



**SANGUEN HEALTH CENTRE**

## **Sanguen Health Centre's Hepatitis C Program: Outcome Evaluation**

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## INTRODUCTION

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The purpose of this report is to summarize outcome evaluation data gathered in 2012-2013 as a part of the evaluation project conducted by the Centre for Community Based Research (CCBR) for Sanguen Health Centre (SHC). CCBR is an established research organization located in downtown Kitchener that has a 30 year history of successful community partnerships producing action-based research that empowers marginalized persons and communities.

The purpose of this evaluation was to two-fold:

- 1) To develop an evaluation framework/evaluation plan and
- 2) To evaluate the outcomes of Sanguen Health Centre's Hepatitis C program.

The first purpose of the evaluation involved a document review well as data collection and analysis to create an evaluation framework that identified Sanguen Health Centre's services and activities, and linked them to their intended short-term, intermediate and long-term outcomes. This process included participatory contributions from SHC staff who provided input on framework development during two focus group interviews.

The framework served as the basis for an evaluation plan for conducting future evaluations of SHC's services and activities. The outcomes of research efforts for this purpose are illustrated in the Program Logic Model attached as appendix to this document and evaluation framework. Both products were presented and discussed with SHC staff at an earlier date.

This report will first briefly describe SHC and services offered for individuals living with or at risk for Hepatitis C (HCV). Afterward, the methods and procedures used for the outcome evaluation will be described. Finally, the report presents findings developed from primary research conducted with individuals in contact with SHC through outreach, screening, treatment, or post-treatment services.

## SANGUEN HEALTH CENTRE

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Sanguen Health Centre provides community-based services for individuals living with or at-risk for Hepatitis C in Kitchener, Waterloo, Guelph, Cambridge, and surrounding areas. The first of its kind in Ontario, SHC's services include specialized Hepatitis C medical assessment and treatment; outreach, education and prevention services; psycho-social support; support groups; peer lead outreach services; and regional HCV service coordination.

### Background

Due to the complex nature of treating HCV, SHC is made up of a multidisciplinary team, including: a physician specializing in HCV treatment; registered HCV nurses; a clinic co-ordinator; an outreach, prevention and education worker; social workers; a regional co-ordinator of services; and additional peer volunteers. Together this team provides holistic, client-centred care to individuals who are at-risk for or living with HCV. SHC undertakes activities in the following areas:

*Medical Care/Clinical Program:* SHC's medical staff offers expert medical care to individuals living with HCV. In addition to treatment, SHC provides access to screening for at-risk individuals, and management of patients through various stages of HCV care. Due to SHC's multidisciplinary team model, individuals from vulnerable populations who are accessing SHC's Outreach or Support Programs are directly linked to SHC's medical services. This allows for greater engagement and retention in HCV medical care. Additionally, SHC accepts referrals from physicians and partner agencies in the community.

*Outreach program:* SHC's Outreach Program engages at-risk individuals using a harm-reduction approach. SHC's outreach services include education, harm reduction supply distribution, referrals, and practical support. Also critical to SHC's outreach services are SHC's Peer Outreach Workers. Peer Outreach Workers are individuals with "lived experience" who work along side SHC staff and act as a bridge between at-risk individuals and SHC. In addition, the outreach program is partnered with the AIDS Committee of Cambridge, Kitchener, Waterloo and Area and the AIDS Committee of Guelph to increase its breadth and ability to provide services across the large region.

*Education and Prevention:* In addition to providing education to individuals living with and at-risk for HCV, SHC also provides extensive education services to the general public, medical professionals, and other service providers. Education is aimed at increasing awareness, providing accurate information about transmission and treatment, and de-stigmatizing HCV.

*Psycho-social Support Program:* SHC provides support services aimed at improving the mental wellbeing of individuals living with or at-risk for HCV. These services include counselling, case management, advocacy, practical support, and assistance navigating the medical and social service system. Support is provided through through appointments, community-based outreach appointments ("street level support"), home visits, and phone/texting support. The support programs cover a host of needs, including preparation for treatment, housing and financial support, and emotional support. These services play a vital role in seeing patients through the entire continuum of care.

*Support Groups:* SHC's support groups lend additional support to individuals at-risk, living with, and undergoing treatment for HCV. These groups are co-facilitated by SHC staff and HCV survivors who can draw upon lived experiences to provide ongoing support throughout the continuum of care.

*Access to Allied Health Professionals:* One of SHC's primary objectives is to increase the capacity of physicians, other medical professionals, and social service providers to better meet the complex needs of people living with HCV. Through education and collaborative partnerships, SHC works to break down the barriers faced by individuals living with HCV..

