

**TESTING FOR HEPATITIS C VIRUS AND PHARMACY-BASED TESTING:
THE PERCEPTIONS OF PEOPLE WHO INJECT DRUGS LIVING IN
NEWFOUNDLAND AND LABRADOR**

by © Catherine Balsom, B.Sc. (Pharmacy), PharmD

A thesis submitted

To the School of Graduate Studies in partial fulfillment of the requirements for the degree of

Master of Science in Pharmacy

Memorial University of Newfoundland

October 19, 2023

St. John's, Newfoundland and Labrador

Abstract

Injection drug use is the most common mode of transmission of Hepatitis C Virus (HCV) infection yet many people who inject drugs (PWID) are unaware they have the virus. A scoping review was conducted to explore the barriers and enablers to testing for HCV. This informed my qualitative study, which involved interviewing PWID to understand their experiences with HCV testing and learn what features of a pharmacy-based HCV testing program are important to them. The study produced 5 themes related to perceptions and experiences of PWID around HCV testing; 'There are multiple reasons why testing is not being done', 'Feelings surrounding testing vary', 'Testing is important for one's own health and the impact on others', 'Access to and relationship with primary care providers affect testing', and 'There is a need for both increased awareness of testing and more testing options'. Five themes were also produced surrounding their perceptions of pharmacy-based testing; 'Pharmacy based testing was seen to be easy', 'The relationship with the pharmacy and pharmacist affects testing', 'Confidentiality would be important to attract people to testing', 'The fast result is often valuable', and 'Less invasive sample collection is appealing to some PWID'. Understanding testing preferences of PWID is important to inform policy enabling improved HCV testing in Newfoundland and Labrador.

Keywords: People who inject drugs, hepatitis C virus, testing, blood borne infections, infectious disease, public health, screening, substance use

Acknowledgements

There are a number of people I would like to recognize for making this thesis possible. First, I would like to send a sincere thank you to my supervisor, Dr. Deborah Kelly. Your support and guidance have been endless, even in the most challenging times. You have been an admirable mentor and colleague and your encouragement to take on this Masters work and continue to succeed throughout the process has meant the world. Thank you for being available to answer all my questions, helping me build connections with other researchers and community partners, and encouraging me to dig deeper throughout my analysis.

I would also like to thank Dr. Lois Jackson and Dr. Shawn Bugden as other members of my supervisory committee. Dr. Jackson, you have inspired me to fall more deeply in love with qualitative research than I ever thought I would. You taught me to leave my ‘bias’ and ‘generalizability’ behind and I have you to thank for much of my new-found enjoyment of qualitative research. Dr. Bugden, you have been a great confidante and mentor throughout this process and I am thankful for your time when I know you have little to spare.

This work would have never been possible without the community partnership through SWAP (Safe Works Access Program) and the mentorship and guidance of Emily and Anna. You have both been so accepting of me wanting to do this research and you have guided me in so many ways, through education to recruitment and I am forever grateful. The connections you have helped foster in the community will be immensely valuable in the future and I hope I am able to impact your organization and clients as much as you have impacted me.

I am forever grateful for the openness of all the participants, I am thankful that you’ve trusted me to share your lived experience, to learn from it and to grow from it. I hope you are

proud of the way I have portrayed your experiences throughout this work and the efforts that come from it.

I would also like to thank Alison Farrell from our Health Sciences Library at Memorial University for her support with my scoping review, providing guidance, running the search and reviewing my work for publication.

I would like to acknowledge the funders who made this research possible. As a part of APPROACH 2.0, this work has been supported by the Canadian Institutes of Health Research (CIHR) BioMedical Team Grant as part of the REACHing for Impact team. I also received support from the Canadian Association for HIV research (CAHR) through their Jumpstarting Participatory Social-Behavioural Health Interventions flipped workshop.

I would like to acknowledge my husband, Blair, for allowing me to take on such a daunting task at a particularly challenging time in our lives and encouraging me to continue through it all. My parents, who have always encouraged me to engage in lifelong learning have undoubtedly supported me throughout this process as well. Without them I would never have the work ethic or love of learning that I have today.

Lastly, I would like to dedicate this thesis to my son Levi, who was just a thought when this started, who was born in the midst of a pandemic as I was gaining momentum in my program, and who has provided immense joy every day; especially when I needed a smile the most. I love you Levi and I hope you love to learn from others as much as I do.

Table of Contents

| | |
|--|------|
| Abstract..... | ii |
| Acknowledgements..... | iii |
| Table of Contents..... | v |
| List of Figures..... | viii |
| List of Tables..... | ix |
| List of Appendices..... | x |
| List of Abbreviations..... | xi |
| Chapter 1: Introduction and Overview..... | 1 |
| Hepatitis C Virus..... | 2 |
| Hepatitis C Treatment Advances..... | 3 |
| Global Perspective..... | 4 |
| National and Provincial Perspective and Associated Injection Drug Use..... | 5 |
| HCV testing process and the pharmacy-based testing option..... | 7 |
| Study Rationale..... | 9 |
| Research Orientation..... | 9 |
| Objective of the Research..... | 10 |
| Research Questions..... | 11 |
| Thesis organization..... | 11 |
| Chapter 2: Scoping Review..... | 12 |
| Introduction..... | 12 |
| Methods..... | 12 |
| Inclusion Criteria..... | 12 |
| Exclusion Criteria..... | 13 |
| Search Strategy..... | 13 |
| Study Selection Process..... | 13 |
| Synthesis..... | 14 |
| Results..... | 14 |

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

Barriers to testing 23

- Self-perceived low risk for HCV 23
- Fear of diagnosis 23
- Stigma 23
- Antipathy in relation to mainstream health care services 24
- Limited knowledge of HCV and testing 24
- Lack of access to and rapport with provider 25
- Lack of motivation or competing priority of drug use 25
- Limited awareness of new treatment options 26

Enablers to testing 26

- Increasing awareness of HCV testing, treatment and cure 26
- Positive rapport with provider and staff 27
- Accessible testing options 28
- Individualized care tailored to the persons’s preferences and priorities 28

Discussion 29

Conclusion 33

Chapter 3: Philosophical Position and Methodology 34

- Philosophical Position 34
- Setting 36
- Participants 37
- Data Collection 37
- Data Analysis 39
- Reflexivity 40

Chapter 4: Results 42

- Introduction to Research Findings 42

Chapter 4A: Perceptions and experiences of PWID surrounding testing for HCV 44

- Multiple reasons why testing is not being done 44
 - Fear of consequences 44
 - Lack of self-perceived risk for HCV infection 45
 - Testing is not a priority 46
 - Stigma 46
- Access to and relationship with primary care provider affects testing 49
- Testing can be emotionally uncomfortable for some but not for others 51

| | |
|--|----|
| Need for increased awareness of testing and more testing options | 52 |
| Testing is important for one's own health and the impact on others..... | 54 |
| Chapter 4B: Characteristics of pharmacy-based testing of importance to PWID | 56 |
| Ease of pharmacy testing | 56 |
| Confidentiality is important | 57 |
| A fast result is often valuable..... | 59 |
| Less invasive sample collection is appealing to some | 61 |
| Relationship with pharmacy/pharmacist affects testing | 63 |
| Pharmacy’s physical space is more comfortable than other settings for testing..... | 63 |
| Positive relationship with the pharmacy staff would attract people to testing | 63 |
| Negative experiences with pharmacists would prevent people from seeking testing in this setting..... | 64 |
| PWID may not go to their regular dispensing pharmacy for testing | 65 |
| Advertising pharmacy-based testing..... | 66 |
| Chapter 5: Discussion | 68 |
| Stigma as a central principle to people’s experiences | 68 |
| Confidentiality in a provincial context | 69 |
| Strengths and Limitations | 70 |
| Important Insights | 72 |
| Impact of this work and recommendations | 74 |
| Future direction..... | 74 |
| Knowledge Translation..... | 76 |
| Chapter 6: Conclusion..... | 78 |
| Final Reflection..... | 79 |
| References..... | 80 |

List of Figures

Figure 1: Study selection for the scoping review..... 80

List of Tables

Table 1: Scoping Review Study Characteristics 16
Table 2: Scoping Review Study Descriptions 17
Table 3: Scoping Review Barriers and Enablers to HCV testing in PWID 20
Table 4: Participant characteristics 43

List of Appendices

Appendix A: Search Strategy..... 89
Appendix B: Recruitment Pamphlet 90
Appendix C: Interview Guide 91

List of Abbreviations

HCV: Hepatitis C Virus

PWID: People Who Inject Drugs

OAT: Opioid Agonist Therapy

DAA: Direct Acting Antiviral

POCT: Point of care testing

STBBI: Sexually transmitted and blood borne infections

SWAP: Safe Works Access Program

Chapter 1: Introduction and Overview

To impact others, we need to first see them, listen to them, and seek to understand them. With a goal of increasing testing for Hepatitis C Virus (HCV) among people who inject drugs (PWID), I sought to understand the experiences and perceptions of these individuals and determine if a proposed pharmacy-based testing program would be appealing to them. The work for this thesis was inspired by my work as a community pharmacist dispensing opioid agonist therapy (OAT) to patients, some of whom have had a history of injection drug use.

One morning a patient came into my dispensary to get their OAT and I was surprised to see that they had jaundice and appeared quite ill. I encouraged them to seek medical attention and arranged for them to get to the nearest hospital. This encounter stalled me, I was shaken and worried about this patient whom I had grown to have a patient-pharmacist relationship with, seeing them almost every day for the past few years. I thought to myself, could this patient be experiencing liver disease? Could this patient have hepatitis C virus (HCV) infection associated with injecting drugs, which I knew they had engaged in in the past? I then thought, how many other patients may have HCV infection? Is this something patients are being screened for? Is HCV risk something they are aware of? How could we encourage testing if it isn't currently being done? As a pharmacist who spent a lot of my day dispensing OAT and counselling patients, I believed there was an opportunity for me to act as an advocate for increased testing and screening in this at-risk population. The patient returned to the pharmacy a few weeks later after being discharged from hospital. I shared my concern with them and they disclosed that they did have HCV infection; they informed me that they had been tested for HCV when incarcerated many years prior and they had received treatment while in the institution. They had never finished the full course of therapy due to side effects, but they expected that they had been cured

as they had never had any issues since. Now that they've had a flare up of HCV infection they have been linked to treatment and began a new therapy. As we were discussing the new treatment, they disclosed that they were worried about their friends since they had shared needles on occasion as they had thought the infection was cleared years ago. This newfound appreciation for the connection between HCV and PWID inspired me to dive deeper; I sought out opportunities to study the experiences of PWID surrounding HCV and to determine how to make testing more accessible and acceptable to this population, specifically through testing at pharmacies.

Hepatitis C Virus

HCV is a blood borne virus; infection occurs through exposure to blood from an infected person most commonly by sharing needles or other equipment used to prepare and inject drugs (1). It can be spread through unsafe injection practices, unsafe health care practices (lack of sterilization procedures, limited discardable supplies, and unscreened blood transfusions), and less commonly through unprotected sexual practices that lead to an exposure to blood (2,3). Once infected with HCV symptoms can appear within 2-6 months, though the majority of cases are asymptomatic but the infection can still be spread during this time. Seventy percent of those infected with HCV will develop chronic infection which can lead to liver fibrosis, cirrhosis, end-stage liver disease, and hepatocellular carcinoma (4). There is no vaccine for HCV and new infections remain a problem, particularly due to low diagnosis rates and the asymptomatic nature of the acute infection. Liver damage happens slowly, often over 20-30 years, meaning the diagnosis may not be picked up for quite some time. Many people are diagnosed for the first time after presenting with devastating conditions of liver cancer and decompensated cirrhosis (2),

suggesting that patients are living with HCV infection for decades but are only being diagnosed when presenting with very late-stage complications. This is particularly problematic since there is a higher rate of complications and mortality when diagnosed late and people may unknowingly pass the infection to others while undiagnosed.

Hepatitis C Treatment Advances

HCV infection was first treated in the 1990s with injectable interferon-based regimens which were associated with frequent intolerable side effects, low efficacy, and high relapse rates (5). There have been major advancements in the treatment of HCV in the past decade with the introduction of oral direct-acting antiviral (DAA) therapies (6). The first DAAs were discovered in 2011, and by 2014, they were approved for the treatment of HCV infection in Canada, revolutionizing HCV treatment (7). These new agents provided simple and quick regimens which were highly effective (95% or greater cure rate) and had few side effects (8,9). They also came with a significant cost; the list price was originally set at about \$60 000 for a 12 week course and initially provinces limited use to patients presenting with hepatic fibrosis of stage F2 or higher (10,11). The use of DAA therapy has been shown to be cost-effective because they effectively stop the progression of HCV and reduce risk of long term complications while increasing quality-adjusted life years (12). Consequently, in 2017, the pan-Canadian Pharmaceutical Alliance successfully negotiated a much better price for DAA HCV medications. By 2018, all provinces in Canada had added DAA medications to their formulary with fewer restrictions (4), now the cost is covered by provincial drug programs, private insurance, or through manufacturer assistance programs (13).

These new treatment options have made curing HCV a reality (14), prompting the World Health Organization (WHO) to call on all countries to invest testing and treatment strategies, with a goal of eliminating viral hepatitis by 2030 (15). Unfortunately, some experts say that without increasing awareness, expanding testing, and linking patients to care it is unlikely that this goal will be met (16). The majority of people living with HCV infection remain untreated (12). One of the main reasons for this is that many of those living with HCV are unaware they have it (2). If people are unaware of their HCV infection and thus not linked to care, they will not be able to realize the advantages of treatment and cure. The WHO notes that prevention interventions such as blood safety initiatives, health-care injection safety, infection control, and harm reduction for PWID can reduce the risk of new infections but the provision of effective harm reduction has been inadequate (15). Even with optimal implementation of prevention strategies, the number of people already infected would remain high for a generation (15). Treatment can prevent deaths, but people need to be aware of their infection to be linked to care.

Global Perspective

Approximately 3% of the world's population has chronic HCV infection, which is an estimated 58 million people, and there are 1.5 million new infections each year (2,17). According to the WHO, HCV occurs in all regions of the world and although the Americas have the lowest prevalence worldwide, an estimated 5 million people in this region live with HCV infection yet only 22% have been diagnosed (18). The primary modes of transmission differ around the world; in developing countries HCV is primarily transmitted through health-related procedures because of poor infection control measures, and in developed countries illicit drug injection is the primary mode of transmission (17).

National and Provincial Perspective and Associated Injection Drug Use

In Canada, 26 people contract HCV infection every day (19). Nationally, HCV causes more years of life lost than any other infectious disease (20). As of 2019, about 1% of Canadians had been infected with HCV in their lifetime and 45% of those infected were people who formerly or currently injected drugs (19). PWID made up between 60% and 85% of all new HCV infections in Canada based on data from 2000-2016 data (21). Similarly, based on a retrospective chart review of patients referred for HCV care in Newfoundland and Labrador (NL) between 1996-2014, 66.1% of diagnosed patients had self-reported intravenous drug use as their risk factor for HCV (22).

Many people living with HCV are unaware of their infection (23). According to the WHO, only 19% of people living with HCV infection around the world are aware of their infection, leaving 81% of those infected unaware of their status (18). The percentage of PWID who are unaware of their HCV infection in Canada has been reported to be as high as 70% (24). The Public Health Agency of Canada's Tracks survey of PWID in Canada assesses the prevalence of HIV and HCV as well as the associated risk behaviours among PWID nationwide. In 2018, among 130 PWID living in NL who took part in the Tracks survey, two out of five participants were HCV positive at the time of the interview and 70.2% of participants with HCV infection were unaware of their positive status (23).

This low level of awareness suggests that PWID are not being screened effectively as part of healthcare with current testing strategies, including within NL. Primary care guidelines recommend screening individuals with current or history of injection drug use for HCV (25); however, PWID often face multiple barriers to medical care. To effectively find and treat

infections in a timely manner and to achieve HCV elimination on a population level, it is necessary to offer repeat testing for people with ongoing risk. Guidelines do not specify the frequency of testing for HCV when injection drug use is continuous; however, one model suggests that frequency of HCV testing should be offered to PWID based on prevalence of HCV infection (25). The authors recommend testing every two years in low prevalence areas (<25%), annually in medium prevalence areas (<50%) and every 6 months in high-prevalence (>50%) settings (26). Based on the Tracks survey of PWID in NL suggesting 41.2% prevalence of HCV infection (23), NL is considered a medium prevalence setting so PWID should be tested on an annual basis. This does not appear to be happening. The Tracks survey found that 84.1% of participants had been tested in their lifetime but only 57.9% had reported being tested at some point over the past 12 months (23).

Lack awareness of HCV status coupled with high rates of sharing injection equipment indicate that the risk of onward transmission among PWID in NL is significant. The Tracks survey found that a lower proportion of PWID in NL reported using sterile injection equipment at last injection compared to the national average, and there was a higher incidence of borrowing injection paraphernalia (23). The authors of the Tracks survey report that although the province has made improvements in services for PWID over the past 20 years they agree with researchers from the Canadian Harm Reduction Policy Project (27) that harm reduction in NL has been embraced ‘in name, but not in substance’. The Tracks study team recommended that an aggressive HCV education, awareness-raising and anti-stigma campaign was needed, as well as improvements in both HIV/HCV testing policies and technology, to increase HIV and HCV testing and status awareness among PWID across NL (23).

HCV testing process and the pharmacy-based testing option

Currently, in order to access HCV testing in NL, people need to get a bloodwork requisition from a provider (primary care Physician or Nurse Practitioner), through Planned Parenthood, or by visiting the sexual health clinic run by the local health authority. After receiving the requisition they have to book an appointment for bloodwork, visit the blood collection laboratory and have the bloodwork drawn from a vein, and book a follow-up appointment with their provider to get their result. This process can take several weeks from request to receipt of results. There are barriers to this multi-step approach to HCV testing (34) and in recent years, a pharmacy-based testing model has been proposed to improve access to testing for sexually transmitted and blood-borne infections (STBBI).

