtis, and E. L. C. Ong, "HIV diagnoses and missed opportunities. Results of the British HIV Association (BHIVA) national audit 2010," *Clinical Medicine* vol. 12, no. 5, pp. 430–434, 2012.

[25] C. Agustí, A. Montoliu, J. Mascort, R. Carrillo, J. Almeda, J. M. Elorza, M. Aragón, J. Casabona, "Missed opportunities for HIV testing of patients diagnosed with an indicator condition in primary care in Catalonia, Spain," *Journal of Sexually Transmitted Infections*,2015-052328, 2016.

[26] M. Helleberg, F. N. Engsig, G. Kronborg, A. L. Laursen, G. Pedersen, O. Larsen, L. Nielsen, J. Jensen, J. Gerstoft and N. Obel, "Late presenters, repeated testing, and missed opportunities in a Danish nationwide HIV cohort," *Scandinavian Journal of Infectious Diseases*, vol. 44, no. 4, pp. 282–288, 2012.

[27] J. H. Nakao, D. E. Wiener, D. H. Newman, V. L. Sharp, and D. J. Egan, "Falling through the cracks? Missed opportunities for earlier HIV diagnosis in a New York City Hospital.," *Int. Journal of STD & AIDS*, vol. 25, no. 12, pp. 887–93, 2014.

[28] M. Arya, S. Patel, D. Kumar, M. Y. Zheng, M. A. Kallen, R. L. Street, Jr., K. Viswanath, and T. P. Giordano, "Why Physicians Don't Ask : Interpersonal and Intrapersonal Barriers to HIV Testing — Making a Case for a Patient-Initiated Campaign," HIV Testing & Diagnosis, vol. 15, no. 4, pp. 306–312, 2016.

[29] I. K. Joore, S. L. van Roosmalen, J. E. van Bergen, and N. van Dijk, "General practitioners barriers and facilitators towards new provider-initiated HIV testing strategies: a qualitative study," *International Journal of STD & AIDS*, vol. 0, no. 0, p. 956462416652274, 2016.

[30] C. V. Johnson, M. J. Mimiaga, S. L. Reisner, R. VanDerwarker, and K. H. Mayer, "Barriers and Facilitators to Routine HIV Testing: Perceptions from Massachusetts Community Health Center Personnel," *AIDS Patient Care STDS*, vol. 25, no. 11, pp. 647–655, 2011.

[31] D. G. Partridge, P. Collini, and M. W. McKendrick, "HIV testing: the boundaries. A survey of HIV testing practices and barriers to more widespread testing in a British teaching hospital," *International Journal of STD & AIDS*, vol. 20, no. 6, pp. 427–428, 2009.

[32] P. B. Wright, G. M. Curran, K. E. Stewart, and B. M. Booth, "A qualitative analysis of provider barriers and solutions to HIV testing for substance users in a small, largely rural southern state," *Journal of Rural Health*, vol. 29, no. 4, pp. 420–431, 2013.

[33] E. M. Simmons, M. J. Brown, K. Sly, M. Ma, M. Y. Sutton, and E. McLellan-Lemal, "Barriers and facilitators to HIV testing in primary care among health care providers," *Journal of National Medical Association*, vol. 103, no. 1943–4693 (Print), pp. 432–438, 2011.

[34] J. E. Mill, R. C. Jackson, C. A. Worthington, C. P. Archibald, T. Wong, T. Myers, T. Prentice and S. Sommerfeldt, "HIV testing and care in Canadian Aboriginal youth: a community based mixed methods study.," *BMC Infectious Diseases*, vol. 8, p. 132, 2008.

[35] A. I. Scheim and R. Travers, "Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men," *AIDS Care*, vol. 0, no. 0, pp. 1–6, 2016.