Each of the activities outlined above fit within the activities, outcomes, and goals outlined in a program logic model that was developed for an earlier stage of the evaluation. The logic model is attached to this document as appendix A

Sanguen Health Centre operates in accordance to the *Proposed Strategy to Address Hepatitis C in Ontario 2009 – 2014* which reinforces the 2007 Ontario Hepatitis Nursing Program mandate to increase treatment capacity with a focus on underserved communities. This proposed strategy describes an inclusive approach to HCV management by providing health services for people who use drugs and other populations at higher risk for HCV, HIV and other blood-borne pathogens, and proscribes

Equal access to high-quality treatment, prevention, support, and educational interventions for all Ontarians at risk of/living with HCV, including First Nations individuals accessing the provincial health care system. (Ontario Hepatitis C Task Force, 2009, p. 10)

Furthermore, the strategy recommends that HCV-related healthcare provision services should align with the principles of harm reduction and equity. This is inclusive of an integrated approach to address HCV that informs the activities of the following five major areas:

*Access Equity* – equal access to high-quality treatment, prevention, support, education

*Harm Reduction Approach* – most immediate, achievable, positive changes, whether or not they reduce consumption

*Effective Partnership and Collaboration* – health services delivery collaboration – community-based, clinical, hospital-based; provincial program areas and other ministries; different levels of government

*Reducing Stigma and Discrimination* – non-judgemental, non-discriminatory delivery to overcome barriers to accessing programs and services

*Monitoring and Evaluation* – track progress, revise goals and objectives based on evaluations, emerging issues, and new technology and treatment advances

*Greater Involvement of People Living with HCV* – in developing policies and programs

In addition to the harm reduction approach, the *Proposed Strategy to Address Hepatitis C in Ontario: 2009 – 2014* also provides framework for action that incorporates the following five goals central to improving HCV treatment strategies:

*Treatment:* Improve access to the treatment continuum; including pre-, during, and post-treatment for people living with HCV.

*Prevention:* Reduce HCV transmission in Ontario

*Education:* Increase knowledge and awareness of HCV prevention, treatment, support services, and care among health care providers, stakeholders, and high risk populations (such as Injection Drug Users)

*Support:* Strengthen the support for people living with HCV and higher risk population so they access services available to them

*Surveillance and Research:* Improve applied research and surveillance on HCV

One of the key objectives emerging from the fifth goal is that efforts to address HCV in Ontario should “Establish data on optimal program/health service delivery models to reach higher risk populations” (Ontario Hepatitis C Task Force, 2009, p. 37). Specifically, the document recommends that the Government of Ontario and HCV service organizations should

Conduct comprehensive program evaluation and operations research to establish the optimal model and best practices for delivering harm reduction and other HCV-relevant programs and health services to higher risk populations. (ibid, p. 37)

The proposed strategy contributes a number of objectives and recommendations that can be utilized to support improvements in HCV treatment across Ontario, and many of these actions have been incorporated or already existed in Sanguen Health Centre’s activities.

## **OUTCOME EVALUATION**

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To evaluate individual outcomes, the evaluation team together with SHC staff, developed the evaluation framework and data collection tools to measure the impact of SHC’s services and activities. This evaluation incorporates the collection of quantitative and qualitative data through survey tracking tools.

### **Data Collection**

Data collection was completed using four main tracking tools, tailored to specific areas of service provided by SHC. Each survey collected general demographic information, followed by service-specific questions. Each survey is outlined below:

**Outreach Survey:** The outreach survey was administered by SHC staff and Peer Outreach Workers to individuals that came in contact with outreach services, and collected data relevant to: service user demographics, SHC service usage, external service usage, treatment, and strengths/challenges to the SHC delivery model.

**Screening Survey:** The screening survey was administered to individuals that were in contact with SHC to be screened for HCV. It collected information about their knowledge of HCV transmission, and qualitative responses about their experiences with SHC.

**Start-of-Treatment Survey:** The start-of-treatment survey was administered to individuals that were commencing medical treatment for HCV. The survey collected information about their referral/access to SHC and the level of informal support that they felt they had access to.

**Post-Treatment Survey:** The post-treatment survey was administered to individuals that had received treatment for HCV. Along with basic information, it collected information about treatment adherence, outcomes, service usage, informal support, and qualitative information about quality of service.

## Participants

Participants in this project consisted of individuals who had contact with the SHC via one of their program branches. This population includes individuals living with HCV; individuals living in situations that put them at-risk of exposure to HCV; and individuals who were in contact with SHC through SHC's outreach services. Participant data was collected anonymously through the use of tracking tools that were completed by SHC staff and volunteers. In total, 98 surveys were collected, including 49 outreach participant surveys, 15 screening participant surveys, 10 start-of-treatment participant surveys, and 24 post-treatment participant surveys.

## Analysis

Data from all four participant surveys was compiled and analyzed electronically using the Statistics Program for Social Sciences (SPSS). SPSS is an effective tool for manipulating large volumes of data.