Pharmacies have been seen as being in an ideal position to offer point-of-care testing for STBBI because of their accessibility and widespread availability in almost every community (35). Pharmacists can increase awareness of HCV risk by providing education to those who receive injection supplies and providing educational materials and advice. Testing services delivered through the pharmacy include providing education about the infection and testing options, interpretation of results and linkage to care, and a chance to ask any questions regarding the potential diagnosis. Since pharmacies dispense medications for all conditions and provide care for a variety of reasons there may be a sense of discretion around getting testing in pharmacies that is different from walking into a needle syringe program or addictions center (35). However, whether pharmacies are seen favourably and whether it is attractive as a venue for testing in this population is uncertain. For example, some PWID may not choose the pharmacy closest to them due to the stigma associated with both drug use and HCV, or they may have negative associations with certain pharmacies.

There is evidence that pharmacy-based testing for HCV can effectively reach PWID. In studies that have piloted testing for HCV in community pharmacies, injection drug use was identified as a risk behaviour in 6.7% (36) to 44.3% (37) of people availing of the service. Another study which looked at whether or not a community pharmacist could reduce HIV and HCV transmission and promote linkage to care for people experiencing homelessness showed that pharmacists may be in an optimal position to promote engagement and retention in care for difficult to treat populations (6). Participants were able to seek testing for HIV and HCV on a walk-in basis at a community pharmacy and attracted multiple PWID; 74% of the participants reported injection drug use. In this study 44% of participants had screened positive for HCV and over half of the participants were referred to care and study participants were highly receptive to the pharmacy-led clinical services and pharmacist involvement in the HCV care continuum. Although this is specific to the homeless population similar results may be seen in the general PWID population and further exploration is warranted.

In 2017, the APPROACH pilot study offered pharmacy-based point-of-care testing (POCT) for Human Immunodeficiency Virus (HIV) infection in two Canadian provinces, NL and Alberta (35). The researchers found that a pharmacy-based testing program for HIV infection, whereby a finger-prick blood sample was used to deliver results within the same visit, was feasible and highly acceptable to participants and pharmacists. The success of this program led to the APPROACH 2.0 study, which launched in December 2022, and focuses on implementing STBBI testing in community pharmacies in NL, Alberta and Nova Scotia. This study builds on the pilot study and expands testing to also include HCV and syphilis through point of care and/or dried blood spot testing options. My research is part of the APPROACH 2.0 study: recognizing the high rate of HCV within the PWID community, my research helped guide

the development of the study in terms of informing how to attract PWID to the option of HCV testing at pharmacies. APPROACH 2.0 and my research, are supported by the Canadian Institutes of Health Research (CIHR) BioMedical Team Grant as part of the REACHing for Impact team.

Study Rationale

Multiple studies have been published describing the barriers to HCV treatment for PWID (28, 29); however, few studies have examined specifically the barriers to testing. Although it is valuable to understand the barriers to treatment, the first step in the care continuum is to ensure that people know their HCV status, which requires available and accessible testing options. If we wish to make a meaningful impact on improving awareness among those living with HCV infection and connecting them with care, we must first understand their needs and preferences as it relates to testing to inform development of effective testing options.

Research Orientation

As part of this thesis, I completed a scoping review of the literature and used these results to inform my research questions and methods for my subsequent qualitative study, and both are discussed within this thesis. This study was situated in NL, Canada and all research participants were living in the Eastern Health region of the province; specifically in or around the capital city of St. John's. Geographically, NL is one of the smallest provinces in Canada with a total population of approximately 520,000 and the majority living in the Eastern Health region (approx. 300 000) (39). There are 224 licensed pharmacies in the province, 80 of which are in the St. John's metro area where this research was conducted (40). Also of note, at the time of this

study, an estimated 26% of people living in NL do not have access to a family physician or primary care provider (41).

I conducted semi-structured interviews and reflexive thematic analysis (30) to develop themes, and the methodology is discussed in detail in Chapter 3. The interviews were conducted during the Summer of 2022 and all themes are specific to this time and place. My position as a pharmacist who has participated in dispensing OAT to patients with a history of injection drug use influenced my interpretation of the themes. I considered that some patients may not find the option of pharmacy-based testing appealing and others may consider it as a most appealing option, perhaps depending on their experiences at pharmacies in the past. Pharmacists sometimes have to enforce regulations surrounding controlled substances that may leave a patient having to wait days for their prescription even if they have run out. Other times they may have to inform a prescriber that a patient is looking for early refills which could signal drug misuse. I thought these experiences could result in strained relationships between patient and pharmacist and negatively impact the appeal of a pharmacy as a testing venue. On the other hand, I have seen pharmacists support patients through challenging addictions, acting as a listening ear or as a liaison to help them access services they need. Having not had a history of injecting drugs myself I wanted to hear from those with lived experience.

Objective of the Research

The goal of this thesis was to gain knowledge on the perspective of PWID on pharmacy-based testing for HCV to inform the implementation of a pharmacy-based testing program. I had two objectives in order to meet this goal, the first was to conduct a scoping review to inform and revise research questions. The second objective was to conduct a qualitative study to explore

both the experiences and perceptions of PWID in the current landscape of HCV testing and the characteristics of the process of pharmacy testing that would be important to them if they were interested. For example, is the discretion and privacy provided by the pharmacy environment important to PWID when being tested? Is the pharmacy setting seen as being accessible and does the speed of the result matter to PWID?

Research Questions

- 1) What are the barriers and enablers to testing for HCV among PWID?
- 2) What are the experiences and perceptions of people living in Newfoundland who inject drugs surrounding testing for Hepatitis C Virus?
- 3) What features of a pharmacy-based testing program for HCV would be important to people who inject drugs?

Thesis organization

This thesis consists of 6 chapters. Following this introduction, Chapter 2 outlines the scoping review which supports the research questions. Chapter 3 provides the methods and description of the data of the qualitative research. Chapter 4 discusses results and is broken down into two sections, Chapter 4A discusses the themes surrounding the perceptions and experiences of PWID on testing for HCV and Chapter 4B discusses pharmacy-based testing for HCV and what features are important to appeal to PWID. Chapter 5 provides a discussion of the findings as well as future direction for related work and Chapter 6 provides a conclusion to the work.

Chapter 2: Scoping Review

Introduction

To determine how what features of pharmacy-based testing would be important to PWID I sought to understand what was known about barriers and enablers to testing within this community. The Public Health Agency of Canada's Tracks survey included testing for HCV as part of the study and found that 70.2% of PWID in NL with HCV infection were unaware of their positive status (23). This suggests the available testing strategies (outside of the Tracks survey context) are not effectively reaching all of those at risk. Understanding the barriers to testing is necessary to address these factors, help to eliminate barriers, and inform development of engaging testing options for people who inject drugs. This is the first step in improving equitable access to testing.

I conducted a qualitative scoping review to determine the barriers and enablers to testing for HCV among PWID. This knowledge helped to refine my research question and guide the design my interview guide. The results of my scoping review in its entirety have been published in BMC Public Health (June 2023)(42).

Methods

Inclusion Criteria

A search was conducted to identify studies which examined barriers and enablers to HCV testing among people who engaged in current injection drug use or had a history of injection drug use. Studies were included if barriers or enablers to HCV testing among PWID were addressed as either the primary or secondary outcome. Studies could be qualitative or mixed-methods provided that sufficient detail was included to permit understanding of the barriers and

enablers. Only those studies which explored the experiences and perceptions of PWID were included. The search was not limited by age as injection drug use is a risk regardless of age. Only full-text publications reported in English were included. Studies were included if they were published during or after 2010 which aligned with the introduction of DAA therapy.

Exclusion Criteria

Studies that did not address barriers or enablers to testing for HCV, and those that only included quantitative survey data were excluded. Studies which took place within prison settings were also excluded as the testing options and influences on accepting testing are expected to be different for incarcerated individuals than those living in the community.

Search Strategy

I met with a librarian to discuss the research question and we developed a search strategy together. A librarian conducted comprehensive literature searches in Medline (via Ovid), Embase (embase.com) and CINAHL (via Ebsco). The search was peer-reviewed by a second librarian using the Peer Review of Electronic Search Strategies checklist (43). The final search strategy can be found in Appendix A.

Study Selection Process

Search results were imported into Covidence, an online primary screening and data extraction tool used for scoping and systematic reviews (44). Two levels of screening were performed to identify articles for inclusion. Level 1 was based on a review of abstracts for relevance, and level 2 involved full-text review to ensure articles met inclusion criteria. The inclusion criteria were imported into the software and used by the reviewers during level 1 screening when considering titles and abstracts and during level 2 screening when completing

the full-text review. An undergraduate pharmacy student (JK¹) and I independently completed both level 1 and level 2 screening, and discrepancies were reconciled through discussion with my supervisor.

Synthesis

Data were charted to compare study designs and descriptions of barriers and enablers which repeated across studies. Coding of the results/findings section of each included study was done line by line by two reviewers (CB and AD²) who independently reviewed each study to identify barriers and enablers associated with testing. The reviewers met to discuss how these compared across multiple studies and the most significant findings are described.

Results

The literature search resulted in 1554 citations (Figure 1). After screening titles and abstracts, 50 studies were selected for full-text screening. Nine studies subsequently fulfilled the eligibility criteria and were included (20–22, 30–35).

¹ I would like to thank Jeremy Keys for his help in data screening

² I would like to thank Aaron Dawson for his help in data synthesis

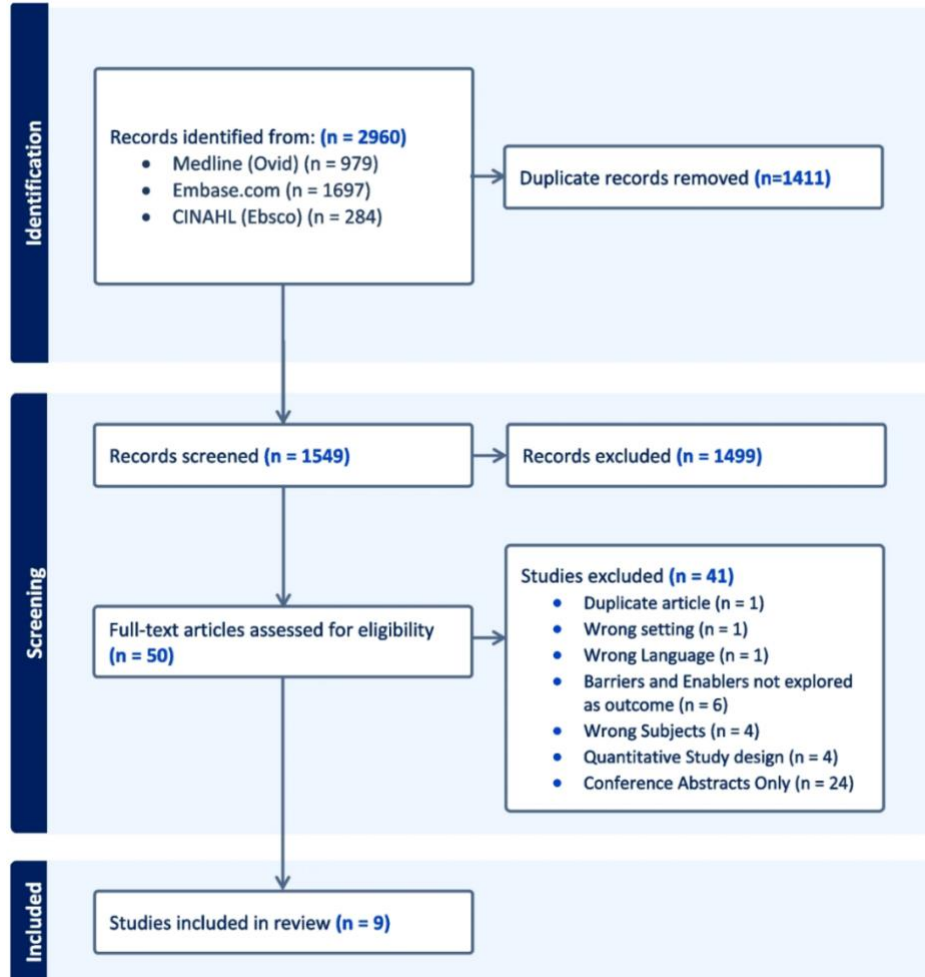


Figure 1: Study selection for the scoping review

Most studies used interview methodology except for one which included data from open ended questions at the end of a survey (45). All reports were relatively recent, published between 2014 - 2021 with the majority after 2017 (Table 1). Studies were set in the United States, United Kingdom or Australia. As most studies were primarily qualitative, they tended to have a small sample size; however, the survey study involved 362 participants (48) and another study involved 48 participants (47).

Table 1: Scoping Review Study Characteristics

| Item (n=9) | | Count |
|---------------------|----------------------------------|-------|
| Year of publication | | |
| | 2014-2015 | 2 |
| | 2016-2017 | 0 |
| | 2018-2019 | 5 |
| | 2019-2020 | 1 |
| | 2021 | 1 |
| Country | | |
| | United States | 4 |
| | United Kingdom | 3 |
| | Australia | 2 |
| Setting | | |
| | Syringe exchange program | 2 |
| | Community based outreach program | 3 |
| | Drug treatment service program | 3 |
| | Inpatient detoxification | 1 |
| Methods | | |
| | interviews | 8 |
| | open-ended survey | 1 |
| Sample Size | | |
| | 10-19 | 2 |
| | 20-29 | 4 |
| | 30-39 | 1 |
| | 40-49 | 1 |
| | 50+ | 1 |

Two studies examined participant experiences with screening or testing for HCV as their primary objective (45,46), and two others looked at the whole care continuum, from HCV screening to treatment and monitoring (31,32) (Table 2). The remaining studies looked at experiences of participants in specific testing programs (47,49) or specific modes of testing delivery such as community-based outreach, point-of-care testing, and social network interventions utilizing peer support (33,48,50). Despite these differences, there were many common barriers and enablers observed across the studies (Table 3).

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

Table 2: Scoping Review Study Descriptions

| Authors, Year, Country | Primary Objective | Inclusion Criteria | Setting | Participant Characteristics |
|-------------------------------------|--|---|--|--|
| Barocas et al., 2014, United States | To examine characteristics associated with HCV screening among PWID utilizing a free, multi-site syringe exchange program and to elicit their perceptions of barriers and facilitators to screening for HCV. | 18 years of age or older, could speak and read English and reported a history of injecting drugs. | Syringe exchange program operating through office-based locations in two large cities and via mobile van units that serve the suburbs, surrounding rural communities, and other smaller cities in Wisconsin. | 69% male Median age of 28 83% white |
| Coupland et al., 2019, Australia | To explore the impact of the Hepatitis C Incidence Transmission community-based outreach model in engaging and retaining newly diagnosed PWID in HCV testing as an entry point into the HCV care cascade. | 16 years of age and older, have injected drugs in the previous 12 months, and acquired HCV infection while enrolled in a community-based prospective observational study of hepatitis C vaccine preparedness. | Community based outreach program in Sydney, Australia. | 57% male. Median age of 27 36% self-reported a culturally diverse background |
| Harris et al., 2018, UK | To inform and assess the HepCATT study. | Drug treatment services clients who currently or previously injected illicit drugs. Aged 19-69. | Drug treatment services program in England. | 79% male Age range 19-69 |

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

| | | | | |
|-----------------------------------|---|---|---|---|
| Harris et al., 2014, UK | To examine participants' accounts of HCV testing, especially regarding barriers to uptake. | 18 years of age or older, proficient in English, currently injecting an illicit drug (within the last 30 days) and having injected illicit drugs for at least six years. | Community based opioid substitution therapy prescribing services and drug user networks in London, England. | 22 HCV antibody negative and 15 positive 73% male Age range 23-57 76% were white British |
| Latham et al., 2019, Australia | To explore the acceptability of point-of-care testing for PWID within the larger Rapid-EC pilot study. | Ages 19-56 with a history of injecting drugs and participating in the Rapid-EC pilot study offering point-of-care testing. | Needle syringe programs in Melbourne, Australia. | 74% male Age range 19-56, median 44 |
| Phillips et al., 2021, UK | To explore the experiences of clients and staff involved in Project ITTREAT and assess the facilitators and barriers to a community-based HCV service. | Drug and alcohol treatment service attendees with current/previous HCV infection and past or current injection drug use that had been offered and/or were engaged in the HCV service. | Drug and alcohol treatment services in England. | 80 % Male 100 % white |
| Skeer et al., 2018, United States | To provide a greater understanding of the perspectives and experiences of young PWID navigating the HCV care continuum, and in turn, to inform future treatment as prevention strategies. | Currently injecting drugs or had injected drugs in the past but weren't actively injecting, self-disclosed HCV positivity and between the ages of 15 and 30. | Community outreach program in Boston Massachusetts. | 50% male. Age range 22-30 87.5% non-Hispanic white |

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

| | | | | |
|--|---|---|---|--|
| <p>Tofighi et al., 2020, United States</p> | <p>To identify the complex interplay of social and environmental factors that influence engagement along the HCV care continuum</p> | <p>18 years of age and older admitted to inpatient detoxification for opioid use disorder.</p> | <p>Inpatient detoxification hospital in New York City. Though the participants were admitted at the time of the interview the questions probed participants experience in the community, not in the hospital.</p> | <p>78% male Age range 21-62 (mean 44) 35% African-American, 26 % Hispanic 65% diagnosed with HCV</p> |
| <p>Ward et al., 2021, United States</p> | <p>To evaluate perceptions of social network interventions for HCV testing, linkage to care, and treatment. In particular, PWID willingness to perform the peer mentor role and to understand the barriers and facilitators of this approach.</p> | <p>18 years of age or older, English speaking, HCV antibody positive and had a history of injection drug use.</p> | <p>Community based research organizations and provider referral in Baltimore, Maryland.</p> | <p>75% male Age range 32-65 (mean 51) 75% Black/African American</p> |