[36] P. O'Byrne, J. Willmore, A. Bryan, D. S. Friedman, A. Hendriks, C. Horvath, D. Massenat, C. Bouchard, R. S. Remis and V. Etches, "Nondisclosure prosecutions and population health outcomes: examining HIV testing, HIV diagnoses, and the attitudes of men who have sex with men following nondisclosure prosecution media releases in Ottawa, Canada.," *BMC Public Health*, vol. 13, no. 1, p. 94, 2013.

[37] S. Holtzman, L. Landis, Z. Walsh, E. Puterman, D. Roberts and K. Saya-Moore, "Predictors of HIV testing among men who have sex with men: A focus on men living outside major urban centres in Canada," *AIDS Care*, vol. 28, no. 6, pp. 705–711, 2016.

[38] K. Bolsewicz, a Vallely, J. Debattista, a Whittaker, and L. Fitzgerald, "Factors impacting HIV testing: a review - perspectives from Australia, Canada, and the UK.," *AIDS Care*, vol. 121, no. December, pp. 1–11, 2014.

[39] Public Health Agency of Canada, "HIV/AIDS Epi Updates - July 2010 - Chapter 3: HIV Testing and Surveillance Systems in Canada," 2010.

[40] "The APPROACH Study," 2017. [Online]. Available: http://www.mun.ca/pharmacy//research/approachstudy.php.

[41] Centers for Disease Control and Prevention, "Terms, Definitions, and Calculations Used in CDC HIV Surveillance Publications," *Center for Disease Control*, no. May, pp. 1–3, 2014.

[42] V. Massari, A. Lapostolle, M.-C. Grupposo, R. Dray-Spira, D. Costagliola, and P. Chauvin, "Which adults in the Paris metropolitan area have never been tested for HIV? A 2010 multilevel, cross-sectional, population-based study," *BMC Infectious Diseases*, vol. 15, no. 1, p. 278, 2015.

[43] S. B. Mannheimer, L. Wang, L. Wilton, H.V. Tieu, C. del Rio, S. Buchbinder, S. Fields, S. Glick, V. Cummings, S.H. Eshleman, B. Koblin, and K.H. Mayer "Infrequent HIV Testing and Late HIV Diagnosis Are Common Among a Cohort of Black Men Who Have Sex With Men in 6 US Cities," *JAIDS Journal of Acquired Immune Deficiency Syndrome*, vol. 67, no. 4, pp. 438–445, 2014.

[44] S. Meanley, A. Gale, C. Harmell, L. Jadwin-Cakmak, E. Pingel, and J. A. Bauermeister, "The role of provider interactions on comprehensive sexual healthcare among young men who have sex with men," *AIDS Education and Prevention*, vol. 27, no. 1, pp. 15–26, 2015.

[45] D. A. Mackellar, S. Hou, C. C. Whalen, K. Samuelsen, T. Sanchez, A. Smith, D. Denson, A. Lansky and P. Sullivan "Reasons for not HIV testing, testing intentions, and potential use of an over-the-counter rapid HIV test in an internet sample of men who have sex with men who have never tested for HIV.," *Sexually Transmitted Diseases*, vol. 38, no. 5, pp. 419–28, 2011.

[46] J. J. Kinsler, M. D. Wong, J. N. Sayles, C. Davis, and W. E. Cunningham, "The Effect of Perceived Stigma from a Health Care Provider on Access to Care Among a Low-Income HIV-Positive Population," *AIDS Patient Care STDS*, vol. 21, no. 8, pp. 584–592, 2007.

[47] A. C. Wagner, T. A. Hart, K. E. McShane, S. Margolese, and T. A. Girard, "Health Care Provider Attitudes and Beliefs About People Living with HIV: Initial Validation of the Health Care Provider HIV/AIDS Stigma Scale (HPASS)," *AIDS Behaviour.*, vol. 18, no. 12, pp. 2397–2408, 2014.

[48] D. P. Conway, M. Holt, D. L. Couldwell, D. E. Smith, S. C. Davies, A. McNulty, P. Keen, P. Cunningham and R. Guy "Barriers to HIV testing and characteristics associated with never testing among gay and bisexual men attending sexual health clinics in Sydney," Journal of the International AIDS Society, pp. 1–8, 2015.