Data was analysed according to the following research questions:

1. Who is the SHC Hepatitis C outreach program reaching?
  - How many people are SHC reaching (i.e. outreach)?
  - Who is making initial contact with SHC (demographics)?
  - Why do people make initial contact with SHC?
  - What outreach supports are people accessing through the SHC outreach program?
2. What are the characteristics of people who are accessing Hep C screening at SHC?
  - How many people are screened for HCV at SHC?
  - How many of those screened had initial contact with SHC through outreach?
  - What outreach supports did they access? How may this have helped them to access screening?
  - What factors enable individuals to access HCV screening?
3. How many people access supports at SHC after receiving positive screening results?
  - Who is accessing supports (demographics)?
  - What supports are people accessing?
  - What is the impact of support on people's decision to enroll in treatment?
4. Of the people screened and found positive, how many enroll in treatment at SHC?
  - What assists people to move through screening to being successfully treated?
  - How many of those who enroll in treatment had been connected to SHC through the outreach program?
  - How many had accessed supports after screening?
  - How many patients attend their scheduled appointments?
  - How many enroll into treatment but do not complete treatment?
  - How many completed treatment successfully?
  - What interactions/factors increase a patients' engagement with the treatment program?



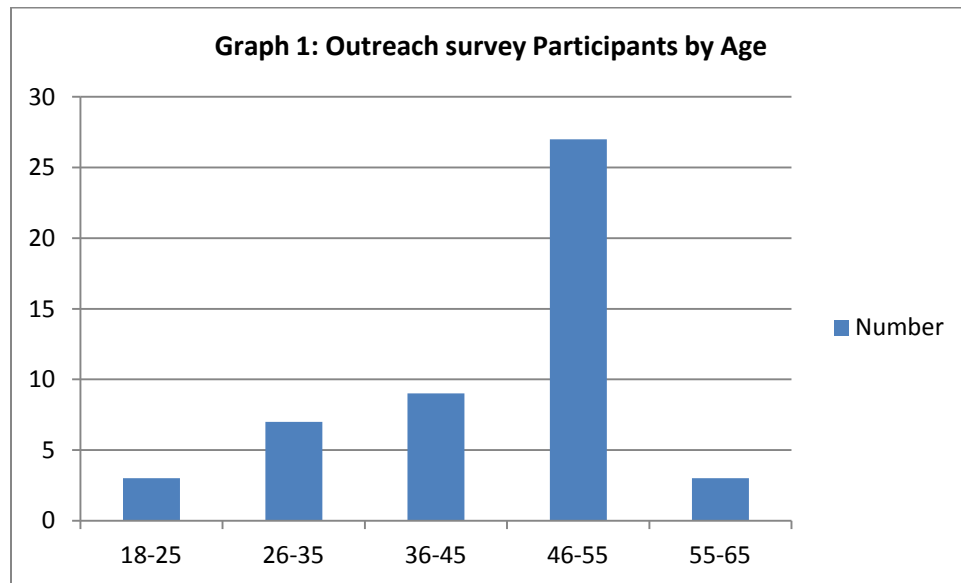
## FINDINGS

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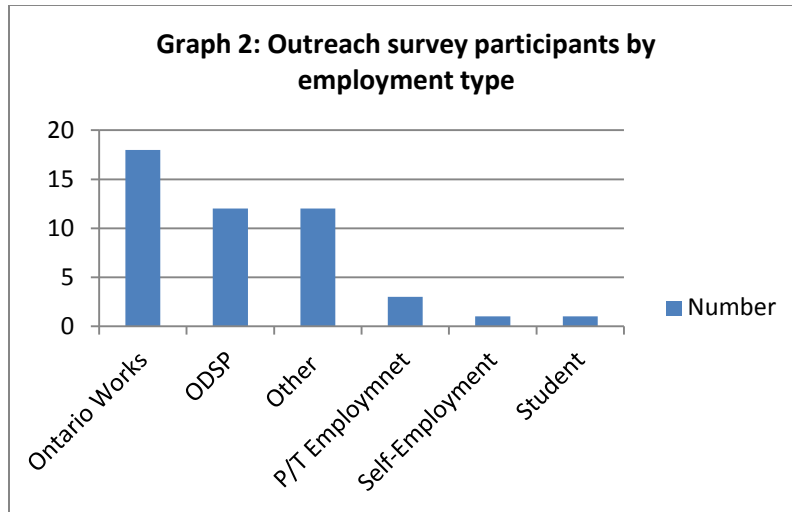
### Outreach Survey

#### *Who are the people who access SHC's outreach services?*

SHC's outreach program collected data from 49 individuals. The majority of the respondents, 61 percent (n=30), identified themselves as male, and 19 percent (n=19) identified as female. Most of the respondents (55%, n=27) were aged between 46 and 55. Age demographics are illustrated graph 1 below. The majority of individuals making contact with SHC's outreach program identified themselves as Caucasian (82%, n=40), with an additional 12 percent (n=6) identifying as Aboriginal.