Table 3: Scoping Review Barriers and Enablers to HCV testing in PWID

| (Authors), year (Country) | Sample | Method | Barriers | Enablers |
|-------------------------------------|-----------------------------------|---|--|--|
| Barocas et al., 2014, United States | n=362 | Open-ended survey questions | Fear of positive test Low perceived risk Stigma associated with HCV and/or IVDU Lab characteristic Lack of access to transportation Time constraints Lack of knowledge of testing Cost Lack of access to MD/PCP Not having to take initiative Lack of rapport with provider Confidentiality Lack of motivation | Health concerns for self or others High perceived risk Lab characteristic Access to transportation Mobile testing center/SEP Adequate time Knowledge of testing Free testing Access to MD/PCP Not having to take initiative Rapport with provider Confidentiality Motivation |
| Coupland et al., 2019, Australia | n=28 at baseline, 25 at 12 months | Semi-structured interviews | | Building trust and willingness to be tested for hepatitis C Making information about HCV testing and treatment salient |
| Harris et al., 2018, UK | n=48 | In-depth interviews, focus groups and observations. | Perceived lack of testing availability Perception of minimal HCV risk Fear of diagnosis and HCV stigma Confusion about the testing and treatment process Aversions to having a venous sample taken Concerns of interferon treatment | Intervention timeliness: capitalising on stability and new treatments Personalized and flexible care HCV visibility and communication structure Streamlined testing and treatment pathways |

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

| | | | | |
|-------------------------------------|-------|-----------------------------------|---|--|
| | | | <p>Desire to move away from a drug user identity</p> <p>Limited psycho-social ‘stability’</p> <p>Testing could be destabilising if it revealed them to be HCV positive</p> <p>Perception of GPs lack of interest in them and HCV more generally</p> | |
| Harris et al., 2014, UK | n=37 | Qualitative life history research | <p>Fear in relation to diagnosis</p> <p>Apathy regarding mainstream health care services</p> <p>Optimism in relation to risk knowledge</p> <p>Confusion in relation to HCV testing and its consequences</p> | |
| Latham et al., 2019, Australia | n=19 | Semi-structured interview | <p>People and place</p> <p>Rapidity of result return</p> | <p>People and place</p> <p>Method of specimen collection</p> <p>Rapidity of result return</p> |
| Phillips et al., 2021, UK | n=15 | Semi-structured interviews | <p>Lack of stability</p> <p>Stigma</p> <p>Negative discourse around testing and treatment</p> | <p>Trusting client-provider relationship</p> <p>HCV as part of recovery pathways</p> <p>Mitigation of previous negative experiences of secondary care</p> <p>Positive narratives around HCV care</p> |
| Skeer et al., 2018, United States | n =24 | Interviews | <p>Deservingness of HCV treatment and stigma</p> <p>Perceived lack of referral to HCV treatment or follow up</p> <p>Disincentives around HCV treatment for PWID</p> <p>Perception of need for treatment</p> | |
| Tofighi et al., 2020, United States | n =23 | Interviews | <p>Limited knowledge of HCV</p> <p>Limited access to healthcare providers addressing HCV</p> <p>Competing priority of use</p> <p>Benign perceptions of HCV infection</p> | <p>Accessibility of testing sites</p> |

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

| | | | | |
|---|--------------|-----------------------------------|---|--|
| | | | <p>Limited awareness of the availability of DAAs</p> <p>Cost</p> <p>Inability to locate or receive referrals for screening</p> <p>Physician preferences to not initiate HCV treatment</p> | |
| <p>Ward et al., 2021, United States</p> | <p>n =20</p> | <p>Semi-structured interviews</p> | <p>Drug use and lack of social support</p> <p>Challenges to providing peer support</p> | <p>Perception of HCV prevalence within networks</p> <p>Willingness to provide support in social networks</p> |

Barriers to testing

Self-perceived low risk for HCV

In the earliest paper, Harris et al. (2014) reported that participants perceived their risk of HCV infection to be minimal. For example, one participant stated that, “Through them years yeah, I have used a spoon that maybe someone else had used on it, but I’ve never used dirty works. You know, nothing dirty” (46). A later study by Harris et al. (2018) (47) reported that there was a perception of minimal HCV risk due to relatively safe injection practices and/or lack of symptoms. Barocas et al. (45) noted that participants perceived their risk of HCV to be low based on never sharing needles, lack of symptoms, and having received a negative test result in the past.

Fear of diagnosis

Fear of learning the test results was a barrier to testing; participants in the study by Harris et al. (2014) stated: "I don't think I'd be strong enough in my mind if I did have it to handle it [HCV] and it could make me spiral worse out of control. That would be my reason", "Just the fright of it [HCV], if I did have it probably, I don't know, the fright of it", "I'd rather not know" and "I'd rather die of ignorance at that time" (24). Participants across multiple studies indicated they were “scared of the result” with one participant in the study by Barocas et al. quoted as saying “I worry about Hep C more than HIV. I’m afraid of what the result might be” and another stating “I’m in denial. I don’t want to hear that I have it” (45).

Stigma

Stigma was a noted barrier in multiple studies (31,45,47,49). Participants in the study by Barocas et al. perceived stigma associated with both injection drug use and HCV infection to be obstacles to seeking HCV testing, and used words such as “shame”, “embarrassment”, and

“taboo” when describing their experience. "People know that most of the time you get tested for Hep C because you're an IV user. People judge you no matter what your results are. That's the worst feeling ever" (45). One participant in the paper by Latham et al. stated the following:

They need more local like clinics. Like in the hood, in the ghetto, in the slums. Not just in the nice part of town – because they look like shit, so they don't really want to go out, you know, to a Johns Hopkins or to a University of Maryland where you've got to go downtown and you've got to see regular people, you know, and feel judged or feel like people are talking about you or watching you (50).

Antipathy in relation to mainstream health care services

Participants actively avoided mainstream healthcare services because they expected discriminatory treatment, posing a barrier for HCV testing. In the study by Harris et al (2014) multiple participants expressed this barrier, one stated: “I've never felt comfortable with any GP because, in the past, when you've gone to a GP you say ‘I wonder if you can help me, I take heroin...’”(exclamation of horror) sorry, I don't deal with that here” (46). Another participant in the same study had never been tested despite reporting 17 years of daily injecting. They stated, “They said to go up to the hospital [for a HCV test], and it's like, I couldn't be bothered to go up the hospital” (46). This reluctance may be due to shame and embarrassment when having to show their scars; “If a doctor wanted to examine us and I'd roll my sleeves up and I've got track marks, it was embarrassing man, it was horrible” (46). Poor venous access and prior negative experiences were reasons to avoid going to get tested in the hospital: “What's the point of going to the hospital? Cause if I can't find a vein, they definitely won't be able to find a vein” (46).

Limited knowledge of HCV and testing

Participants expressed limited knowledge of HCV; in the study by Tofighi et al. one participant stated: “I don't even really fully understand Hep C. You get that from needles?” (32).

Harris et al. (2014) cited multiple quotes from participants suggesting the misconception that HCV transmission risk is equal between injecting and sexual practices:

I shared with him because he was never unfaithful to me"and "I know I haven't got it [HCV] anyway... [because] I've probably had less than five sexual partners in the last 10 years and of them none of them are users (24).

Some participants had the misconception that there was a vaccine for Hepatitis C; "I've had boosters for hep C. I'm not due anymore boosters now" (24). There was an optimism among some participants that a lack of identifiable symptoms meant they did not have HCV (24).

Lack of access to and rapport with provider

Both lack of access to a medical doctor/primary care provider and a lack of rapport with the provider are barriers to HCV testing. Two of the included studies noted limited access to healthcare providers for HCV care as a barrier (32,46) and Barocas et al. noted lack of rapport with provider as a barrier (45). One participant in the study by Harris et al. (2014) stated "I had one doctor who tried, you know, 'Oh you need to go and get tested, 'and like he'd frighten me then and I'd go and see another doctor next time." (46). Skeer et al. also noted this as a significant barrier with one participant stating: "They are very uneducated on addiction. They have a big stigma when it comes to addicts. If they find out you're an addict, their whole demeanor changes. They rush you, they slam things, they are very impatient with you and it's very saddening to see" (31).

Lack of motivation or competing priority of drug use

Two of the included studies noted disinterest in testing as a barrier. Barocas et al. (45) noted a 'lack of motivation' as a barrier to testing and the study by Ward et al. (50) found that ongoing drug use was a barrier to engagement in testing since it superceded testing as a priority. Ward et al. investigated the impact of social network interventions and note that the network

members had difficulty prioritizing anything outside of avoiding withdrawal, therefore HCV testing engagement was limited. One participant stated “I brought my brother here but he keeps getting high. I brought his girlfriend here but they just keep getting high, man; they don’t want the help”(50).

Limited awareness of new treatment options

The paper by Ward et al. (50) described the lack of awareness of treatment options that result in cure and without believing in a cure, participants may not get tested:

I think because [network members] still don’t realize that there is a cure for [HCV]...Because I just recently heard about the cure for it. And when I first heard it, I didn’t want to believe it neither. Because they were always ‘no cure, no cure, no cure’and then all of a sudden somebody said there’s a cure. And so one person said what you’ve been constantly hearing, [that] there’s [no cure], you begin to believe what you hear” (45).

Harris et al. (2018) (47) also noted a barrier to be concerns about interferon treatment, which was an older, poorly tolerated therapy with low efficacy. Tofighi et al. (32) noted the limited awareness of the availability of the newer oral drug therapies as a much better tolerated and highly efficacious treatment to be a barrier.

Enablers to testing

Increasing awareness of HCV testing, treatment and cure

Increasing awareness of cure helped to engage PWID. One participant in the study by Coupland et al. stated that their knowledge of HCV and the treatment has changed: “[What was your understanding?] When you got it [HCV], you got it, that’s it. And you’ll eventually die from it. [But now?] Yeah, I know you can clear it and you can live a normal life” (33).

Ward et al. noted that social networks could help to increase awareness of HCV testing since there was an overwhelming willingness of the participants to discuss HCV testing and

treatment with people they have injected drugs with. Many of the participants felt comfortable discussing HCV and many had already had conversations with network members about HCV (50). One participant shared

We're already doing something we have in common...I'm talking about something positive, like going to the program and going to groups and meeting therapists and stuff like that. I would feel more comfortable about, 'Hey, man, you ever had your Hep C checked out? Because you know we do a lot of damage to our bodies, man, when we are out here using.' That's how I would approach it" (50).

This was echoed by another participant who stated:

Hire me. I would [encourage people to get tested and treated for HCV]. I mean, it would give me something to do. It would make me feel better... Because I would only be doing it for so many hours. And you have to go in certain neighborhoods too. That's another thing. Where there is drug use. And who's best to go but an ex-addict (50).

Traditionally, negative stories have dissuaded clients from seeking treatment but positive word of mouth stories have made a difference in encouraging people to get tested. Stories of newer, more effective and better tolerated therapies, convenient dry-blood-spot testing (which uses a fingerstick blood sample versus having to take a venous blood sample), and Fibroscan® technology to assess liver damage instead of having to get a liver biopsy to determine eligibility for treatment, have all facilitated engaging participants in care (49). One participant spoke about the new treatment options: "It's just general, you just sit and talk, but everybody's raving about this new stuff, everybody claims that 'oh I know someone that's done it'" (49).

Positive rapport with provider and staff

Coupland et al. noted the high level of rapport with staff at the community outreach center made a significant difference in engaging PWID;

It's cool to come and talk to youse and hang out whereas a doctor does not have the same rapport that you would get with me or anybody else. The doctor would go 'Oh yeah, you've got it, this is what you can do, okay see ya later.' Whereas you care a little bit more (33).

Having well informed and non-judgemental care providers helped as well: “Youse are young and, you know, up with shit. That helps too. Youse have got knowledge of how things are in the streets and what not, because of what youse do” and “There’s no judgment here. You are very understanding and easy going” (33). Latham et al. found that having site staff that “deal with [drugs and related issues] every day” was important as it meant that they were “not judgemental” (48). This theme was repeated in research by Phillips et al.:

I mean, I have to say I think [HCV Nurse] is one of the main people behind and she’s, she’s so friendly and nice that she just puts you at ease anyway. There’s not like, you’re not dealing with fearful doctors with a sense of impending doom on all sides (49).

Having providers who are invested in each individual was also helpful, one participant in the study by Harris et al. (2018) stated:

She’s even phoned me up to say, listen, don’t forget, if you don’t want to go, let me know. She’s good enough, she could have just sent me a letter out and just said, well, I sent him a letter, he never turned up (47).

Accessible testing options

Accessibility of testing was important. Barocas et al. (45) noted free testing, access to transportation, and mobile testing centers/syringe exchange programs are all enablers to testing. Ward et al. (50) noted that physically reaching people in their community was helpful. This was echoed in research by Tofighi et al.;

I am not gonna go to no building and get tested [for HCV] because I don't have the time for that. If that mobile van is sitting out there, and they telling me that's what it's for, I will go in there. It will ease my consciousness (32).

Individualized care tailored to the persons’ preferences and priorities

Choice around testing options is important. Latham et al. found that participants had discrepant views about the type of sample collection used for testing. Some participants preferred a mouth swab as a method of testing: “It’s like less hassle getting blood sounds really intense,

but doing a mouth swab, sounds really non-chalant. I'd come every week if that's all that it was", while another stated:

I'd rather just do the blood work [from a vein]. Cause I'm not just worried about hep C. I'm worried about the whole lot. So I'd rather do the blood 'cause then I'll know I haven't got hep C, hep B and HIV (48)

There were discrepant views regarding the importance of having rapid return of results as well; most preferred a same-day result whereas for others the same-day result was unnecessary. Those that preferred the same-day result noted that it "saves a lot of stress" if the result is negative and "get[s] the ball rolling sooner rather than later" if the result was positive (48). Others found it unnecessary to get a result in the same day:

I don't do things like share with other people, give my blood to other people, make other people vulnerable to it, so I don't have to worry... That's why it doesn't matter to me if they give me the result today or next week, whatever (48).

Coupland et al. noted that making information about HCV testing and treatment salient and tailored to the individual also helped with engagement in testing:

The part about my kids really stuck out, 'cause that was the part that was important to me most of all. And you answered my questions regarding that. I think a doctor would have jabbered on a bit. You answered my questions then you went 'And this is the other parts which could affect your life'. When you gave me the result, you answered my questions first and then you gave the spiel afterwards (33).

Discussion

The purpose of this scoping review was to explore the qualitative data that exists in the literature regarding the barriers and enablers to HCV testing as experienced by PWID. There are several quantitative studies that provide insight into the barriers and enablers to testing for HCV in this population, however, there are a limited number of studies which explore qualitative data. Qualitative research produces rich, detailed and valid process data based on the participant's perspectives and interpretation to give a more in-depth understanding of the barriers and enablers

(51). Qualitative data would provide further insight into the barriers and enablers that affect testing for HCV in PWID that the quantitative research may not provide.

This scoping review identified nine studies that provided some data regarding the barriers and enablers to HCV testing, which were included in the review; however, in most cases this was not the primary objective of the studies. My search strategy may have missed papers in the grey literature or those that were written in non-English language. I did focus only on PWID not those who used drugs by other means (i.e. oral or inhaled) though these behaviors have also been associated with increased risk of HCV infection (52,53). Nevertheless, the findings are relevant to my research question as the studies were relatively recent, having been published in the past decade with the majority in the past 5 years, coinciding with the WHO setting the goal of eliminating HCV by 2030 in 2016. HCV is now being acknowledged as a higher health care priority and more research is being done in this area. The experiences and perceptions of PWID are now being explored in HCV research, acknowledging that this is a priority population to support and engage in testing and care.

There is agreement of common barriers and enablers seen across studies. However, the size of the cities where PWID live, the perception of stigma, and the accessibility of physicians and HCV testing options may be different in NL. NL is a province with vast geography and the capital city of St. John's and surrounding area has a relatively small population, approximately 210, 000 people (39), compared to large major cities. All the studies in this review were set in cities with large populations such as New York City (8.5 million (54)) and Boston (650 000 (55)) in the United States, and Sydney, Australia (5.28 million (56)), which raises the question as to whether the experiences of PWID in these large urban areas is similar or different to those who live in smaller centers. The availability of testing options may be different and there may be

greater concerns over confidentiality, as studies suggest people in smaller communities experience more embarrassment around stigmatizing illnesses (57). In NL, HCV testing must be ordered by a physician or nurse practitioner typically in clinic or hospital settings; there are no testing options by peers or through community-based organizations, such as the ones described by some of the studies in the scoping review, offered routinely (outside of research studies). Testing may be offered as part of OAT programs but anecdotally it has been said that this is not done consistently or that testing may be offered upon entry into the program only and not offered again, even for people who continue to use drugs and having ongoing risk. It has been reported that an estimated 26% of people living in NL do not have access to a family physician or primary care provider (41), suggesting that access to HCV testing may be limited.

HCV testing options are expanding and point-of-care screening for HCV is available as an option in Canada. The OraQuick Rapid Antibody Test® approved by Health Canada detects antibodies to HCV with a 95.9% sensitivity and a 99% specificity (58). This option involves a finger-prick blood sample which is tested immediately on site and can provide results within 20 min (59). In comparison, standard HCV testing which measures HCV RNA (to distinguish between a past and or current infection) requires a venipuncture blood sample that is collected at a lab and usually takes several days to weeks for results to be processed and returned to the individual. Thus, point of care testing options can be more convenient by bringing the testing technology to the individual, eliminating the need for a visit to the laboratory, and providing a result in the same visit. It should be noted that in the event of a reactive result on a point of care antibody test, the result must be confirmed by standard HCV RNA testing at the lab; however, if the point of care test is negative, there is no need for confirmatory testing. Newer HCV point of care testing technology that can measure HCV RNA directly are under study, which may

eventually eliminate the need for confirmatory testing, however, in NL currently these testing options are not readily available outside of research study or special projects.

The evolution of testing opportunities may help to address some of the barriers and enablers that have been highlighted by this scoping review though point-of-care testing is not reliably funded in any jurisdiction in Canada, making this another largely inaccessible testing option (60). If this option was more widely available it would allow PWID to choose their preferred method of sample collection (finger-stick versus venipuncture) and have the option of a screening test that would provide a quicker result if this was of interest to them. This supports the enabling factors identified in this scoping review of ‘accessible testing options’ and ‘individualized care tailored to the person’s preferences and priorities’. As testing continues to evolve the potential for an approved HCV RNA point-of-care test would further enhance testing by removing the need for a confirmatory laboratory test and make testing even more accessible.