[49] A. Bourne, D. Reid, F. Hickson, S. Torres-Rueda, and P. Weatherburn, "Illicit drug use in sexual settings ('chemsex') and HIV/STI transmission risk behaviour among gay men in South London: findings from a qualitative study: Table 1," *Sexually Transmitted Infections*, vol. 91, no. 8, pp. 564–568, 2015.

[50] J. Galbraith, J. H. Willig, J. B. Rodgers, J. P. Donnelly, A. O. Westfall, K. L. Ross-Davis, S. L. Heath "Evolution and Escalation of an Emergency Department Routine, Opt-out HIV Screening and Linkage-to-Care Program.," *Public Health Reports*, vol. 131, pp. 96–107, 2016.

[51] J. S. Haukoos, E. Hopkins, A. A. Conroy, M. Silverman, R. L. Byyny, S. Eisert, M. W. Thrun, M. L. Wilson, A. B. Hutchinson, J. Forsyth, S. C. Johnson, J. D. Heffelfinger, "Routine opt-out rapid HIV screening and detection of HIV infection in emergency department patients," *JAMA - Journal American Medical Association*, vol. 304, no. 1538–3598 (Electronic), pp. 284–292, 2010.

[52] D. a E. White, T. Sadoun, T. Tran, and H. J. Alter, "Increased acceptance rates of HIV screening using opt-out consent methods in an urban emergency department.," *Journal of Acquired Immune Deficiency Syndrome*, vol. 58, no. 3, pp. 277–82, 2011.

Appendix A: Interview Consent Form

TITLE: Delayed Diagnosis of HIV in Newfoundland. A Quantitative and Qualitative Study

INVESTIGATOR(S): Sarah Boyd, Peter Daley, Deborah Kelly, Jill Allison, Michael Grant, Kim Burt, Carla Penney

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care or normal treatment.

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.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

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

1. **Introduction/Background:**
   The Public Health Agency of Canada says that about 75,500 Canadians are infected with HIV but about 21% don't know they are infected. About 2,570 new HIV infections occurred in Canada in 2014. Because people are still getting infected with HIV more needs to be done to make sure people who are at risk get tested. HIV treatment has been shown to help people live longer and reduces the rate of infection. We want to know what factors help people decide whether or not to get tested so we can provide good health teaching to prevent HIV infection.

2. Purpose of study:

The purpose of this study is to try to find out why some people might delay getting tested for HIV and what kinds of programs will help people who are at risk get tested earlier in their illness.

3. Description of the study procedures:

This study uses interviews to find out about how people made the decision to get tested for HIV. The researcher has some questions they will ask but you will also be asked if you want to tell us anything else about your HIV test and diagnosis. The researcher will record the interview, if you agree, and a member of the research team will type out the answers you give after the interview. You can decide not to answer some questions if you chose.

4. Length of time:

The interview will last up to 1 hour and will take place at a place where you are comfortable. The researcher may contact you to ask a follow up question at some time in the month after the interview.

5. Possible risks and discomforts:

There are no physical risks to taking part in the study. The researcher will be asking you about your HIV diagnosis. This may be painful or make you feel sad. If you feel distress during the interview, the researcher will end the interview and we will call the social worker at the HIV clinic for support. You can stop the interview at any time.

6. Benefits:

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. For example we may be required by law to allow access to research records. Your name will not be used and all information that might identify you will be taken out before we write about anything you tell us.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team**.**

Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your

- information from study interviews

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 be destroyed. Once the information is used for publication it cannot be removed.

Information collected and used by the research team will be stored at Memorial University Faculty of Medicine. *Dr. Peter Daley* is the person responsible for keeping it secure.

Your access to records

You may ask the *study doctor or researcher* to see the information that has been collected about you.