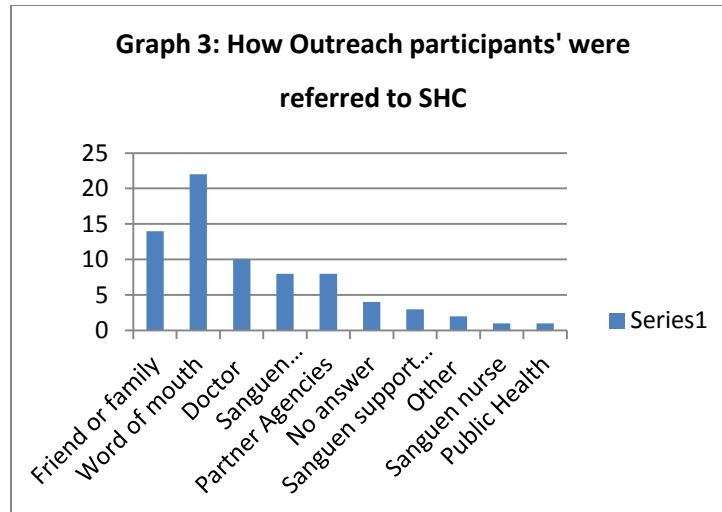
Most participants reported that their source of income was through some form of government programming or other form of income not listed in the questionnaire. Receiving income from Ontario Works (37%, n=18) or ODSP (24%, n=24) were reported by a large portion of the respondents as well as a large group of participants reported to use more than one form of income, including those not listed in the questionnaire. These additional sources were recorded as other (24%, n=12) and included sources like CPP, spouses, WSIB, personal funds, or no support. These results are illustrated in graph 2 below.



When asked about living arrangements, participants indicated a wide range of options and often selected more than one choice. The most frequent response was renting (43%, n=21), and second was homeless (18%, n=9). One third of participants (34%, n=17) reported living in temporary conditions (shelter, living with relatives, living with a friend), another 18 percent (n=9). None reported home ownership.

At the point of contact, participants were asked if this was their first experience with the SHC Outreach Program. More than half of the participants, (61 %, n=30) responded that they had had prior experience with the program. Of those who had a prior history, 70 percent (n=21) had been in contact with outreach services more than 5 times. Almost all respondents (98%, n=48) reported that they were not currently being treated for Hepatitis C.

Participants were asked how they had connected with Sanguen Health Centre. They were read a list of options, and some respondents selected more than one. Most of the respondents (45%, n=22), including those who were in their first contact, reported that they had come into contact because of word of mouth. 29 percent (n=14) had received recommendations from family or friend, and another 20 percent (n=10) had been recommended by a doctor. Referrals from a SHC nurse (2%, n=1), SHC support staff (6%, n=3), and Public Health (2%, n=1) all rated low. This information is illustrated below in graph 3.



The responses were split when asked about knowledge of SHC's harm reduction supply delivery program. More than half of response, (57%, n=28) were affirmative while 43 percent (n=21) were negative. Of the 28 respondents that were knowledgeable of the program, 75 percent (n=21) had not accessed it. Additionally, when asked if they had attended a HCV or HIV workshops provided by SHC, 84 percent (n=41) of participants reported that they had not. Respondents were also asked about the type of information they needed when accessing outreach services; their answers are summarized in Table 1 below.

**Table 1: Information sought by outreach survey participants**

Information sought	N	%
No answer	22	45
Facts about Hepatitis C	15	31
Hepatitis C treatment	12	24
Protecting myself from getting Hepatitis C	10	20
Safer sex	10	20
Safer snorting	8	16
Safer injection drug use	7	14
All of the information listed	5	10

When the respondents were asked if they had been tested for Hepatitis C, more than half of them, (63%, n=31) reported that they had and 34 percent (n=17) reported that they had not. As a follow up question they were asked where the testing had occurred, and responses covered a broad range of local, provincial, and international options (e.g. KW Hospital, London, Jail, the Bahamas).

***Service Knowledge, Needs and Improvements***

The final grouping of questions for the outreach survey asked respondents to provide feedback and opinions about service needs, awareness, usage, and improvement. The first question asked respondents about perceived barriers to Hepatitis C testing. The respondents were read a list of options and could select more than one response as they saw fit. The most common answer (41%, n=20) was