Point of care technology enables testing to be provided in non-healthcare settings, and supports the option of pharmacy-based testing models, which has not been studied explicitly to understand whether it would be preferred or acceptable to PWID. Pharmacy-based testing is a setting for HCV testing that was not explored in this scoping review. The APPROACH 2.0 study team hypothesized that a pharmacy-based testing program could overcome some of the barriers that have been identified in this scoping review (35) . For example, pharmacy-based testing could be seen as an accessible option in the community since pharmacies are widely available throughout many geographical areas. Pharmacy-based testing, which offers point-of-care or dry blood spot testing, could offer a solution to those who may not want to be tested via a blood sample drawn from a vein. Pharmacy based testing may address stigma as a barrier if PWID see the pharmacy as a discrete place for testing, as pharmacies offer many various services, however,

some patients may experience healthcare related stigma at pharmacies and may see this as a barrier. To my knowledge there has been no research done to specifically assess whether a pharmacy-based testing program is appealing to PWID, therefore, one of my aims is to explore this with PWID in NL.

Conclusion

My scoping review found that there has been some research surrounding barriers and enablers to testing for HCV in PWID over the past decade, though it has not been focused to specifically address testing in this population as a primary objective. Nevertheless, some common barriers and enablers to testing for HCV were observed, though how these apply to PWID in smaller communities is unknown. A pharmacy-based testing program may overcome some of the barriers identified in the literature, however, the perspectives of PWID is unknown. This forms the basis for my research, which will be described in subsequent chapters.

Chapter 3: Philosophical Position and Methodology

Through the scoping review I was able to gain understanding of what other research has shown in this area and use this to revise and refine my research questions based on the barriers and enablers to HCV testing in PWID that were discovered. I then set out to learn about the current environment of testing for HCV in St. John's, NL. I needed to understand the perceptions and lived experiences of PWID in NL to be able to explore the characteristics that would make a pharmacy-based testing appealing to those who were interested. The best way to embark on this journey was through qualitative research, specifically through one-on-one interviews. Interviews would allow me to hear detailed perspectives from each individual to really explore the experience of that particular person. After hearing from multiple individuals I would be able to determine if there were commonalities between experiences. Focus groups were considered but I felt that this methodology may allow for just some voices to be heard and that experiences may not be shared in much detail. There was a recognized power differential between myself and the participants in the interviews, as I was a healthcare provider and researcher, but in the focus groups there could have also been power differentials between individual participants. I felt that people may not want to share their experiences in this environment due to the stigmatized nature of the topic of injection drug use and surrounding HCV and I wanted to provide a safe comfortable environment for open sharing of ideas, thus I ultimately decided on one-on-one interviews.

Philosophical Position

To complete this research I adopted a relativist ontology under a social constructivist paradigm.

Ontology: Ontology relates to theories of what exists or what is “real” and tells us what it is we think we can know (30). Guba and Lincoln describe the relativist ontology as a paradigm in which realities are multiple, intangible mental constructions that are socially and experientially based, local and specific in nature (61). Constructions are not “true” in an absolute sense, but they are informed and alterable based on a person’s experiences. There are multiple, apprehendable and sometimes conflicting social realities that are the products of human intellects that may change as their constructors become more informed and sophisticated (61). Under this lens, objective knowledge is not possible and there is no single truth to discover but the knowledge is context dependant and produced within relationships and interactions (30). The goal of relativism research is to attempt to understand the social construction of meaning articulated by the participants. This ontology is particularly fitting for this research question as each participant knows their own individual truth and there is not one true universal reality. An individual’s interpretation of their own HCV risk, the factors that impact whether they get tested, and their acceptability (or not) of a pharmacy-based testing program will all be dependent on the participant’s lived experience and their relationships with the healthcare system, with others in their community, and with pharmacies as well.

Epistemology: Epistemology relates to what we think it’s possible to know, and therefore how we should go about trying to know it (30). Creswell describes how constructivism acknowledges that subjective meanings are formed through interactions with others and historical and social norms in the lives of individuals (62). Each experience is personal and will shape perceptions, beliefs, and the individual’s reality. Constructivism is founded on the premise that research practices *produce* rather than *reveal* evidence (63). Fitting the research question, this paradigm understands that the themes developed through reflexive thematic analysis reflect

the perceptions of each individual, there is no objective reality, and the themes produced are a co-creation of both their expression and my interpretation as a researcher, which are also dependant on context of time and place. Reflexivity is a fundamental principle of reflexive thematic analysis, both personal and functional. Personal reflexivity relates to how the researcher's values shape their research and the knowledge produced (30) whereas functional reflexivity relates to how the methods and other aspects of design shape the research and knowledge produced (30). Reflexivity is incorporated into the constructivist epistemology to allow for true exploration of the data and co-creation of themes through personal reflection and adaptation of the interview questions.

The goal of my research is ultimately to influence policy which will make HCV testing more accessible and acceptable for PWID and increase testing and diagnosis, therefore it is important to understand the participants' experiences of HCV testing and what characteristics of pharmacy testing they think are important. Understanding the individual experiences and respective 'realities' of PWID in this community will be best understood using this research paradigm.

Setting

This study was situated in NL, Canada and all research participants were living in the Eastern Health region of the province; specifically in or around the capital city of St. John's. Geographically, NL is one of the smallest provinces in Canada with a total population of approximately 520,000 and the majority living in the Eastern Health region (approx. 300 000) (39). There are 224 licensed pharmacies in the province, 80 of which are in the St. John's metro area where this research was conducted (40). Also of note, at the time of this study, an estimated

26% of people living in NL do not have access to a family physician or primary care provider (41).

Participants

Participants were recruited between June and August of 2022. Recruitment was based on criterion sampling including those who currently are injecting drugs or have a history of injecting drugs, and living in the St. John's metro area of NL. Recruitment was facilitated through partnership with the local Safe Works Access Program (SWAP), a safe injection supplies distribution program, who provided study pamphlets to their clients who dropped-in or received local drop-off of clean injection supplies (Appendix A), which acted as an invitation to participate. This recruitment method was accompanied by snowball sampling recruitment as participants were encouraged to share my contact information with their peers.

Ethics approval was granted from the Newfoundland and Labrador Health Research Ethics Board (Reference # 2022.071).

Data Collection

Individuals who were interested in participating were invited to call the researcher to arrange a time to conduct the telephone interview. Participants were consented to participate over the phone when they called to express interest in participating and they were offered a choice of doing the interview over the phone or in-person (at SWAP or at the researcher's office at Memorial University). Each participant was given a cash honorarium of forty dollars in appreciation of their time and sharing their knowledge. All participants chose to do the interview over the phone and I delivered honoraria to the participant's home shortly following each

interview. Field notes were taken during the interviews and after meeting each participant. Audio recording was used and interviews were transcribed verbatim from the recordings, then checked for accuracy and the recordings were deleted. To protect privacy, participants were assigned a pseudonym in the interview transcripts based on the top names in Canada during their birth year (64). If participants became uncomfortable or experienced any anxiety, emotional and/or psychological distress due to the nature of the questions participants could skip questions, take a break or stop answering. A list of local resources for psychological support was provided if needed.

A semi-structured interview guide (Appendix C) was used. The guide was developed in two sections based on the research questions. Because it was important to understand a participant's experience with HCV testing, the first part of the interview asked about the participant's experiences with HCV testing and explored these experiences, including whether knowing their HCV status was important to them or not and why. The second part of the interview started with me providing a description of what a pharmacy-based testing program would look like and then asked for their reaction and feedback regarding whether they would engage with this option. This section attempted to understand factors that were important to them related to pharmacy-based testing. Participants were also asked for their ideas on how to promote this testing option to their peers. The interview guide was reviewed by two individuals working with SWAP and their feedback was used to clarify wording to ensure the questions would be understood by the participants. The interview guide was used generally to guide the discussion, with broad overview questions and probes that changed over time in the direction of new hunches and as some probes became irrelevant. Consistent with relativist ontology, I was aware of the power differential between myself and the participants so in conducting the interviews I

tried to present myself in an authentic way to establish trust and rapport (30). As such, I made every effort to be authentic during my time with each participant to ensure they felt respected and listened to.

Data Analysis

Interviews were transcribed within 24 hours and coding, memos, and preliminary analysis of each interview were completed before moving onto the next. This allowed for reflexivity and adaption of probing questions for subsequent interviews. Reflexive thematic analysis was performed using an inductive coding approach, whereby categories and relationships were developed, and memos were written to eventually form themes (65). Each interview was transcribed manually, and significant concepts and ideas were coded by highlighting significant phrases. Reviewing interview transcripts, making notes, and journaling helped to interpretatively reflect on the data; Braun and Clarke refer to this stage as data familiarization (30). The next stage was coding the data; all relevant features of the data were tagged with a coding label. The coding process was iterative and changed over time as data became more familiar and relationships were established between codes across transcripts and codes that had similar meanings were condensed. My supervisor, Dr. Debbie Kelly, was engaged to review transcripts and coded extracts to ensure all potential codes were recognized and to ensure there was no significant misinterpretation of the data. A master list of codes with matching data extracts was developed. Like clusters of codes were arranged together to form themes, which were used to organize and draw relationships between codes and coded data (66). Transcripts were reviewed to look for confirming and disconfirming evidence for each theme. Themes were refined and subthemes were developed. Data extracts that best represented

participants experiences were selected to illustrate themes and sub-themes. Both my supervisor DK and I agreed on the final themes.

Reflexivity

Throughout the research process I routinely reflected on my assumptions of the data, my choices and actions in interview questioning and in coding the data. As qualitative research is a subjective process, it is important to understand that the researcher brings their “own histories, values, assumptions, perspectives, politics, and mannerisms into the research – and we cannot leave those at the door” (66). As mentioned, my background as a community pharmacist who has participated in dispensing OAT to patients with a history of injection drug use has influenced my interpretation of the themes. My position as a pharmacist may also affect the information that the participants chose to share with me, based on their experiences with pharmacists in the past. Having dispensed opioids and OAT to people with addiction issues I know first-hand that the perceived “policing” of the amount of medication a patient receives often falls on the pharmacist which can negatively impact the relationship with patients. However, I have also seen how the pharmacist can act as a confidante and a care provider for patients who are struggling or looking for someone to help them navigate their addiction journey. I considered that some patients may not find the option of pharmacy-based testing appealing and others may consider it as their only option that was of interest. Having not had a history of injecting drugs myself I wanted to hear from those with lived experience. When reading and reflecting on the interview transcripts, I considered the impact of my position as a pharmacist on the interpretation of themes and on what the participants chose to share with me, and I made efforts to ensure that my positioning was made clear in the writing. Journaling and field notes were done throughout the analysis process;

this reflexive writing helps to identify and keep track of personal thoughts, feelings, and emotions, and sheds light on unconscious and changing preconceptions because of the emerging study (67). Revisiting the journal entries corresponding with each transcript helped to give more context to the data.

As a new researcher in this area, it was important to me that the participants felt like they had power and control to determine how they wanted to participate. The addition of snowball recruitment allowed participants to share this opportunity with peers, they were given the choice of when and how to do the interview (in person or via phone), and they were provided cash honoraria which I delivered to them to make it as easy as possible. Recognizing that there may be a power dynamic at play, with me being a pharmacist and also a researcher, I wanted to ensure they felt respected and honored for their participation. Using reflective thematic analysis as my method allowed me to adapt the research questions to explore the perceptions and experiences of PWID in more detail. Because I do not engage in these behaviours I wanted to be able to follow where the participants experience took me. The one-on-one interview allowed the freedom of evolving questions into a conversation, exploring the specific circumstances and ideas that the participant shared. This method allowed me to ask probing questions related to the information shared and allowed me to craft my own curiosity for each individual and react to what each participant said.

The following chapter discuss the results of this qualitative work.

Chapter 4: Results

Introduction to Research Findings

To determine whether PWID would be interested in testing for HCV at community pharmacies, I needed to understand the current landscape of testing in this population. I needed to know if testing was currently being done, if so, was it being offered or were people seeking out opportunities for testing. I also wanted to understand the motivations for testing, and if testing wasn't being done, what was stopping people from testing. Is HCV something that PWID are generally aware of? Is it understood that injection drug use increases risk for HCV? I pursued to find these answers by developing a set of interview questions about perceptions and experiences of PWID surrounding testing for HCV (Appendix B). I began by asking 'tell me about your thoughts about Hepatitis C in general'. The participant's response then guided follow-up questions and conversation surrounding their testing experiences, motivations to get tested or reasons not to get tested, and their thoughts surrounding the importance of testing for HCV. The themes produced through the initial part of the interview were not specifically related to pharmacy-based testing and thus I have separated these themes from those discovered in the latter part of the interview.

I have chosen an integrated approach to presenting my findings whereby data extracts (results) and analytic narrative (discussion) are discussed for each theme instead of writing this as separate results and discussion sections. Braun and Clarke suggest this style of reporting, rather than separating results and discussion, to highlight the interpretive work and active subjective role of the researcher in reflexive thematic analysis (30). The analytic narrative contains connections with, and develops the analytic points in relation to, other literature and is showcased at the end of the demonstration of each theme.

Table 4: Participant characteristics

| Participant pseudonym | Self-identified Gender | Age | OAT* | Tested before | Sought/Offered test |
|------------------------------|-------------------------------|------------|-------------|----------------------|----------------------------|
| Amanda | Female | 37 | Yes | Yes | Offered |
| Michael | Male | 44 | Yes | Yes | Offered |
| David | Male | 64 | No | No | N/A |
| Jason | Male | 52 | Yes | Yes | Sought |
| Matt | Male | 22 | No | Yes | Offered |
| Sam | They/them | 31 | Prior | Yes | Both |
| Alex | Fluid | 20 | Unknown | Yes | Both |
| Robert | Male | 58 | Yes | Yes | Offered |
| Jennifer | Female | 48 | No | No | N/A |
| Sarah | Male | 46 | Yes | Yes | Offered |
| Chris | Male | 40 | Yes | Yes | Sought |

*OAT: actively on Opioid Agonist Therapy (OAT)

Eleven participants were recruited and consented to partake in a semi-structured interview. All participants opted for telephone interviews, which ranged in length from 20 to 50 minutes. Participants ranged in age from 20 to 64 years, and there was a mix of gender identities and hepatitis C status (positive or negative by participant self-report) (Table 4). All participants identified as having used injection drugs; some were involved in OAT programs and some were not. Most participants noted previously having been tested for Hepatitis C and few had reported never being tested. Those that had been tested in the past may have just been tested once over their lifetime despite ongoing risk through continued injection drug use. The following chapters describe the findings in detail.

Chapter 4A: Perceptions and experiences of PWID surrounding testing for HCV

Five overarching themes that relate to the perceptions and experiences of PWID surrounding testing for HCV are presented: “there are multiple reasons why testing is not being done” and “feelings surrounding testing vary”. There is a belief that “testing is important for health” but “access to and relationship with primary care providers affect testing” and participants felt “there is a need for both increased awareness of testing and more testing options”.

Multiple reasons why testing is not being done

Some participants reported that they had not been tested previously, and those who had been tested indicated that they were not tested regularly. Those that reported previously being tested may have just been tested once in their lifetime although they continue to be at risk due to ongoing drug use. Some of the influences on the decision not to be tested for HCV included the fear of consequences, testing not being a priority, and stigma surrounding both injection drug use and HCV infection.

Fear of consequences

Multiple participants noted fear or anxiety surrounding getting tested; in some cases, this fear stemmed from the potential for negative consequences if the result was positive. One concerning consequence was if their physician learned they were positive and labelled them as an intravenous drug user it could potentially mean that they would stop providing prescriptions for their prescribed opioid therapy. Jennifer spoke about her fears as follows:

And where I got like chronic back pain and like I got a medical history with that like 20-30 years long, I'm always like in the back of my head I'm afraid like, I would never want to be labeled with anything like it's important to me, because like [taking this medication] that's how I walk. Like I'm getting really bad really fast and I just don't

want to be shoved over to that side, ya know what I mean? Cause I've seen it lots and it's terrible.

This concern was echoed by Jason who stated:

It would be a lot easier and if people would know it's not a thing that like would be told to their doctor or something like that until they knew for sure, it would be a lot easier for them. A lot of people I know are right stressed out about [losing access to prescribed opioids] right?

Fear of the result also impacted testing; Matt said:

Um... I think it's something that I should probably have done, from certain situations, but it's something that I'm just nervous to get done, that's about as far as my thought train goes on it, it's nothing more than the nervousness of the result.

One participant indicated that a lack of education and fear surrounding the result can prevent testing. Sam shared, "A lot of people don't know the actual risks or they're afraid to get tested. If they're using with their friends and that maybe there's a fear there, maybe a lack of education."

Lack of self-perceived risk for HCV infection

Some participants did not know much about HCV symptoms or the increased risk of contracting the virus with IV drug use. Risk of transmission was discussed more often in the context of sexual activity than from injection. Robert noted:

I wasn't aware that Hep C was so rampant until a couple of years ago. There's a whole community of us that kind of... sleep around... and I found out that some of the young girls don't even know that that's a thing, and I said you don't have to share it's just something that happens. And especially if we are going round just banging each other.

Jason stated that he thought about HIV risk but HCV did not cross his mind after being accidentally pricked when using drugs with friends, he stated:

She stuck me right in the forehead with it, she tripped up and ah, we were doing heroin and I got so angry I actually stuck her hand down in with a piranha.... First thing I thought of was that she gave me HIV right?

He also mentioned: “Well right away when I first got stabbed, right in my forehead, right in the forehead, what a shot. I did not know exactly what Hepatitis did to ya right, I started reading up on stuff.”

Testing is not a priority

Many participants noted that testing wasn't something they thought about and it was not a priority. Jennifer stated;

Um, I never really ever thought about it... I've never [been tested], never had any reason to. I might be wrong in saying that, that's how I think of it, I don't know if I should think of it in any different way.

'Clean' practices led to assumptions that they did not have HCV in many cases, meaning testing was not a priority.