9. Questions or problems:

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

Principal Investigator's Name and Phone Number

Sarah Boyd

709-691-9673

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:

Ethics Office at 709-777-6974
Email at info@hrea.ca

This study has been reviewed and given ethics approval by the Newfoundland and Labrador Health Research Ethics Board.

10. Declaration of financial interest, if applicable

No persons are receiving money for doing this study.

After signing this consent you will be given a copy.

Signature Page

Study title: Delayed Diagnosis of HIV in Newfoundland. A Quantitative and Qualitative Study

Name of principal investigator:

Sarah Boyd

To be filled out and signed by the participant:

	Please check as appropriate:
I have read the consent .	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 Sarah Boyd 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 future care

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I understand how my privacy is protected and my records kept confidential Yes { } No { }

I agree that the study doctor or investigator may read the parts of my hospital Yes { } No { }

records which are relevant to the study.

I agree to be audio taped Yes { } No { }

I agree to take part in this study. Yes { } No { }

_____ _____ _____

_

Signature of participant Name printed Year Month Day

_____ _____ _____

Signature of person authorized as *Name printed* *Year Month Day*

*Substitute decision maker, if applicable*_____

_____ _____ _____

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 Name printed Year Month Day

Telephone number: _____

Appendix B – HREA Approval

HREB

Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue
St. John's, NL
A1B 2X5

August 18, 2016

Room 1J421 Health Sciences Centre
300 Prince Phillip Dr.
St. John's, NL A1B 3V6
Canada

Dear Dr. Daley:

Researcher Portal File # 20170406
Reference # 2016.181

RE: "Reasons for Delayed Diagnosis of HIV in Newfoundland. A Quantitative and Qualitative Study."

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Chair under the direction of the Health Research Ethics Board (HREB). ***Full board approval*** of this research study is granted for one year effective **July 7, 2016**.

This is your ethics approval only. Organizational approval may also be required. It is your responsibility to seek the necessary organizational approval from the Regional Health Authority (RHA) or other organization as appropriate. You can refer to the HREA website for further guidance on organizational approvals.

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

- Application, approved
- Revised Script for telephone recruitment, approved
- Revised consent form, approved
- Revised data extraction form, approved
- Letter to custodian, approved
- Interview guide, approved

MARK THE DATE

This approval will lapse on July 7, 2017. It is your responsibility to ensure that the Ethics Renewal form is submitted prior to the renewal date; you may not receive a reminder. The Ethics Renewal form can be found on the Researcher Portal as an Event form.

If you do not return the completed Ethics Renewal form prior to date of renewal:

- ***You will no longer have ethics approval***

Appendix C – Chart Review Case Report Form

Timeliness of HIV Diagnosis Research Project Case Report Form Quantitative Study July 28, 2016
CONFIDENTIAL

Inclusion Criteria

Y N New diagnosis of HIV in Newfoundland and Labrador Jan 2006- Jan 2016
Y N Age >=18 years
Y N Included in Study
Assigned Study Number

Demographic Information

Postal Code
Gender M F Other Unemployed Part time employed Full time employed
Student Retired Disabled
Date of first HIV diagnosis Date of last negative HIV test Y Y Y Y
Site of Diagnosis Hospital Primary Care ER STI Clinic Other
Risk Group (include all that apply) Sex with same sex; Sex with opposite sex; IVDU; Endemic; Blood transmission; Mother to child transmission
HIV Testing: HCW initiated; Patient initiated; Unknown
Country of birth Immigration year Y Y Y Y
Prior HIV Test If prior positive, set that as date of first diagnosis
D D M M Y Y Y Y Result Pos Neg
D D M M Y Y Y Y Result Pos Neg
D D M M Y Y Y Y Result Pos Neg
No Prior testing

Clinical Information

CD4 at diagnosis cells/mm3 % CD8 cells/mm3 %
Viral load at diagnosis log copies/ ml
WHO clinical staging Primary HIV infection Clinical stage 1 2 3 4
CDC Category A Category B Category C