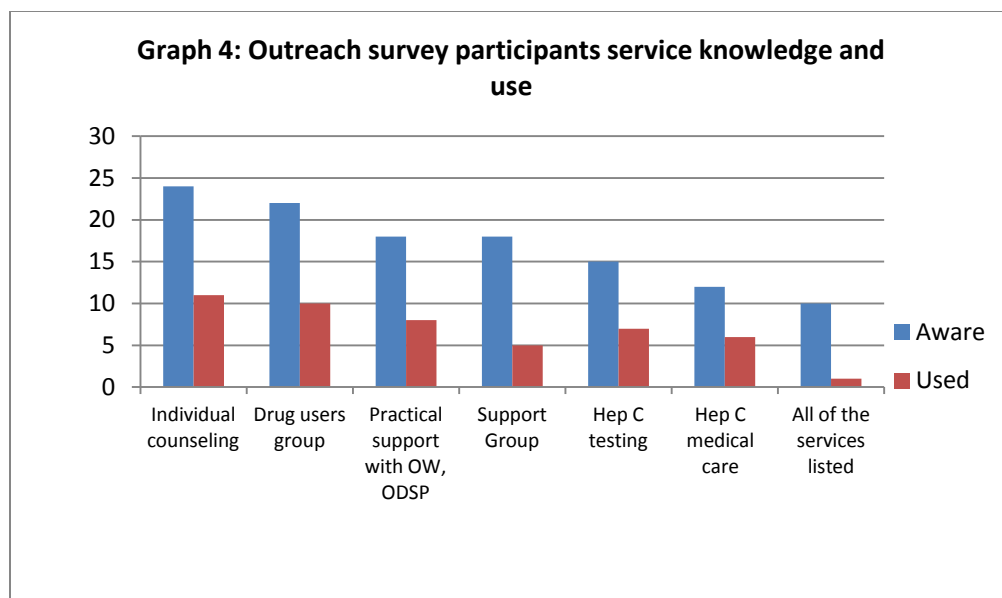
that individuals would be unsure about what will happen if they test positive. Another frequently selected response (39 %, n=19) was that participants felt that many people do not know about when/where testing is available. The third most common response (29%, n=14) was that participants felt a lack of trust with professionals. These responses are illustrated in table 2.

**Table 2: Outreach survey participants’ perspective on reasons to avoid HCV screening services**

<b>Reason</b>	<b>N</b>	<b>%</b>
Unsure what will happen if test positive	20	41
Don’t know about where /when testing is available	19	39
Lack of trust with health professionals	14	29
Lack of transportation	13	27
Unable to get to places during business hours	11	22
Struggle with getting blood taken	8	16
Struggle to remember appointments	7	14
Not a priority at this time	6	12
All of the reasons listed	4	8
Other (no health card, scared, stigma)	3	6
No answer	2	4

Respondents were asked how Sanguen Health Centre could make it easier to be tested for Hepatitis C, most (59%, n=29) suggested that that drop-in testing would be helpful. Another 41 percent (n=20) of respondents suggested that testing be offered at different locations, 29 percent (n=14) felt that different hours of testing were needed, 20 percent (n=10) felt that all of the listed changes should be implemented, and 8 percent (n=4) suggested other improvements, including providing transportation, dropping health card requirements, and fitting it into their schedule.

Respondents were provided with a list of services offered through SHC and asked about their knowledge and usage of these services. At least 20 percent of the respondents were aware of each service; however, usage levels were much lower. These results are presented in graph 4.



Finally, respondents were asked about how Sanguen Health Centre could improve its services. Respondents were read a list of options and asked to indicate all that applied. Each of the possible responses was well-selected and included the following suggestions: see table 3.

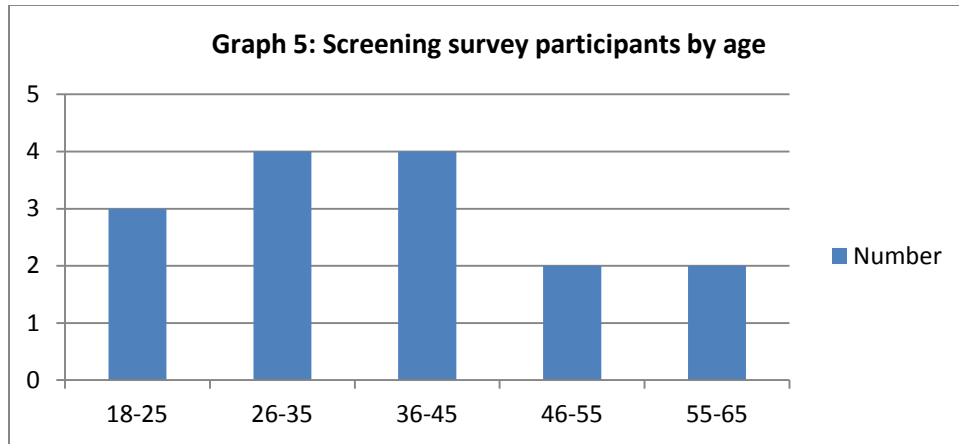
**Table 3: Outreach survey participants' suggested improvements for Sanguen Health Centre services**

Improvement	N	%
Offer services at other locations	21	43
Offer travel help	19	39
Offer more information about the service	17	35
Offer services outside of business hours	16	33
Offer help with food	15	31
Attend more community events	11	22
All of the services listed	6	12
Other (anonymous)	1	2

## Screening Survey

### *Who Are the People Getting Tested for HCV?*

Sanguen Health Centre collected data from 15 individuals undergoing screening for HCV. The majority of the respondents (80%, n=12) were male and 20 percent (n=3) were female. The age range of participants was fairly evenly distributed across all options from 18 to 65 years of age, and most (87%, n=13) respondents identified as Caucasian/white. Two respondents (13%) identified as Aboriginal/First Nations. Participants' ages are illustrated in graph 5, below.