Chris shared that addiction could supersede getting tested due to the length of time testing takes and he would not go to the hospital to get tested:

Because it takes 2 hours sometimes, it's a long time, and you know, an addict, is always... thinking about a fix ya know what I mean? By the time you left the hospital if you didn't get what you were looking for you'd be dopesick.

With the priority in addiction being getting the next dose, testing may be an inconvenience and not a priority.

Matt also expressed his denial surrounding his drug use as it relates to testing not being a priority for him; “I've been in denial about my addiction for a while. So when it comes to testing for a disease related to it... or a condition or whatever, it's almost like I feel in my brain I don't have to.”

Stigma

Stigma surrounding the diagnosis was also a factor preventing testing for HCV. Participants described stigma surrounding the diagnosis of Hepatitis C as well as stigma

surrounding injection drug use. Testing positive for HCV was seen to have a negative connotation within social circles and people would not want to risk becoming an outcast from peers. Michael stated: “Yeah well no one wants people to know they have Hep right? It’s like you have leprosy then where everyone wants to be away from ya right?” Even going to get tested was seen to have stigma attached. David stated: “When you go in to [get tested], if you’re put in that category as an injector then you’re probably not going to get anybody to [get tested] because they’re automatically going to be, ya know, have that label.” Participants experienced stigma from healthcare staff due to injection drug use alone, with or without having HCV infection. Amanda stated “I find there’s a little bit of stigma, people kinda like look down on IV drug users, even the doctors at the Health Sciences, I still felt a bit looked down upon.” There was a recognition that stigma affects PWID in many ways and there was an acceptance of that being the way that it is. Amanda stated “He was a liver specialist and I remember it was almost like, being looked down upon or what not. I guess he was a doctor and I’m not”. Robert also said

There’s such a stigma, We’re some of the most brilliant but most judged people in the world and I don’t really give a shit about it. It’s just the way it is. I get it, you haven’t walked down that road, but I just have to laugh.

The stigma applied in health care systems to PWID could result in them being treated differently if they were labelled as injectors and this would make them not want to get tested.

There were aspects of this theme that were reflected in the scoping review, but there were some differences as well. The first reason for why testing was not being done that I explored was the fear of consequences, including concerns about possible negative consequences if their physician learned they sought testing for HCV. This theme was consistent with my experiences as a community pharmacist often involved patients disclosing information to me that they did not want to get back to their physician due to fear of implications. Oftentimes patients would request

early refills on their opioid prescriptions but when I told them I could only release it early if the prescribing physician allowed it, they would not want me to ask for the permission. The idea that they did not want their physician to know about their drug use or potential misuse was echoed by the participants in this research; the potential for testing for HCV to risk losing prescriptions for opioids or OAT if the physician was made aware was often an important reason not to get tested. This is not a theme that had come up in the scoping review but was a strong message in my work.

Fear of the test result was a theme that was seen in the scoping review and in this study. There may be fear of the result being positive because of the social impact it can have, concerns could surround what their friends may think of them if they had HCV infection or if they've accidentally spread it to their friends while using together. The details of why the diagnosis is feared was not disclosed by participants in this study nor cited through studies included in the scoping review. Matt was nervous about the result but was not clear why; similarly in the scoping review some participants stated they were afraid but they did not elaborate. The reasons could vary, perhaps the concern is for their own health and longevity and the fear of facing morbidity and mortality. Participants could share Sam's concerns about the impact it could have socially and they may be concerned about the stigma surrounding the diagnosis. More work could be done to explore the concept of fear of diagnosis and the reasons why this fear exists.

The lack of perceived risk was noted in other studies as discussed in the scoping review as well. If people do not think of themselves as being at risk of HCV, either due to not being aware of the symptoms or risk factors for infection, or because they relate risk of transmission more to sexual activity than injection drug use, they will not be as likely to seek testing.

The idea that testing was not a priority among PWID was seen in other studies as well as mine. The scoping review revealed the lack of motivation or competing priority of drug use as barriers to testing for HCV. The idea that clean practices means that there is not a need to get tested for HCV was also seen in the scoping review where a barrier was noted to be ‘self-perceived low risk of disease’ because participants reported using clean injection practices.

The final reason identified in this study for testing not being done was stigma. Stigma was also noted as a barrier to testing in the available literature as shown in the scoping review. Stigma is also discussed further in Chapter 4B as it was a common theme explored in response to the questions surrounding pharmacy-based testing.

Access to and relationship with primary care provider affects testing

Some participants had access to a general physician and were more likely to have been tested in the past; “Um I know [my status], I got treated a couple of years ago, um I hooked up with a doctor, [Physician name] and she took care of all of that” – Robert.

Many participants stated they did not have an accessible family physician and weren’t aware of their options for testing. Sam stated: “And I think a big part of it for me where I used to be tested regularly years ago when I was using opiates but now I don’t have a family doctor, and not knowing what my options are”. Chris also did not have access to a family doctor outside of care within the prison system: “I haven’t seen a family doctor in years, just besides the institutional ones that do the basic checkup when you come in right”. Alex stated: “I have one, he’s just never in and doesn’t know how to answer his phone. So I do have one, but I’m looking for a new one”, showcasing that even though he has a family doctor, care is not something he can easily access. The lack of access to a primary care provider makes it difficult to avail of the

traditional route of testing, which involves getting a requisition for bloodwork and receiving the results through follow-up with this provider.

Some participants had negative relationships with their family physician which affected testing for HCV. David stated: “Yeah, well, yeah but ah, our rapport is not really good ... I mean he’s a real asshole and he’s very close minded and he has no empathy towards me whatsoever, none.”, and Amanda said: “Yeah, like doctors try to brush you off and like try and hurry you up and you only have 10-15 minutes with them and sometimes you need longer, and now with just the phone it’s even worse”. Chris also echoed this sentiment:

I don’t have a doctor first of all, and I ain’t never going to get one. I guarantee you right now, I’d die 80 years old and a doctor will be begging me and I’ll be like ‘get the fuck away from my bed let me fucking die alone.

Without accessible family physicians, participants are likely not to get tested regularly as this is the current most common route to access testing. Other opportunities for testing that did not involve a family physician were mentioned throughout interviews, including testing through institutional programs when incarcerated, testing through Nurse Practitioner-based clinics set up by community-based organizations, and testing when hospitalized. Some participants had availed of these alternative options for testing due to the negative rapport with their family physician or when they did not have access to one. Others had not been tested because of the lack of access.

The scoping review also revealed the repeated theme of ‘lack of rapport with provider’ as a barrier throughout the literature, which complements ‘positive rapport with provider’ as an enabler to testing. The scoping review also indicated ‘antipathy in relation to mainstream healthcare services’ was a barrier to testing that also shared a common thread with this theme, citing examples of physicians not being respectful of those who inject drugs, shame and embarrassment about scars at testing sites, and not being bothered to go to the hospital.

Testing can be emotionally uncomfortable for some but not for others

Testing for HCV was uncomfortable or nerve wracking for some participants; “[I felt] nervous, but definitely like it was something that needed to be done” – Alex, and “It was no different than any other test, same thing as any other test, a little bit nerve wracking, especially if you’re an IV user and that right?” – Sarah. When asked how it felt while being tested for HCV Amanda said: “Ahhh... Dirty, if that makes sense. I felt dirty, the bottom of the barrel, kinda like Oh my God I can’t believe this is happening to me type thing.”

Other participants felt that testing wasn’t uncomfortable when it was combined with a long list of other items; “I was offered a test. Along with a couple other tests. A NP I saw through the clinic recommended a large list of tests to me. It was a pretty normal experience I guess. It wasn’t awkward or anything.” – Matt. Like Matt, Sam did not find it uncomfortable; they stated:

I guess where I did the blanket testing for everything it kinda covered everything and I didn’t think much about it because I didn’t alienate it in my head. It kinda threw it all together and they tested it for everything and they ask everything and it’s like ‘just everything please, thank you.

Not singling out HCV during testing was seen as a positive thing, it cut back on the discomfort surrounding testing and prevented them from feeling the same stigma as if only HCV was ordered for testing.

Feelings surrounding testing varied and for those who did not feel uncomfortable it was noted to be because the test for HCV was not singled out and brought to attention. Some participants who appreciated their risk of infection given their history of injection drug use felt nervousness and anxiety about getting tested. ‘Fear of diagnosis’ was an identified barrier to testing in the scoping review and appears to be a common idea among PWID as seen earlier. The fear of consequences in this work included the fear of diagnosis.

Need for increased awareness of testing and more testing options

There was a recognition that not enough people are getting tested. Sam shared: “It’s really important and I feel that I guess not enough people are getting tested at the right time”. They also noted that they weren’t aware of testing options: “Not knowing what my options are, and hearing if there was like more posters or educational opportunities at pharmacies and that, like ‘hey this is where you can go to get tested that would be great.’”

There was also a recognition that treatment is now more tolerable and accessible and this is yet another reason increased testing should be done to link people to a cure:

One time they never had the cures that they have today but, like, I think myself. If you’re unlucky enough to get any type of disease but lucky enough to have a cure for it, I think that probably should be educated more. And like, ya know, whatever can be done to make that possible – Jennifer

And

The treatment is available, they can take a pill, anybody can get cured at any time, why should there not be widespread HepC testing, why should people be going around with HepC when they could simply go to their doctor, get a pill - Chris

There was a strong sentiment that people are deserving of a cure now that the price has decreased from what it was and also the idea of acceptance that they would not be offered treatment at the previously more costly price tag. The increased potential for access to curative therapy was seen as an important message when encouraging people to get tested and when developing new testing options such as the proposed pharmacy-based testing model:

You should put that in there, you should be like ‘times have changed’ I think you should kinda be like, I don’t know if this is going to be part of your thesis or whatnot. I write my own papers of course. But if you want to put in ‘the times have changed, treatment isn’t what it used to be. It’s not a 20-thousand-dollar treatment only available to federal inmates or on a 6- and 12-month waitlist. The times have changed. Hep C treatment is readily available so why isn’t Hep C testing readily available – Chris

Many participants shared experiences of being in OAT programs and it was suggested that this is a missed opportunity to engage patients, to provide education about HCV transmission and risk, and to encourage regular testing. Sam stated:

I think [OAT programs] could definitely do more. And it's something they could use to educate people, it's like, when I started the program, they told me when you first start you might not feel good and stuff so just swallow stuff, because you're still trying to find out your dose, but do you think anyone really does that? {laughs} And you're just tested the one time, and for the first month or two you're still using and they don't do a blood test again. I think I only had the one blood test the whole time I was down there.

Michael mentioned having the OAT dispensing pharmacist bring up the offer of testing as an opportunity to engage: "Most times pharmacists will call you up to give you your Suboxone® or methadone and they could mention it while you're in the consultation."

There are a lot of missed opportunities to engage people by offering testing. There was an overall sentiment that participants would be accepting of an offer to test; "I'm all for it" – Robert, and "Well, I think it's a good idea! Ya know, everyone would like to know. Ya know. There's not much else to say on that, it is ah, I can't see anyone wanting to turn it down!" – David. If more PWID were offered testing from healthcare providers it appears that there could be a high rate of acceptance.

The scoping review showed similar themes. A barrier to testing was 'limited awareness of HCV and testing' and an enabler was 'increasing awareness of HCV testing and treatment and providing positive narratives surrounding care'. This is a commonality across the literature and highlights the importance of education to this community regarding their risk and testing opportunities.

Testing is important for one's own health and the impact on others

All participants noted that testing for HCV is important, and even those who don't think of it often shared that they felt it was important to do. There were various reasons for testing mentioned. Participants noted the important impact of knowing one's status on relationships; "Well of course it's really important. For me, because I wouldn't be, ah, I wouldn't be flirting with other girls if I knew I had Hep C that's for sure" – Chris, and "Yup yup, knowing in general actually is important, because if you're in a relationship with someone or you know, you yourself would want to know if you're sick"- Amanda. The effect of knowing their HCV status on the relationship with others was noted more often than the effect on oneself, showing the caring nature of the participants and consideration of their impact on others.

Another reason why testing was seen to be important was parental responsibility and caring. Alex noted "I had a pregnancy scare that definitely led me to get tested" –and Amanda stated:

Ahh well [testing is] very important actually, because I have two small kids, so ya know. So if I had to cut myself and they cut themselves and then it would be blood-on-blood and I could've transferred it to them.

Participants also were aware that it was important to know HCV status to make appropriate decisions for their own health: "Well it's just helpful, because something as simple as taking Tylenol cause codeine's hard on the liver, so you have to avoid codeine and avoid drinking, and stuff like that that's hard on the liver ya know." – Michael, and "It's very important, it's my health, it's my body, I'm getting older, not younger {laughs}" – Jennifer. When asked what led them to getting tested in the past, Alex considered both themselves as well as others they may relationships with, they stated:

I guess safety all around, I'm someone who in the past, and that's not to say that in the future it won't happen again, but hopefully it doesn't, but I'm someone that has shared

needles. Obviously, I'm 21 years old, I'm sexually active, so it's incredibly important that I know what's going on with my physical health or my mental health but my sexual health as well.

There was recognition that there is a risk of contracting or spreading HCV infection when sharing needles and therefore a reason to be concerned about their own health, but also the health of others. This theme was not mentioned in the scoping review. Since the motivation for testing was not the primary focus of the studies included in the scoping review, it may not have been probed during the other authors' interviews. However, it is an important finding in this study and should be explored further.

Chapter 4B describes participant views on the pharmacy-based testing model and what aspects of this testing option might be important to overcome barriers to testing.

Chapter 4B: Characteristics of pharmacy-based testing of importance to

PWID

Next, participants shared their views regarding HCV testing through the pharmacy-based testing model being proposed by the APPROACH 2.0 study. I sought to determine if pharmacy-based testing for HCV would be appealing to PWID and what features would be important to them.

Five themes are discussed: “Ease of pharmacy testing”, “Confidentiality is important to attract people to testing”, “A fast result is often valuable”, “Less invasive testing is appealing to some”, and “The relationship with the pharmacy and pharmacist affects testing”.

Ease of pharmacy testing

Multiple participants perceived pharmacy-based testing to be easy because it would be accessible, convenient and fast. There was an appreciation that pharmacies are accessible in their proximity, with the recognition of a pharmacy being in almost every neighbourhood, Matt stated:

Yes, if it was as simple as, I mean I live in an area of close proximity to a lot of pharmacies and I work at a place with a pharmacy, so if it was literally that simple, if like anyone of the pharmacies near me in my travels would offer that service I would very much regularly go as long as I was using.

Like Matt, Sarah noted the proximity: “I just like it because it’s close to me, the pharmacy is really close to me. Pretty much next door so.”

The pharmacy testing option was seen to be simple and more convenient, requiring less steps to complete the testing process; “I’d prefer to go to the pharmacy. There’s a couple procedures there eliminated right from the get go. Going to the doctor to get the requisite done,

that's a pain in the hole in itself" – David, and "Cuts down on the driving time, the babysitter time, the waiting time, the gas bill, it's just overall so much more beneficial" – Jennifer.

The pharmacy option was also perceived to be faster, requiring less waiting time; "I'd rather go into the pharmacist. Cause like I said, there's no big line ups" – Amanda, "Oh yes, people will probably go there to get tested because it's shorter than standing in line to get tested at the hospital" – Michael, and "I think testing option at the pharmacist will help cut back on waiting room time, trying to find family doctors to do the testing and all that, I think it will make it much more accessible"- Sam.

None of the studies included in the scoping review asked specifically about pharmacy-based testing options so there is no comparative research to consider. However, the scoping review noted that an enabler to testing was 'accessible testing options'. If participants view pharmacy-based testing to be easy, convenient, simple, and fast it may be considered an accessible testing option and ultimately be seen as an enabler to testing. Although pharmacy-based testing was not an option included in the studies within the scoping review, Barocas et al. (45) noted that free testing, with access to transportation, and mobile testing centers/syringe exchange programs were all enablers to testing. Through the APPROACH study, pharmacies would offer testing at no charge to participants and would be more accessible which aligns with the enabling factors cited by Barocas et al. (45).

Confidentiality is important

Some participants preferred the pharmacy testing option as they saw it as more confidential and private;

Oh the pharmacy route [would be preferred], that's the nicer sounding option. Especially if that's the reason that I'm going to get tested. If my goal is to get tested for HIV or

Hepatitis C or something along that line, I would much prefer the discrete system like the pharmacy where it looks like you go in to talk about medication and then come out. Nobody knows why you're in there, it's behind closed doors. - Matt

And

It would be the first place I'd go; I would rather go to the pharmacy to get tested over the hospital. I mean now it doesn't matter to me but back then I would've rathered to go to a pharmacy because of the, ya know, the stigma of it, ya know? You might run into someone in the hospital, and they're asking what are you doing there and that, and they might even know the person taking the blood and they might say yeah that person is here to get checked for Hepatitis. They're not supposed to say anything but they do, I know that for a fact, like it gets back to your parents, and then it's all downhill from there, which it shouldn't be. -Jason

Other participants expressed their main concern about the pharmacy option would be if it weren't a private environment. Alex stated: "Honestly, I think the only thing would be like doing it out in public, but like you said, it would be in the private case room so I can't think of anything." When asked what would turn them off from pharmacy-based testing Michael replied: "Putting a sign up saying they're testing for hepatitis {laughs}. The only concern is that people would know that's why they're going there", and Jason stated "[The only thing that would be a turn off] was if there was a line of people like stood up behind ya kinda thing". These participants could see that there is a potential for a lack of confidentiality at the pharmacy. The importance of staff members at the pharmacy respecting and upholding confidentiality was brought up. David said: "Well the confidentiality part of it would [be a turn off], because, some pharmacies, the assistants aren't very cooperative in their confidentiality right. Like I've heard these people talking about other people behind their backs," while Amanda added:

Ummm... I don't know [what would be a turn off], I don't think anything would. Probably just like if you knew one of the pharmacists there or you knew the pharmacy tech and they knew what you were there for.