Comorbidity at diagnosis

Respiratory
Cardiovascular Explain
Renal
Gastrointestinal
Psychiatric
Musculoskeletal
Malignant
Infection
Endocrine
STI's Syphilis Gonorrhea Chlamydia HSV Other
Hepatitis
Cigarette use at time of diagnosis Packs per day
Alcohol use at time of diagnosis Units per week
Recreational drugs use at time of diagnosis Cocaine IVDU Ecstasy

Timeliness of HIV Diagnosis Research Project Case Report Form Quantitative Study July 28, 2016

CONFIDENTIAL

☐ Opioid ☐ Other ☐ Marijuana

Method ☐ Injected ☐ Root ☐ Injested ☐ Inhaled

☐ AIDS indicator condition ☐ PCP ☐ MAC ☐ CMV ☐ lymphoma

☐ Other (_____)

Symptoms at Diagnosis

- ☐ Asymptomatic
- ☐ Respiratory
- ☐ Cardiovascular
- ☐ Skin
- ☐ Musculoskeletal
- ☐ Head and Neck
- ☐ Central Nervous System
- ☐ Gastrointestinal
- ☐ Weight loss
- ☐ Fatigue

Explain

Healthcare Contact in 5 years Prior to Diagnosis Starting Date D D M M Y Y Y Y

ER Visit	D D M M Y Y Y Y	Reason
ER Visit	D D M M Y Y Y Y	Reason
ER Visit	D D M M Y Y Y Y	Reason
ER Visit	D D M M Y Y Y Y	Reason
Clinic Visit	D D M M Y Y Y Y	Reason
Physician	D D M M Y Y Y Y	
Clinic Visit	D D M M Y Y Y Y	Reason
Physician	D D M M Y Y Y Y	
Clinic Visit	D D M M Y Y Y Y	Reason
Physician	D D M M Y Y Y Y	
Clinic Visit	D D M M Y Y Y Y	Reason
Admission	D D M M Y Y Y Y	Discharge D D M M Y Y Y Y
Hospital		
Reason		
Admission	D D M M Y Y Y Y	Discharge D D M M Y Y Y Y
Hospital		
Reason		
Admission	D D M M Y Y Y Y	Discharge D D M M Y Y Y Y
Hospital		
Reason		

Appendix D – Interview Guide

Thank you for agreeing to talk to me about your experience with HIV testing. Everything you tell me will be confidential. I am also not concerned with how you came to be HIV positive. You do not have to share that with me. I am more interested in learning about the way testing is accessed and how people make decisions about getting tested. You may choose not to answer any of the questions if you'd like.

Can you tell me about yourself?

How old are you?

How long have you lived in NL?

Can you tell me about your diagnosis of HIV?

When were you diagnosed?

Did you think you might be at risk for HIV? (again you do not have tell me about your specific risk factor if you do not want to)

Did you know the risk factors for HIV before you got tested?

How did you decide to get tested for HIV?

- ➔ What lead you to make the decision to be tested?
  a. Did you ask your doctor or did they suggest testing?
     If doctor initiated: Was testing offered specifically because your care giver identified that you had some risk factors?

Did you ever think about getting tested prior to the time you were diagnosed?

i. Had you been tested in the past?
   If no: What stopped you from getting tested in the past?

Where did you have your HIV test?

Is testing available in your community?

Can you tell me about the process for getting tested?

Who gave you the results of your test?

What information were you given by your doctor before the test was done?

What information were you given after you received the results of your test?

Can you tell me about what has happened since you were tested?

A. Are you on medication?

b. Have you had some counselling?
c. Who provides care for your HIV

Is there anything else you want to tell us about the process of getting tested for HIV in your community?

Thank you again for sharing your story with me. If this interview has made you upset in any way feel free to contact the social worker Cheryl Schulz. Do you have her number? Her number is 777-5885.