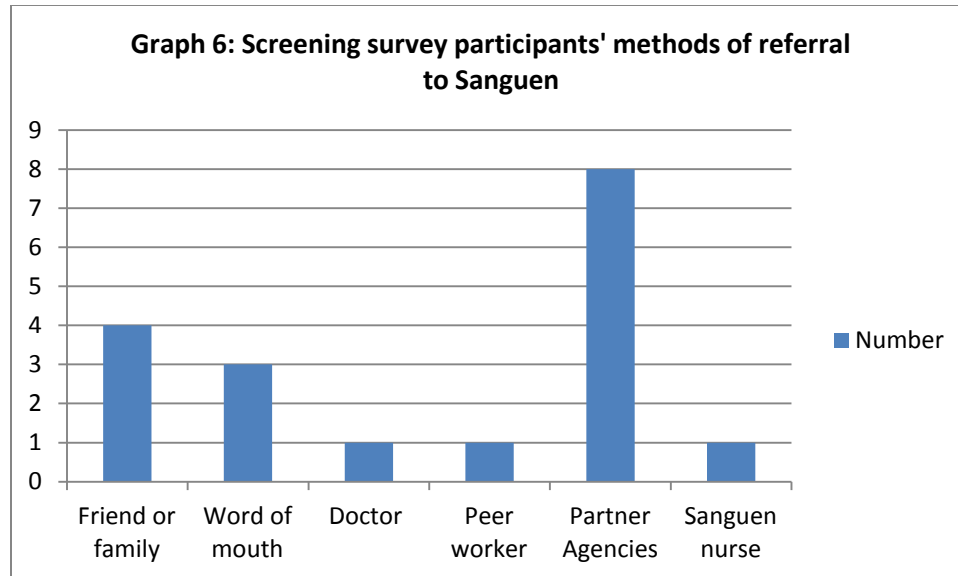


The majority of respondents (70%, n=12) were receiving income through government programs (i.e. Ontario Works and ODSP), another 2 (13%) reported being on the waiting list for Ontario Works, 2 reported part-time employment, and one respondent reported self-employment. Approximately half (47%, n=7) of the respondents indicated that they were currently renting their housing, 27 percent (n=4) reported a shelter as their housing, 2 (13%) were living in subsidized housing, and 2 (13%) were living with relatives or a friend.

***Service Knowledge, Needs and Improvements***

After providing demographic information, participants completed a questionnaire that assessed service usage, referral, and HCV-related knowledge. To begin, most of the respondents (73%, n=11) indicated that this was their first time being screened for HCV at SHC. Of the three (20%) who indicated that they had been screened before, all indicated that they had undergone tests 2-5 times prior.

Most (53%, n=8) of the participants had connected with SHC through referral from a community partner or other agency. An additional 27 percent (n=4) had been recommended to the service by a friend or family member, 20% (n=3) had heard of the program through word-of-mouth, and one respondent each indicated that they had connected to SHC through a nurse, peer worker, or doctor.



When asked about services, only 13 percent (n=2) of the respondents indicated that they had attended one of SHC’s HCV or HIV workshops; one had reported attending a SHC support group and the other SHC’s nutritional workshop. Additionally, almost half of the participants (47%, n=7) reported not using any of the services available. Of those that had used services, some of whom reported multiple service usage, most (33%, n=5) had had contact with street level support and outreach. Service usage is illustrated below in table 4.

**Table 4: Sanguen Health Centre services used by screening survey respondents**

Services Used	N	%
None	7	47
Street level support/outreach	5	33
Support group	3	20
Practical supports	3	20
Harm reduction supplies	2	13
Facebook/online support	2	13
Referrals to community resources	1	7
Individual counseling	1	7
One-on-one meetings	1	7
Financial support	1	7
Support through texting/phone	1	7
Sanguen education sessions/workshops	1	7

HCV knowledge was assessed through the use of two Likert scale questions and a cumulative question. The first Likert scale asked residents how strongly they agreed with the statement “I know how Hepatitis C can be transmitted.” 40 percent (n=6) felt that they agreed with the statement and another 20 percent (n=3) strongly agreed. Additionally, 20 percent (n=3) stated that they strongly disagreed.

Respondents were then asked about their agreement with the statement that “I know how Hepatitis C can be prevented.” Again, most (53%, n=8) respondents agreed or strongly agreed with this statement, but an additional 33 percent (n=5) either disagreed or strongly disagreed with it.