Confidentiality was not identified as a significant barrier in the scoping review as discussed previously. However, the study by Barocas et al (45) listed confidentiality as both a barrier and enabler (if confidentiality was present). This study asked participants “what makes it harder for you to get tested for hepatitis C?” and “What makes it easier for you to get tested for hepatitis C?” Confidentiality was a barrier noted by only 3 of 349 participants and an enabler noted by only 9 of 349 participants (45). Although confidentiality was a factor it does not appear to be a strong sentiment in this study in Wisconsin, USA; the authors note that most participants were from Milwaukee, the largest city in the state, and that the experiences of those living in smaller centres may be different. Other studies in the scoping review did not mention confidentiality. In smaller centres, such as the St. John’s area of NL where my study participants were located, confidentiality and discretion were identified as very important issues.

A fast result is often valuable

The pharmacy-based testing model presented to participants makes use of point of care testing technology, which provides a faster screening test result as compared to standard laboratory testing. Some participants felt this would alleviate fear or anxiety associated with waiting for the result. When asked how important it was to get a result quickly Michael replied: “Extremely, if I didn’t know I had it and had a fear that I did I’d want to know right away, wouldn’t want that sitting in my head, I’d want to know right away” and Sarah stated “It is important! Because sometimes you’d be stressin’ waiting for it. Gee sometimes you wait weeks.” This was repeated throughout other interviews as well:

I think for me yeah, like getting it quickly would be the best, because maybe I’ve been using in dirty places and I’m nervous or something now, and I want to go in and I want a quick response. Like ‘so do I have to go set up an actual doctor’s appointment now or is it possible for me to find out, like if I’m not a positive positive’ I’m like ‘Peuf’. I like that

you do that, basically the screening thing, like I said, if I was using in a dirty place and I was nervous I'd be like 'Oh shit maybe I was high and used someone else's needle', you never know right? - Sam

Another reason why the quick result was important was that it could have significant impact, Sam said "I think it would save lives because you know if I go out somewhere and I know I got tested, like I'm always careful with my needles, like I bottle them up, but like thinking like some people don't"; knowing the status may impact the practice of sharing needles if someone is getting tested regularly. The impact on sexual relationships was also brought up;

Well, you could have a partner, there's a hundred reasons. You could want to be getting in a relationship with someone and have to wait on the results. And then, I mean, let's face it. We know the way love is. You can't hold off if two people, chemistry mixes, and you're there. - Chris

A quick result would also relate to more action taken. Participants relayed that the longer they wait the less likely they are to act on it or seek out the result. Chris stated:

Of course it's important, well I'll tell you, for my personality, I'm the type of person that gets stuff done. I always tackle everything right away and get it done within a day or two, but I'm the type of person that if I start something and I don't finish it it would likely end up on the back burner for quite some time. Most often times just stays there, if I don't do it right away usually I'll just leave it there.

This was echoed by Matt;

If I felt I had symptoms or something, if I felt extremely unwell and I thought that was the cause then the longer you push it the more stressful it gets. Seven days is almost enough to have my brain pull back from the situation.

Fast results, in this case, just 30 minutes, could potentially attract PWID to this testing option for these reasons.

The only study in the scoping review which mentioned the speed of the result was the study by Latham et al. (48). In this study the participants had discrepant views on the rapidity of the result return, most did prefer a same-day result whereas for others the same-day result was unnecessary. Those that preferred the same-day result did note that it "saves a lot of stress" (26

p921). Although most participants in my study did note the importance of a fast result there were also some discrepant views in this work. Jason stated “I do like the quicker option but like if I do have to wait a week or two for sure but having the results the same day would be amazing”, and when asked if they would mind waiting a week for the test David said “No, no, I mean it’s a test”; in this case it was acknowledged that test results take time. Knowing that the quick time to result is important to most PWID is vital in designing testing options that will appeal to them, including those offered through pharmacies.

Less invasive sample collection is appealing to some

Getting tested for HCV through traditional testing requires a venous blood sample, whereas the proposed pharmacy-based testing option would allow for a finger prick blood sample. When asked which they would prefer, participants’ opinions varied. Some preferred the finger prick just because it was faster: “Finger prick, or whatever, whatever way is fastest” – Jason, and “Awww don’t really matter to me! Finger prick probably would be the best, cause it’s quicker, something like the glucose monitor, makes your finger a bit tender but - {laughs}” - Amanda.

Other participants preferred the finger prick because of a fear of needles or bloodwork:

Um, I would probably, as funny as this is, I’m afraid of needles, so I would probably get the finger prick. Yeah, when people find out that I’m an IV user and I’m also afraid of needles they get very confused. But I don’t like other people giving me them. - Alex

And

I prefer finger prick. It's easy, and I don't know what it is, even though I was an IV drug user, watching the blood squirt outta me into the vial it's fuckin... I don't know, I just don't like looking at blood. - Michael

Sam brought up the point that injection of a needle into a vein to draw bloodwork could be triggering for those who are trying to be/stay sober;

I wasn't injecting for 5 years right, and anytime I'd go get bloodwork it would be kinda, bringing me back to needles, and like that kind of thing, and would put me back in a really bad headspace for a little while right? And I used to avoid bloodwork after I got sober right... Because they say you get addicted to the feel right? Even the prick, like it's a whole ritual right, even like setting it up. So I know I wouldn't mind as an injector right now, but if I was someone say, just going into my recovery from using needles, maybe it would be better to go with a finger prick.

Other participants brought up the point that it is sometimes challenging for bloodwork technicians to get blood from their veins due to their history of injecting drugs and the associated damage caused; "Well either way it doesn't matter, but they might have a hard job drawing it from me, it's the hard shape that they're in now" – David, and

For me it would probably be the finger prick, I don't usually mind getting my blood drawn at all, I mean obviously because I'm an injector {laughs}, um, but sometimes I do get frustrated when people are new at it and it's like I could hit myself better than you can hit me right now and they're picking and poking at me like sometimes it frustrates me and stuff – Sam

A different opinion was that bloodwork would be preferred because it's familiar and less painful; "I'd take the bloodwork; I've always got a needle in my vein anyways. For me, I don't like finger pricks, I'm not a diabetic, I don't have finger pricks. They hurt!" – Chris.

The preferred method was different for different individuals, most preferred finger prick but some did not prefer one over the other and one preferred bloodwork. The scoping review also found that 'personalized care' was an enabler to testing, the studies included in the review showed that participants had discrepant views about the type of sample collection just as was seen in this study. Improving testing access by offering choices for testing modalities is an important way to personalize care and improve testing uptake.

Relationship with pharmacy/pharmacist affects testing

Participants shared various reasons why they would prefer pharmacy-based testing to the traditional route of testing and these were often related to the relationship with the pharmacy or the pharmacist.

Pharmacy's physical space is more comfortable than other settings for testing

Being in the pharmacy may feel less clinical and may normalize the testing experience. This environment may be less stressful than other testing options and may put people more at ease. Most participants were accepting of pharmacy-based testing for HCV and noted that the physical space would feel more comfortable than going the traditional route through primary care providers' offices and then hospitals for bloodwork. David stated:

Well I guess the environment, you wouldn't feel, ya know, you'd feel more comfortable, you wouldn't feel like there was a big major problem, ya know right, like you're just goin' in for a test. The hospital always got that gray feeling with it ya know, I'm in the hospital, what happens if something goes wrong, ya know?

Positive relationship with the pharmacy staff would attract people to testing

The relationship with the pharmacist also plays a role in attracting people to the pharmacy-based testing option. Some participants perceived the pharmacist and the pharmacy staff as being care givers and there was comfort in going to someone who knew them and cared about them; "I'd go to my pharmacy because I know these people really good right" - Jason and "Yeah, I'd rather go to someone that I know, especially someone that knows the medications that I'm on, etcetera" - Alex. Sam echoed this comment;

And on top of that too, there's kinda a relationship built with your pharmacist. So over the years, a friendly face is kinda nice to see, someone that you've gone to before or just an area that you feel comfortable with is pretty cool too.

The attitude of the pharmacist towards PWID affected the attractiveness of pharmacy-based testing; Alex stated "Well for one, pharmacists I feel, well in most cases and in ideal cases,

are a lot less judgmental because they do deal with methadone and Suboxone® so they do see addicts.”

Negative experiences with pharmacists would prevent people from seeking testing in this setting

The most common sentiment of the participants was that the pharmacy option would be preferable however, there was one strong opposing view. Robert shared discordant views from other participants and preferred testing through the traditional route solely based on the negative experiences they had with pharmacists. He shared his history of conflicts with pharmacists in the past surrounding OAT and stated: “I don’t like pharmacists. They just seem much more judgmental than a doctor” and “Well... Ah... It would have to be a whole different situation all together [to consider the pharmacy testing option]. I’d have to not have a family doctor. I don’t know. I’d go get a doctor first myself.”

Matt noted that pharmacists aren’t always accepting of PWID and the specific pharmacist working would affect the appeal of pharmacy-based testing:

The only thing about going to the pharmacy that wouldn’t be appealing is just that the occasional pharmacist is judgy, but that’s as far as it goes from my experiences. It’s a bit of a coin toss when you go into the pharmacy to buy a pack of needles and it’s either they glare at you or they say ‘here you go sweetie’, I don’t want the former doing the test {laughs}.

There was also a feeling of distrust towards those on OAT programs at the pharmacy which could negatively impact testing, Sam noted:

But now, they put a locked door in between [the pharmacy and the front store]. It was kinda like we used to have access to the store, and we asked to have access to the store too because we have to buy groceries and stuff like that. But now, even though there’s a door you have to walk all the way around. It’s kinda like they act like ‘we gave you the choice’ but this is our way to make sure no drug addicts get in and steal stuff right? I don’t know, it’s kind of weird. There’s a lack of trust or whatever.

If people feel that they are not trusted they may feel that testing in this setting is attractive to them.

PWID may not go to their regular dispensing pharmacy for testing

There were differing opinions on whether the participants would go to their regular dispensing pharmacy to get tested or would rather go to a different pharmacy for testing. Some felt it did not matter what pharmacy offered the testing; “Yeah no it doesn’t matter. And I’ve become somewhat shameless when it comes to this because it’s somewhat hard to hide” – Matt, and Sarah stated “Yeah I’d go, wouldn’t bother me. I’d go to the same pharmacy, doesn’t make no difference to me.”

In some cases the participants stated strong opinions that they would not go to their regular pharmacy due to fear of consequences surrounding access to prescription opioids or OAT. Jennifer shared;

Nooo I would not want to go to my own. I could possibly change my tune right, the only thing I’m afraid of there, is like I said earlier, discrimination right? Like my medication is so important to me and I have to be on it the rest of my life, surgeons can’t do nothing for me, so like ya know what I mean? I can’t afford to be, like ya know, pushed to the side line because of a bit of, whatever I does.

Sam shared this sentiment but surrounding how it may affect access to OAT:

Yeah [I would go to my pharmacy] but I can also understand some people not wanting to go, I guess it depends, I’m off methadone now, so I wouldn’t mind going there now, but I know some people would be kind of cautious or nervous if they are still using say on these programs, they might kinda hold back to get testing out of fear they’d get in trouble at the program that they’re on that they’re using. So it depends on that kind of thing too.

Chris was uncertain whether they would go to their regular pharmacy for testing because it could affect their reputation or future work or social opportunities.

I’m not worried about being discriminated against, I would just ah, I don’t know, it’s just, I get along with them and I think I’m [an athlete] and a student and I take pride in myself, and I don’t want to tarnish my reputation and my image ya know? The social swag like, where I’m a student I look at pharmacists and pharmacy techs as kinda like people I’d hang around with and be friends with and I wouldn’t want to tarnish my reputation and be, what do they say, outcasted. When you’re put out of a circle. Ya know what I mean?

The perspective shared from participants was consistent with my experience as a pharmacist. I have seen many people who have had positive relationships with pharmacy staff and also those who have had negative experiences at pharmacies or with some pharmacists. As I was interviewing participants I had concerns that some may have been sharing overly positive sentiments about pharmacy-based testing because they were aware that I was a pharmacist and I was worried that they would tell me what they believed I wanted to hear. However, each participant that was pro-pharmacy testing shared concrete reasons why they thought this way and the discordant view of this participant was also explored.

Although none of the studies in the scoping review asked about pharmacy-based testing but “positive rapport with provider” was noted as an enabler and “lack of rapport with provider” was a barrier. The pharmacist will be the provider in the case of pharmacy-based testing and the rapport, and the relationship, with the pharmacist and pharmacy will be key to attracting PWID to testing options.

This theme is very specific to pharmacy and showcases the intricacies of the perceived consequences of participants that contribute to their choice to go to their regular pharmacy or not. This adds immense value for consideration when developing a pharmacy-based testing model and will impact recruitment for screening, ensuring that pharmacists are open to screening patients that aren't regular customers of their pharmacy since they may not feel comfortable being tested at their regular pharmacy.

Advertising pharmacy-based testing

Throughout the interviews, information was also collected to determine the most effective ways to advertise the pharmacy-based testing service to inform the larger APPROACH

study. Many ideas were shared including advertising through needle-exchange programs (similarly to how the participants found out about this study), distributing pamphlets through doctor's offices, putting up posters at pharmacies, health care centers and community bulletin boards, advertising on the radio and news channels and more. Important points about effectively engaging PWID specifically were mentioned. For example, one participant noted that targeted advertising through Facebook may not necessarily be seen by PWID because they may not be open about their injection drug use on the platform. Participants stated that following the recruitment strategy that I used in this study (i.e. including pamphlets with clean needle supplies through community-based programs like SWAP) could effectively spread the word about the testing options at pharmacies. The APPROACH study team was able to use this information to adjust the advertising of the pharmacy-based testing study to be able to attract PWID.

The themes outlined within this chapter give important insight into the thoughts and feelings of PWID. All of these themes should be considered when designing and implementing pharmacy-based testing programs to make them appealing to PWID. Pharmacy-based testing for HCV is seen to be easy due to accessibility, proximity, and speed of the result. The fast result is often valuable but may not always be necessary. Confidentiality is important to PWID in this setting and the fast result is often valuable to alleviate any anxiety surrounding the result. The preferred method of getting the blood sample varied between participants with some preferring a venous blood sample through bloodwork and others preferring the finger-prick blood sample. The pharmacy setting is important; the relationship with the pharmacy and/or pharmacist provides comfort in testing for most individuals but it is important to consider that PWID may or may not go to their regular dispensing pharmacy for testing due to perceived consequences.

Chapter 5: Discussion

This research provided rich data which allowed for a thorough analysis and exploration of the research questions. After researching what was known from the literature on a broad scale, I was able to assess the nature of the local environment of HCV testing among PWID in NL and then specifically approach the idea of pharmacy-based testing. Some key differences were discovered between the themes within this work compared to the previously available literature outlined in the scoping review. There are some important take-away messages for consideration, which have important bearing on policy and efforts to improve HCV testing for PWID.

Stigma as a central principle to people's experiences

There was a clear message throughout interviews that stigma has tremendous impact on testing and the issue of stigma underlies all the themes discovered through this analysis. Stigma was also seen as a barrier to testing in the scoping review and it is more broadly known to be strongly associated with Hepatitis C. The British Columbia Center for Disease Control (BCCDC) calls stigma a 'side effect' of Hepatitis C and relates stigma to the contagious nature of the disease and the association with illicit drug use (68). The BCCDC states "fears about transmission, fueled by misinformation about HCV, combine with moral judgements that people with HCV are less worthy' of help" (68). Recognizing that stigma occurs in healthcare at diagnosis when people are most vulnerable and need the support of their providers, it is important to create a safe and positive health environment and provide assistance and support for stigmatized people to prevent declines in quality of life (68).

There are three levels of stigma commonly identified in the health literature; perceived/felt stigma, enacted stigma and self/internalized stigma (69). Perceived (or felt) stigma refers to negative social attitudes and fears of discrimination. People with HCV infection often

have a history of IV drug use and due to the stigma in society they are often blamed for the disease, viewed as being irresponsible, accountable and ‘unworthy’ (70), which can lead to discrimination (perceived or real) in health services. Perceived stigma can also prevent HCV from being a public priority (71); testing has to be seen as a priority in healthcare systems in order to be accessible. Enacted stigma involves discriminatory behaviors directed outwards towards other individuals, usually from the community or family level but it can also come from healthcare providers (69). In this study, one participant explained a scenario where a locked door was put in place between the pharmacy dispensary for OAT and the retail store and made the individual feel judged solely based on their history of drug misuse. Self (or internalized) stigma refers to the internal negative feelings that one has towards themselves. In the case of HCV and PWID, this could involve feelings of shame, guilt or feeling unclean (71). This stigma will affect a person’s quality of life and self-esteem, it can impede success of diagnosis and treatment, it leads to high levels of anxiety and exaggerated fear of transmission, and it can be a major cause of social isolation and reduced intimacy in relationships (70). It can also lead to avoidance of healthcare services, including testing for HCV, and the perception that they are not worthy of accessing expensive, effective treatment (71).

Confidentiality in a provincial context

Confidentiality could attract PWID to testing in pharmacies when they are seen as being private and discrete, but it is also a concern for others who see pharmacies as a place that may not be confidential. Confidentiality did not emerge from the scoping review as a major influencer on testing access but was an important theme in this study may reflect the small and close-knit population in St. John’s, NL and the increased chances of individuals knowing the staff at the pharmacy, the clinicians, either physicians or nurse practitioners, or those at the bloodwork

center. The impact of confidentiality, or lack thereof, on a person's access to healthcare has been shown to be more significant in rural areas than in urban areas (72). In one study comparing the practices of clinicians in rural areas to non-rural areas, clinicians reported that patients living in rural areas had expressed more concern about knowing the clinicians both personally and professionally, had more concerns over confidentiality, and had more embarrassment concerning stigmatizing illnesses (57). St. John's (population 111,000) is not considered rural by definition but it is significantly smaller in population than other larger cities such as Boston, New York and Sydney as discussed in the scoping review.

Strengths and Limitations

The interviews provided rich data and produced strong themes, allowing me to learn a lot about the experiences of PWID surrounding HCV testing and hear many suggestions on how pharmacy-based testing could be effectively implemented to appeal to PWID. The research was the first of its kind; no other studies were found which answered these research questions in this province or in Canada. The ability of this research to inform the larger APPROACH study and future pharmacy-based testing programs that appeal to HCV will be valuable while working towards the HCV elimination goal put forth by the WHO. My position as a pharmacist with experience caring for PWID and an understanding of the workings of community pharmacy allowed a particular interpretation of the themes that may have added valuable insight and understanding, specifically related to the second research question surrounding pharmacy-based testing.