The final two questionnaire items asked respondents about their knowledge of HCV transmission and prevention. Specifically, the first question presented respondents with a list of possible means of transmission and they were asked to indicate which apply. Most of the respondents (87%, n=13) were able to correctly name some of the listed causes of transmission (including shared injection drug equipment, and shared tattooing equipment); however, no participants were able to accurately identify all of the every methods of transmission. A cumulative summary of the responses are listed below in table 5.

**Table 5: Screening survey participants’ knowledge of HCV transmissions**

<b>HCV Transmission method</b>	<b>N</b>	<b>%</b>
Sharing injection drug-using equipment	13	87
Sharing tattoo/piercing equipment	13	87
Sexual contact	11	73
Direct exposure to infected blood	9	60
Blood transfusion prior to 1992	8	53
Sharing inhalation/snorting equipment	7	47
Born with Hep C	4	27
Family history	3	20
Drinking too much alcohol	3	20
Having Hep A/B and it gets worse	2	13
Mosquitoes in other countries	2	13
From someone who is a carrier	2	13
All of the ways listed	1	7

The second question presented respondents with a list of ways to prevent Hepatitis C transmission and were asked to indicate all that apply. Most of the respondents (73%, n=11) indicated that all of the ways listed could contribute to protection from HCV transmission.

**Table 6: Screening survey participants’ knowledge of HCV prevention**

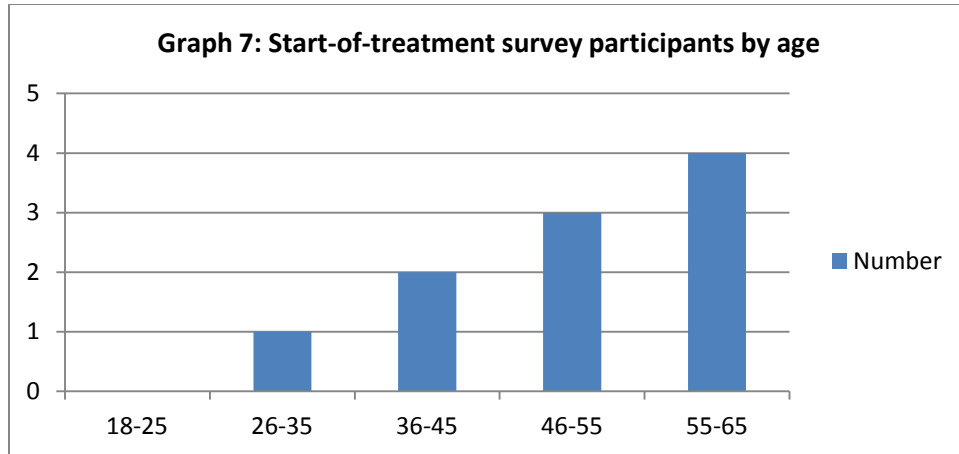
<b>Prevention of HCV transmission</b>	<b>N</b>	<b>%</b>
Using new, sterile needles	12	80
Practicing safe sex	12	80
Not sharing needles, toothbrushes, or razors	12	80
All of the ways listed	11	73
No answer	2	13



## Start-of-Treatment Survey

### *Who are the people accessing services from SHC after receiving positive screening results?*

A start-of-treatment survey was administered to individuals who had tested positive for HCV but had not yet undergone treatment. In total, 10 of these surveys were collected. 50 percent (n=5) of the respondents identified as male and an additional 50 percent identified as female. Most of the respondents (90%, n=9) were aged 36 or older, including 4 individuals aged 55-65 years, and only one individual was aged 25-35. Most of the respondents identified as Caucasian/white (90%, n=9) and one person identified as Aboriginal/First Nations.



Participants were asked to identify all of their current type of employment. Most of the respondents (60%, n=6) were receiving some form of government support (i.e. Ontario Works, ODSP); additionally, one individual was self-employed and one was employed full-time, and three indicated other types of employment (unemployed, CPP). All of the respondents indicated that they were living in some form of stable housing; the largest single choice was renting (40%, n=4), three people (30%) indicated that they were home owners, two (20%) indicated living in subsidized housing, and one participant reported living with relatives. Only one respondent indicated that they had been homeless in the past 5 years.