As this study is set within the context of the St. John's area of NL, the themes that were produced are specific to this setting and participant demographics. I have described the specific setting and provided demographic information about the participants so those who read my

research can evaluate the potential for applying this analysis to other contexts and settings in an attempt to maximize the potential for transferability. There is a lack of research in rural and remote areas and the same themes may not be produced if interviewing participants in these areas. The same applies to larger urban areas, as St. John's is much "smaller" in population and cultural characteristics than other larger cities within Canada.

For those who reported being tested in the past I did not ask for verification. Many participants assumed they were being tested through bloodwork that was ordered but this may not be the case. In one example, Robert mentioned being worked up for arthritis and assumed testing for HCV was done as part of that bloodwork but it may not have been; HCV is not commonly associated with arthritis and would not typically be a part of the regular diagnostic testing for this condition. Jessica also assumed that they were tested for HCV whenever bloodwork was done at the hospital but HCV is not often included in routine testing for other indications, meaning they may not know their true status if the testing was not done. There may have also been a desirability bias in that participants may be more likely to report to a pharmacist that they had been tested or they may over interpret any testing as being tested for HCV infection. Participants may have also overstated their perceived importance of testing and may have provided more positive views on pharmacy-based testing. I encouraged open and honest expression by participants a safe and relaxed environment in an attempt to mitigate this but it remains a possibility.

I was fortunate to have good uptake to my call for participants through a very successful collaboration with SWAP and snowball recruitment. However, this may have resulted in a less heterogeneous mix of participant experiences than if I had also recruited patients through a recovery centre, which was another method of recruitment I had considered. Other missing

perspectives from this work are that of PWID with Indigenous backgrounds or People of Color. Health inequalities exist in Canada and health services often don't match the needs of Black and other racialized communities (73), however, I did not explore issues related to race and ethnicity in this work as I did not ask participants their ethnicity, there is more work needed to hear the voice of these individuals. None of the participants disclosed having an Indigenous identity to me nor did Indigenous-specific context or issues come out from the interviews. Indigenous peoples and People of Color are noted to frequently encounter dismissive attitudes, biased treatment and racism from healthcare workers (73) and the testing experience may differ in these populations. This is just one study in this specific area and more research is needed.

Important Insights

Ongoing testing is important in screening for HCV. Many PWID in NL have reported testing for HCV in the past (84.9%) (23) but this may have been just once in their lifetime, and they may not be participating in regularly screening despite ongoing injection drug use as a risk factor. According to one model, in a setting with medium chronic HCV prevalence among PWID (as is the case in Canada), even with 90% testing coverage and 100% retention in care, testing every 2 years was not sufficient to achieve an incidence reduction target of 80%, as suggested by the WHO to reach their elimination targets (26). This reiterates the importance of regular frequent testing, especially for people with ongoing risk. Matt had shared that he had been tested in the past, but this was prior to him injecting drugs on a regular basis; his risk may have been quite low prior to injecting drugs but he did not receive testing after he became at higher risk. Increased education surrounding testing is important, from healthcare providers informing patients what they are being tested for specifically and by encouraging people to ask what exactly is being tested and whether it includes HCV. Most of those who had been tested in the

past were offered testing, others actively sought out testing. This suggests that there is an opportunity for health care providers to engage PWID in testing, as offers are often accepted.

This research highlighted that PWID have many reasons not getting tested for HCV. The most cited reasons for avoiding healthcare services in the Tracks survey in NL included stigma on part of the staff or neighbours (33.3%), fear of being ‘outed’ as a person who injects drugs (31.8%), and interference by law enforcement (20.9%) (23). Both stigma and a fear of being ‘outed’ or ‘labeled’ were seen within the themes of this research, in different context. The greater interference concern in this study was from the pharmacist themselves and whether they might inform the prescribers that the person was an injection drug user, as there was significant concern regarding potential detrimental consequences in terms of access to prescription opiates or OAT therapy.

Overall, most PWID in this study found the option of pharmacy-based testing to be appealing to them. There was a strong sentiment that an offer of testing from a healthcare provider would be accepted, and that the pharmacy-based testing option would be easy and convenient. Confidentiality was key to attracting PWID to testing and the relationship with the pharmacist and pharmacy often provided comfort in testing. However it was noted that some pharmacists could be ‘judgy’, perpetuating stigma and negatively impacting PWID wanting to get tested through this route. The preferred method of sample collection for testing differed as did the value of a fast result, though most participants did feel a fast result would alleviate anxiety surrounding the result. There are complexities to the decision to go to the regular dispensing pharmacy or seek out testing at an alternative pharmacy, as there are perceived potential consequences in testing at their regular pharmacy and these affect the decision. In

future, as pharmacy scope of practice expands, pharmacies may be offering testing for a variety of conditions and this may normalize the pharmacy-testing experience.

Impact of this work and recommendations

The themes produced and discussed in Chapter 4B add a pharmacy-specific lens to the available literature. The acceptability of a pharmacy-based testing option for PWID has not been explored previously but has promise as a means to improve access to HCV testing. Participants provided important insight about aspects to consider to best design a testing program in this venue. The theme of ease of testing applies to both the testing modality, less steps involved, and the pharmacy itself, being located close by and accessible. Additional considerations relate to the testing modality, i.e., the speed of the result and the method of sample collection; and others are specific to the pharmacy environment, i.e., the relationship with the pharmacy and pharmacist, whether or not the participants would go to their regular pharmacy, and the confidentiality of the space.

Pharmacy-based HCV testing models should consider ways to create welcoming, non-stigmatizing environments that offer privacy and confidentiality in the testing environment, and how best to invite or promote testing services to encourage uptake by PWID. Without a safe space committed to decreasing stigma surrounding both injection drug use and HCV infection as a diagnosis we may cause more harm than good. Educating the pharmacists who will be providing these tests about the stigma associated with both IV drug use and HCV infection will be important when developing these testing options.

Future direction

This study took place in St. John's, NL, which has a relatively small population in comparison to larger cities, but there could be additional significant differences in the

perceptions of PWID living in more rural and remote areas of this province. Participants were recruited from the Eastern Health region and ultimately all participants lived within St. John's metro area. This is where healthcare services for the province are concentrated and there may be differences in terms of access to testing in more rural and remote areas of the province. Almost 40% of the population of NL live within the St. John's metro area but another 40% of people live in rural areas, which are defined as having populations of less than 5000 people (74). Although there is currently a family physician shortage throughout the province, the number of people without a primary care provider is higher in rural areas (75). Testing in NL is currently offered primarily through primary care providers, physicians and nurse practitioners, therefore, not having a primary care provider limits access to testing. There is also lack of awareness of HCV, which may be more prominent in rural NL, Jennifer shared that she was unaware of HCV until they moved to 'town' a few years ago from a more rural community in the province. Future work could explore similar research questions in the context of more rural and remote areas within NL.

Another avenue for further exploration is HCV testing access and perspectives of Indigenous PWID. Nationally, in 2016, the rate of newly diagnosed HCV was three times higher in First Nations living on reserve than the overall Canadian population (76). There is limited data regarding the epidemiology of HCV within Indigenous populations in Canada but one large population-based study in Manitoba indicated that the epidemiology of HCV among First Nations people is different from non-First Nations persons (77). The authors of this study show that within this Indigenous population, HCV infections occur in a significantly younger age group, that are more often female and residents of urban communities, and that the burden of HCV is increasing at a greater rate than in the non-First Nations population (77). In 2016, there were almost 46 000 Aboriginal people in NL accounting for 8.9% of the population (78) and NL

is home to four peoples of Indigenous ancestry: the Inuit, the Innu, the Mi'kmaq and Metis. Approximately 53% of the Indigenous population in NL were living in rural areas and just 12.9% were living in large population centers (78). The impact of HCV within the setting of the NL Indigenous population has not been well studied. However, 34.9% of the NL Tracks survey participants self-identified as Indigenous, with a higher proportion living on the West Coast of the island of NL and a much lower proportion in St. John's (66.7% in Stephenville and 43.3% in Corner Brook vs. 22.2% in St. John's) (23). This survey found that only one in ten Indigenous respondents reported having access to Indigenous-specific health services (23). There could be a different cultural impact within the Indigenous experience coupled with the rural living experience and associated decreased access to healthcare services which could have negative impacts on screening for HCV in this population. Future research would be valuable to explore if Indigenous communities would be interested in research on HCV screening programs, including those at pharmacies.

Knowledge Translation

The results of this analysis are relevant to non-pharmacy testing venues who seek to attract PWID as well, as there were valuable insights gained surrounding what features of testing are important to PWID in general. The speed of the result, the accessibility of testing options, and the preferred method for taking a blood sample are all factors that would apply to any testing experience including those outside of the pharmacy environment. Additionally, the concerns about stigma, privacy and confidentiality, and relationship with testing providers are all important aspects for any testing program to effectively engage PWID in any environment.

In addition to publishing my results in academic journals, I intend to share findings with pharmacists, community-based organizations who work with PWID, clinics that offer testing,

and government policy-makers. I hope to co-create knowledge translation materials with PWID to engage audiences and share these important messages. I hope to increase awareness of HCV and testing opportunities in the public through sharing videos and other media. I intend to develop infographics related to the themes surrounding pharmacy-based testing to share with the Pharmacists' Association of Newfoundland and Labrador and pharmacists directly to engage and educate pharmacists on how to decrease stigma related to HCV and injection drug use. I intend to share my findings with government and policy makers to bring awareness to low testing rates and suggestions on how to improve policies to make testing more acceptable and accessible to PWID. I also intend to develop curriculum along with people with lived experience to be shared with pharmacy students and potentially nursing, social work and medical students at Memorial University surrounding HCV and injection drug use and the stigma surrounding both.

Chapter 6: Conclusion

This thesis presents the experiences and perceptions of PWID regarding testing for HCV and considerations for pharmacy-based testing. The scoping review identified barriers and enablers to testing; barriers included the perceived low risk for HCV, a fear of diagnosis, stigma, antipathy in relation to mainstream health care services, lack of rapport with provider, lack of motivation or competing priority of drug use, and limited awareness of new treatment options. Enablers to HCV testing among PWID included increasing awareness of HCV testing and treatment and providing positive narratives surrounding care, having a positive rapport with the provider, providing accessible testing options, and providing personalized care.

I conducted a qualitative study of PWID to address two research questions. The first question explored the experiences and perceptions of PWID around testing for HCV, and the analysis produced the following themes: There are multiple reasons why testing is not being done and feelings surrounding testing vary. There is a belief that testing is important for health but access to and relationship with primary care providers affect testing and participants felt there is a need for both increased awareness of testing and more testing options.

The second research question explored the factors of a pharmacy-based testing that would be important to PWID and produced five themes: pharmacy-based testing was seen to be easy and the relationship with the pharmacy and pharmacist affects testing. Confidentiality would be important to attract people to testing, the fast result is often valuable to relieve anxiety, and the preferred method of sample collection varies between PWID.

The overall results of my research demonstrated that the experience of PWID and their motivations for testing are complex and consideration is required when developing HCV screening initiatives to engage this population. The results have potential to positively impact the

development and successful roll-out of HCV screening programs that are attractive to this population and ultimately increase case-finding and access to treatment.

Final Reflection

I felt a strong sense of personal achievement while submitting this Master's thesis but more importantly I have found a new appreciation and affection for qualitative research. When I started this thesis, I considered a mixed methods approach which felt more comfortable at the time, coming from a positivist and primarily quantitative way of thinking about research and the 'truth'. Through course work and connecting with other researchers I grew more interested in the qualitative approach and now I cannot think of a better way to answer these research questions than undergoing a qualitative reflexive thematic analysis. Every part of this work has been enjoyable, and nothing has felt like 'work'. Part of me feels sad that this work is complete, but I know there is a lot of potential for future exploration and many different avenues this could take. I am considering venturing from this Master's journey into the world of a PhD student to expand on this work and the relationships I have built within this community. I hope that I can provide impact through this work and the 'work' to come.

References

1. Centers for Disease Control and Prevention. Centers for Disease Control and Prevention. 2021 [cited 2023 Jun 6]. Hepatitis C. Available from: <https://www.cdc.gov/hepatitis/hcv/index.htm>
2. World Health Organization. World Health Organization. 2022 [cited 2022 Dec 22]. Hepatitis C. Available from: <https://www.who.int/news-room/fact-sheets/detail/hepatitis-c>
3. CATIE - Canada's source for HIV and hepatitis C information [Internet]. 2023 [cited 2023 Jun 6]. Preventing transmission of hepatitis C during sex. Available from: <https://www.catie.ca/hepatitis-c-an-in-depth-guide/safer-sex>
4. Mak LY, Cruz-Ramón V, Chinchilla-López P, Torres HA, LoConte NK, Rice JP, et al. Global Epidemiology, Prevention, and Management of Hepatocellular Carcinoma. *Am Soc Clin Oncol Educ Book*. 2018 May;(38):262–79.
5. Friedman RM, Contente S. Treatment of Hepatitis C Infections with Interferon: A Historical Perspective. *Hepat Res Treat*. 2010;2010:323926.
6. Kherghepoush S, McKeirnan KC. The role of community pharmacies in the HIV and HCV care continuum. *Explor Res Clin Soc Pharm*. 2023;9.
7. Action Hepatitis Canada [Internet]. [cited 2023 Jun 3]. Treatment Access. Available from: <https://www.actionhepatitiscanada.ca/treatment-access.html>
8. Lichtenstein GR. Advances in Hepatitis C Virus Treatment. *Gastroenterol Hepatol*. 2015 Jul;11(7):432.
9. Donaldson SR, Radley A, Dillon JF. Future destinations and social inclusion scoping review: how people cured of hepatitis C (HCV) using direct-acting antiviral drugs progress in a new HCV-free world. *Subst Abuse Treat Prev Policy*. 2022 Jun 8;17(1):45.
10. Shakeri A, Srimurugathan N, Suda KJ, Gomes T, Tadrous M. Spending on Hepatitis C Antivirals in the United States and Canada, 2014 to 2018. *Value Health*. 2020 Sep 1;23(9):1137–41.

11. Marshall AD, Saeed S, Barrett L, Cooper CL, Treloar C, Bruneau J, et al. Restrictions for reimbursement of direct-acting antiviral treatment for hepatitis C virus infection in Canada: a descriptive study. *Can Med Assoc Open Access J*. 2016 Oct 14;4(4):E605–14.
12. Dhiman RK, Premkumar M. Hepatitis C Virus Elimination by 2030: Conquering Mount Improbable. *Clin Liver Dis*. 2021 Jan 13;16(6):254–61.
13. CATIE - Canada's source for HIV and hepatitis C information [Internet]. 2022 [cited 2023 Jun 2]. Getting ready for hepatitis C treatment. Available from: <https://www.catie.ca/hepatitis-c-an-in-depth-guide/getting-ready-for-hepatitis-c-treatment>
14. Amoako A, Ortiz-Paredes D, Engler K, Lebouché B, Klein MB. Patient and provider perceived barriers and facilitators to direct acting antiviral hepatitis C treatment among priority populations in high income countries: A knowledge synthesis. *Int J Drug Policy*. 2021 Oct;96:103247.
15. World Health Organization. Global hepatitis report 2017 [Internet]. Geneva: World Health Organization; 2017 Apr [cited 2022 Dec 22]. Available from: <https://apps.who.int/iris/handle/10665/255016>
16. Cox AL, El-Sayed MH, Kao JH, Lazarus JV, Lemoine M, Lok AS, et al. Progress towards elimination goals for viral hepatitis. *Nat Rev Gastroenterol Hepatol*. 2020 Sep;17(9):533–42.
17. Kamal SM, Ghoraba D. Chapter 1.2 - Epidemiology and Modes of Transmission of HCV in Developing Countries. In: Kamal SM, editor. *Hepatitis C in Developing Countries* [Internet]. Academic Press; 2018 [cited 2023 Jun 3]. p. 13–22. Available from: <https://www.sciencedirect.com/science/article/pii/B9780128032336000023>
18. World Health Organization. Global progress report on HIV, viral hepatitis and sexually transmitted infections, 2021 [Internet]. 2021 Jul [cited 2022 Dec 22]. Available from: <https://www.who.int/publications-detail-redirect/9789240027077>

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

19. Public Health Agency of Canada. People living with Hepatitis C (HCV) in Canada [Internet]. 2022 [cited 2023 Jan 6]. Available from: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/infographic-people-living-with-hepatitis-c.html>
20. Kwong JC, Ratnasingham S, Campitelli MA, Daneman N, Deeks SL, Manuel DG, et al. The Impact of Infection on Population Health: Results of the Ontario Burden of Infectious Diseases Study. Braitstein P, editor. PLoS ONE. 2012 Sep 4;7(9):e44103.
21. Public Health Agency of Canada. Public Health Agency of Canada Infographic on hepatitis C virus infection in Canada. *Can Commun Rep.* 44(7–8):189.
22. Malebranche M, King D, Leonard J. Descriptive epidemiology of hepatitis C in individuals referred for specialized HCV care in Newfoundland and Labrador, 1996–2014. *Can Liver J.* 2018 Oct;1(3):107–14.
23. Smith C. Tracks survey of people who inject drugs (PWID) in Newfoundland and Labrador (NL), Phase 4 (2017-2019) Summary report. 2020;
24. Statistics Canada Government of Canada. Seroprevalence of hepatitis B and C virus infections: Results from the 2007 to 2009 and 2009 to 2011 Canadian Health Measures Survey [Internet]. 2013 [cited 2023 Jan 6]. Available from: <https://www150.statcan.gc.ca/n1/pub/82-003-x/2013011/article/11876-eng.htm>
25. Canadian Task Force on Preventive Health Care. Recommendations on hepatitis C screening for adults. *Can Med Assoc J.* 2017 Apr 24;189(16):E594–604.
26. Scott N, Sacks-Davis R, Pedrana A, Doyle J, Thompson A, Hellard M. Eliminating hepatitis C: The importance of frequent testing of people who inject drugs in high-prevalence settings. *J Viral Hepat.* 2018 Dec;25(12):1472–80.
27. Hyshka E, Anderson-Baron J, Karekezi K, Belle-Isle L, Elliott R, Pauly B, et al. Harm reduction in name, but not substance: a comparative analysis of current Canadian provincial and territorial policy frameworks. *Harm Reduct J.* 2017 Dec;14(1):50.

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

28. Morris MD, Mirzazadeh A, Evans JL, Briceno A, Coffin P, Hahn JA, et al. Treatment cascade for hepatitis C virus in young adult people who inject drugs in San Francisco: Low number treated. *Drug Alcohol Depend.* 2019 May;198:133–5.
29. Souliotis K, Agapidaki E, Papageorgiou M, Voudouri N, Contiades X. Access to treatment for Hepatitis C among injection drug users: results from the cross-sectional HOPE IV study. *Int J Equity Health.* 2017 Dec;16(1):101.
30. Braun V, Clarke V. *Thematic Analysis: A Practical Guide.* SAGE Publications Ltd.; 2021. 376 p.
31. Skeer MR, Ladin K, Wilkins LE, Landy DM, Stopka TJ. ‘Hep C’s like the common cold’: Understanding barriers along the HCV care continuum among young people who inject drugs. *Drug Alcohol Depend.* 2018 Sep 1;190:246–54.
32. Tofighi B, Lee JD, Sindhu SS, Chemi C, Leonard NR. Engagement in the Hepatitis C care continuum among people who use drugs. *J Subst Use.* 2020;25(4):343–9.
33. Coupland H, White B, Bates A, Park JN, Iversen J, Maher L. Engaging people who inject drugs in hepatitis C virus testing and prevention through community-based outreach, in Sydney, Australia. *Drug Alcohol Rev.* 2019 Feb;38(2):177–84.
34. Shehata N, Austin T, Ha S, Timmerman K. Barriers to and facilitators of hepatitis C virus screening and testing: A scoping review. *Can Commun Dis Rep.* 2018 Jul 5;44(7–8):166–72.
35. Kelly DV, Kielly J, Hughes C, Gahagan J, Asghari S, Hancock S, et al. Expanding access to HIV testing through Canadian community pharmacies: findings from the APPROACH study. *BMC Public Health.* 2020 Dec;20(1):639.
36. Gauld N, Perry J, Jackson C, Gane E. Feasibility and outcomes of a hepatitis C screening programme in community pharmacies. *N Z Med J.* 2020 Nov 20;133(1525):74–83.
37. Buchanan R, Hassan-Hicks P, Noble K, Grellier L, Parkes J, Khakoo SI. *The Pharmaceutical Journal.* [cited 2022 Dec 22]. Integrating community pharmacy testing for hepatitis C with specialist care.

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

Available from: <https://pharmaceutical-journal.com/article/research/integrating-community-pharmacy-testing-for-hepatitis-c-with-specialist-care>

38. Grootendorst P. Pharmacy location and medical need: regional evidence from Canada. *BMC Health Serv Res.* 2022 Nov 3;22(1):1309.
39. Statistics Canada Government of Canada. Profile table, Census Profile, 2021 Census of Population - Newfoundland and Labrador [Province] [Internet]. 2022 [cited 2023 Mar 27]. Available from: <https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/index.cfm?Lang=E>
40. Newfoundland and Labrador Pharmacy Board (NLPB) [Internet]. [cited 2023 Aug 9]. Available from: <https://nlpb.portalca.thentiacloud.net/webs/portal/register/#!/search/all/0/20/all/all/false/business>
41. Roberts D. CBC News. 2023 [cited 2023 Jun 8]. Number of people without a family doctor in N.L. has risen to 136,000, says medical association | CBC News. Available from: <https://www.cbc.ca/news/canada/newfoundland-labrador/family-doctor-shortage-numbers-1.6710100>
42. Balsom CR, Farrell A, Kelly DV. Barriers and enablers to testing for hepatitis C virus infection in people who inject drugs – a scoping review of the qualitative evidence. *BMC Public Health.* 2023 Jun 1;23(1):1038.
43. Sampson M, McGowan J, Cogo E, Grimshaw J, Moher D, Lefebvre C. An evidence-based practice guideline for the peer review of electronic search strategies. *J Clin Epidemiol.* 2019;62(9):944–52.
44. Covidence - Better systematic review management [Internet]. [cited 2023 Jan 9]. Available from: <https://www.covidence.org/>
45. Barocas JA, Brennan MB, Hull SJ, Stokes S, Fangman JJ, Westergaard RP. Barriers and facilitators of hepatitis C screening among people who inject drugs: a multi-city, mixed-methods study. *Harm Reduct J.* 2014;11(1):1.
46. Harris M, McDonald B, Rhodes T. Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low? *Drugs Educ Prev Policy.* 2014 Aug 1;21(4):333–42.

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

47. Harris M, Bonnington O, Harrison G, Hickman M, Irving W, the HepCATT team. Understanding hepatitis C intervention success—Qualitative findings from the HepCATT study. *J Viral Hepat.* 2018 Jul;25(7):762–70.
48. Latham NH, Pedrana A, Doyle JS, Howell J, Williams B, Higgs P, et al. Community-based, point-of-care hepatitis C testing: perspectives and preferences of people who inject drugs. *J Viral Hepat.* 2019 Jul;26(7):919–22.
49. Phillips C, Schulkind J, O’Sullivan M, Edelman N, Smith HE, Verma S, et al. Improving access to care for people who inject drugs: Qualitative evaluation of project ITTREAT-An integrated community hepatitis C service. *J Viral Hepat.* 2020 Feb;27(2):176–87.
50. Ward KM, McCormick SD, Sulkowski M, Latkin C, Chander G, Falade-Nwulia O. Perceptions of Network Based Recruitment for Hepatitis C testing and treatment among persons who inject drugs: a qualitative exploration. *Int J Drug Policy.* 2021 Feb;88:103019.
51. Stecker A, McLeroy K, Goodman R, Bird S, McCormick L. Towards integrating qualitative and quantitative methods: an introduction. *Health Edu Q.* 1992 Spring;19(1):1–8.
52. Tortu S, McMahon JM, Pouget ER, Hamid R. Sharing of Noninjection Drug-Use Implements as a Risk Factor for Hepatitis C. *Subst Use Misuse.* 2004 Jan 1;39(2):211–24.
53. Wilton J, Wong S, Purssell R, Abdia Y, Chong M, Karim ME, et al. Association Between Prescription Opioid Therapy for Noncancer Pain and Hepatitis C Virus Seroconversion. *JAMA Netw Open.* 2022 Jan 12;5(1):e2143050.
54. U.S. Census Bureau QuickFacts: New York city, New York [Internet]. [cited 2023 Apr 21]. Available from:
<https://www.census.gov/quickfacts/fact/table/newyorkcitynewyork/PST045221#PST045221>
55. U.S. Census Bureau QuickFacts: Boston city, Massachusetts [Internet]. [cited 2023 Apr 21]. Available from: <https://www.census.gov/quickfacts/bostoncitymassachusetts>

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

56. Sydney Population 2022/2023 [Internet]. [cited 2023 Apr 21]. Available from: <https://www.populationu.com/cities/sydney-population>
57. Warner TD, Monaghan-Geernaert P, Battaglia J, Brems C, Johnson ME, Roberts LW. Ethical Considerations in Rural Health Care: A Pilot Study of Clinicians in Alaska and New Mexico. *Community Ment Health J*. 2005 Feb;41(1):21–33.
58. Catlett B, Hajarizadeh B, Cunningham E, Wolfson-Stofko B, Wheeler A, Khandaker-Hussain B, et al. Diagnostic Accuracy of Assays Using Point-of-Care Testing or Dried Blood Spot Samples for the Determination of Hepatitis C Virus RNA: A Systematic Review. *J Infect Dis*. 2022 Sep 21;226(6):1005–21.
59. CATIE - Canada's source for HIV and hepatitis C information [Internet]. 2023 [cited 2023 May 24]. Hepatitis C point-of-care testing: What is its impact on testing and linkage to care? Available from: <https://www.catie.ca/prevention-in-focus/hepatitis-c-point-of-care-testing-what-is-its-impact-on-testing-and-linkage-0>
60. Canadian Network on Hepatitis C Blue print Writing Committee and Working Groups. Blueprint to inform hepatitis C elimination in Canada [Internet]. 2019 [cited 2023 May 24]. Available from: https://www.canhepc.ca/sites/default/files/media/documents/blueprint_hcv_2019_05.pdf
61. Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: *Handbook of qualitative research*. SAGE Publications Ltd.; 1994. p. 105–17.
62. Creswell JW, Creswell JW. *Qualitative inquiry and research design: choosing among five approaches*. 3rd ed. Los Angeles: SAGE Publications; 2013. 448 p.
63. Willig C. Beyond appearances: A critical realist approach to social constructionist work. In: *Social constructionist psychology: a critical analysis of theory and practice*. Buckingham, UK: Open University Press; 1999. p. 37–52.
64. Campbell M. Behind the Name. [cited 2023 Jan 13]. *Popular Names in Canada (Ontario and BC)*. Available from: <https://www.behindthename.com/top/lists/canada/1983>

65. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–97.
66. Braun V, Clarke V, Weate P. Using thematic analysis in sport and exercise research. In: *Routledge handbook of qualitative research in sport and exercise*. First. London: Routledge; 2016. p. 191–205.
67. Sparkes AC, Smith B. *Qualitative Research Methods in Sport, Exercise and Health: From Process to Product*. 1st ed. London: Routledge; 2013. 288 p.
68. British Columbia Center for Disease Control. *Stigma & Hepatitis C: A Fact Sheet for Health Care Providers* [Internet]. BC CDC; [cited 2023 Jan 10]. Available from: http://www.bccdc.ca/Health-Info-Site/Documents/Hepatitis_Stigma_Fact_Sheet.pdf
69. Clum G, Chung SE, Ellen JM, Adolescent Medicine Trials Network for HIV/AIDS Interventions. Mediators of HIV-related stigma and risk behavior in HIV infected young women. *AIDS Care*. 2009;21(11):1455–62.
70. Marinho RT, Barreira DP. Hepatitis C, stigma and cure. *World J Gastroenterol WJG*. 2013 Oct 28;19(40):6703–9.
71. Saine ME. *Measuring Disease-Related Stigma Among Patients with Chronic Hepatitis C Virus Infection* [Internet] [Ph.D.]. [United States -- Pennsylvania]: University of Pennsylvania; 2019 [cited 2023 Jan 19]. Available from: <https://www.proquest.com/docview/2381576743/abstract/ED5CBD9DD7434D07PQ/1>
72. Townsend T. Ethics Conflicts in Rural Communities: Privacy and Confidentiality. In: *Handbook for Rural Health Care Ethics: A Practical Guide for Professionals*. p. 128–41.
73. Government of Canada CI of HR. *Science and better health for Black people - CIHR* [Internet]. 2022 [cited 2023 Aug 9]. Available from: <https://cihr-irsc.gc.ca/e/52855.html>

74. Government of Newfoundland and Labrador. Rural Lens: Accessing Regional Policy Implications, A Guide for Public Bodies [Internet]. Government of Newfoundland and Labrador; 2019 [cited 2023 Jan 10] p. 8. Available from: <https://www.gov.nl.ca/pep/files/Rural-Lens.pdf>
75. CBC News. CBC. 2022 [cited 2023 Jan 10]. 125,000 people in N.L. don't have a family doctor, says medical association poll | CBC News. Available from: <https://www.cbc.ca/news/canada/newfoundland-labrador/nlma-family-doctor-shortage-poll-2022-1.6473963>
76. Government of Canada; Indigenous Services Canada. Hepatitis C in First Nations living on reserve [Internet]. 2019 Oct [cited 2023 Jan 10]. Available from: <https://www.sac-isc.gc.ca/eng/1569955684724/1569958287940>
77. Uhanova J, Tate RB, Tataryn DJ, Minuk GY. The epidemiology of hepatitis C in a Canadian Indigenous population. *Can J Gastroenterol*. 2013 Jun;27(6):336–40.
78. Statistics Canada Government of Canada. Focus on Geography Series, 2016 Census - Province of Newfoundland and Labrador [Internet]. 2017 [cited 2023 Jan 10]. Available from: <https://www12.statcan.gc.ca/census-recensement/2016/as-sa/fogs-spg/Facts-PR-Eng.cfm?TOPIC=9&LANG=Eng&GK=PR&GC=10>

Appendix A: Search Strategy


- 1 substance abuse, intravenous/ or exp Drug Users/ or Buprenorphine, Naloxone Drug Combination/tu or exp Methadone/tu or Opiate Substitution Treatment/ 25813
- 2 ((methadone or suboxone or opiate or opioid) adj2 (treatment or therapy or therapeutic or clinic)).tw,kf. 13219
- 3 ((people or person or persons or women or woman or men or man) adj2 (inject* or "use" or uses or using or used or usage or addict* or depend* or misus* or abus*) adj (drugs or drug or substance or substances or heroin* or dope or 'china white' or smack or cocaine or blow or bump or coke or rock or snow or toot or crack or meth or Molly or MDMA or crank or ecstasy or flake or Krokodil or crocodil or methamphetamine* or fentanyl or ketamine or DMT or PCP or barbiturate* or opiate* or opioid* or narcotic* or 'bath salts')).tw,kf. 5094
- 4 (pwid or pwud).tw,kf. 2182
- 5 ((drugs or drug or substance or substances or heroin* or dope or 'china white' or smack or cocaine or blow or bump or coke or rock or snow or toot or crack or meth or Molly or MDMA or crank or ecstasy or flake or Krokodil or crocodil or methamphetamine* or fentanyl or ketamine or DMT or PCP or barbiturate* or opiate* or opioid* or narcotic* or 'bath salts') and (inject* or intravenous or IV)).tw,kf. 232780
- 6 ((illicit or illegal or recreational) adj2 (drug or drugs or substance or substances) adj2 ("use" or uses or using or used or usage or addict* or depend* or misus* or abus*)).tw,kf. 10474
- 7 1 or 2 or 3 or 4 or 5 or 6 262577
- 8 exp Hepatitis C/di, dg 9602
- 9 ((test* or screen*) and (Hepatitis C or Hep C or HCV)).tw,kf. 22943
- 10 (exp Hepacivirus/ or exp Hepatitis C/) and (test* or screen*).tw,kf. 16659
- 11 (satisf* or percept* or enable* or perspectiv* or attitud* or opinion* or view or views or preferenc* or experienc* or barrier* or facilitat* or motivat* or challeng* or obstacle* or knowledge).tw,kf. 4846690
- 12 exp Attitude to Health/ 429382
- 13 exp Patient Satisfaction/ 92138
- 14 11 or 12 or 13 5035472
- 15 8 or 9 or 10 29565
- 16 7 and 14 and 15 979

Appendix B: Recruitment Pamphlet

I NEED YOUR HELP IN A RESEARCH STUDY


I want to learn about testing for Hepatitis C in people who inject drugs and see if a pharmacy-based testing option would be appealing

STEP 1




I'm looking to talk to people who inject drugs about testing for Hepatitis C. You don't have to have been tested!

STEP 2




Share your voice! The interview can be in-person, virtually or by phone and should take about 45 minutes

STEP 3



You'll receive \$40 for sharing your experience

STEP 4



That's it! I'll write about what I learn - I hope it will improve the testing process and encourage more people to get tested

Ready?

Call Cathy - 864-2097
or connect with SWAP - 757-7927

If you have questions regarding your rights as a research participant please contact the Health Research Ethics Authority at (709) 777-6974 or info@hrea.ca

Appendix C: Interview Guide

Thank you for meeting with me today to discuss testing for Hepatitis C! I am happy to be able to learn from your experiences! My goal is to take what I learn today and use it to provide information about what is important to people when accessing testing for HCV at a pharmacy.

- 1) Before we get started, would you mind telling me your gender and age category, for example, 20-24, 25-29, 30-34, 35-39, etc.?
- 2) Tell me about your thoughts on testing for Hepatitis C.
 - a. How important is it to you that you know your Hepatitis C status? Tell me why you feel that way.
 - b. Tell me about your experience with getting tested for Hepatitis C in the past.
 - i. Have you been tested in the past? If no, why is that do you think?
 - ii. Have you ever thought about getting tested?
 - iii. How did you feel when getting tested?
 - iv. Were you offered a test or did you seek it out on your own?
 - v. Why did you decline a test?
 - vi. What led to you getting tested/not getting tested?
 - vii. Where did/would you go to get tested?
 - c. If you chose to get tested for Hepatitis C, what made you decide to get tested?
- 3) There is going to be a project that offers testing through Pharmacies starting next Fall where you could walk into the participating pharmacies and ask for a test for Hep C. The test involves a finger-stick blood sample and the pharmacist would do the test in the private counselling area; you could get your result back in about a half an hour or they could call you back with the result later.
 - a. What do you think of this idea as a way to get tested?

- i. Do you think you would go? Why or why not?
- b. Can you tell me a little about the parts of the pharmacy option would turn you off?
 - i. What concerns would you have about the pharmacy option?
- c. Tell me about the parts of the pharmacy test that would be appealing to you.
 - i. What about the pharmacy option would be an advantage over the other options?
- d. If you were to choose where to get tested given current options and the pharmacy option, what would be your choice?
- e. Different testing options take different lengths of times get the result. What do you think about the time it takes to get your result?
 - i. How important is it for you to get your result quickly?
 - ii. Would you prefer to get your result the same day or would you mind waiting a week?
 - iii. How would you like to receive your result?
- f. Different testing options mean different ways of actually getting the samples. It could be a finger prick or a blood draw. What would be your preference for getting the sample?
 - i. What would be more appealing, getting a finger prick or having a blood draw?
- g. We would want to reach people who inject drugs and let them know about this pharmacy option; how would we get the word out and let people know about this option?

PERCEPTIONS OF PEOPLE WHO INJECT DRUGS SURROUNDING TESTING FOR HEPATITIS C

- i. How would you be most likely to learn about this option?
- ii. What would be the best way to reach your peers?