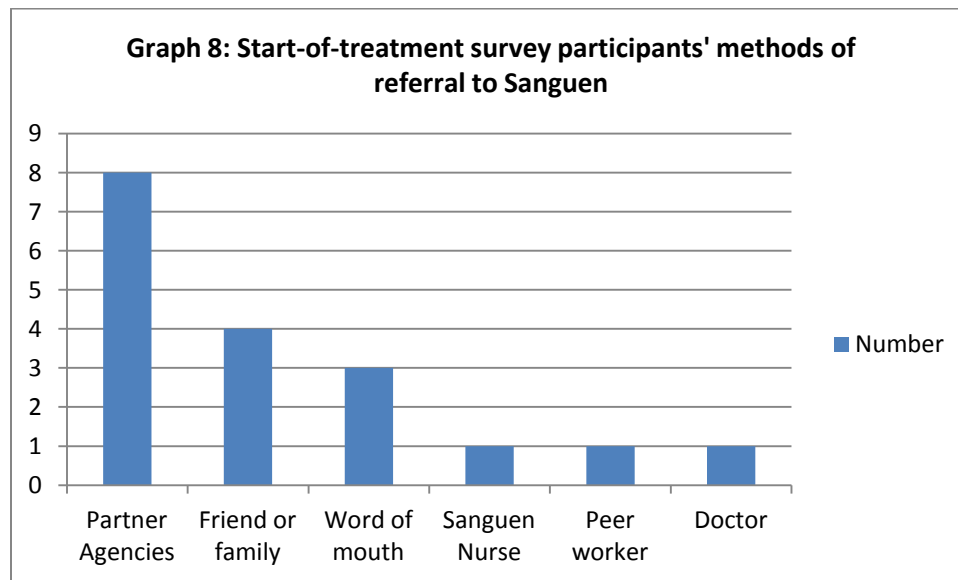
Respondents were also asked about previous diagnosis. They were presented with a list of mental and physical ailments and asked to indicate all that applied. Many of the respondents indicated some form of mental health concern but none indicated other health issues. This information is presented in table13 below

**Table 7: Mental and physical health concerns experienced by start-of-treatment survey respondents**

<b>Mental/Physical health issues</b>	<b>N</b>	<b>%</b>
Anxiety	5	50
Depression	4	40
Post-traumatic stress disorder	3	30
ADHD	0	0
Other mental health concern	2	20
HIV	0	0
Cardiovascular disease	0	0
Diabetes	0	0
Other	3	30

***Service Knowledge, Needs and Improvements***

The second part of the questionnaire focused on service-related questions. Participants were asked first to identify how they had come in contact with the SHC. The majority (60%, n=6) reported that they had been referred to the service by a doctor; an additional one each reported referrals from a SHC nurse, SHC support staff, Public Health, and community partner/other agency. Participants were also asked about the timeline of their HCV diagnosis. 40 percent (n=4) reported that they had become aware more than four years ago; 30 percent (n=3) had been diagnosed between 2 and 4 years ago; and 20 percent (n=2) had become aware less than 2 years ago.



Participants were asked to indicate which of the services offered by SHC they had used before treatment. They were presented with a list of options and asked to indicate all that applied. 60 percent (n=6) of the respondents did not provide an answer, indicating that they had not used any services prior. The service usage of the remaining four participants is detailed below in table 14. Respondents were

also asked to indicate what other services/supports they had used outside of SHC. These responses are illustrated in tables 8 & 9 below.

**Table 8: Sanguen Health Centre services used by start-of-treatment survey participants**

<b>Sanguen services</b>	<b>N</b>	<b>%</b>
Individual counseling	3	30
Sanguen education sessions/workshops	3	30
Support group	2	20
Addictions support	2	20
Street level support	1	10
Referrals to community resources	1	10
Practical supports	1	10
One-on-one meetings	1	10
Financial support	1	10

**Table 9: External services used by start-of-treatment survey participants**

<b>External services</b>	<b>N</b>	<b>%</b>
Walk-in clinic	4	40
Community Health Centre	2	20
Family Doctor	5	50
Hospital	2	20
Food bank	2	20
St John's Kitchen	1	10
Welcoming drop-in centre	1	10
Withdrawal management (detox)	1	10
Self-help groups	2	20
Family and friends	2	20
Counseling	2	20
Other (Stride/c.v.i.)	1	10

A series of Likert scale statements were presented to the participants, who were then asked to rank their agreement with statement. The statements focused on personal support networks. While data extrapolation was not possible due to the small sample size, several points of interest are present. For instance, there was strong agreement with most of the statements; however, questions about intimacy and family disagreements were more evenly distributed. This could indicate a loss of intimacy for individuals who have recently been diagnosed with HCV. The Likert scale results are presented in table 10 below.

**Table 10: Start-of-treatment survey participants responses to Likert scale statements**  
**(Key: 1=Strongly disagree, 3=Somewhat agree, 5=Strongly agree)**

Statement	Rating				
	1	2	3	4	5
I have family members who make me feel safe, secure and happy.	0	0	0	5	5
I have friends who make me feel safe, secure and happy.	0	0	1	2	7
If something went wrong, no one would help me.	5	4	1	0	0
There is someone I trust, to whom I could turn for advice if I were having problems.	0	0	1	2	7
There is no one with whom I feel comfortable talking about problems.	5	3	1	0	1
I have a feeling of intimacy with another person(s).	1	2	2	1	4
There are people I can count on in an emergency.	0	0	1	3	6
I provide support to my friends.	0	0	1	6	3
I provide support to my family member(s).	2	0	1	3	4
I have a lot of serious disagreements and arguments with my family.	4	2	2	1	1

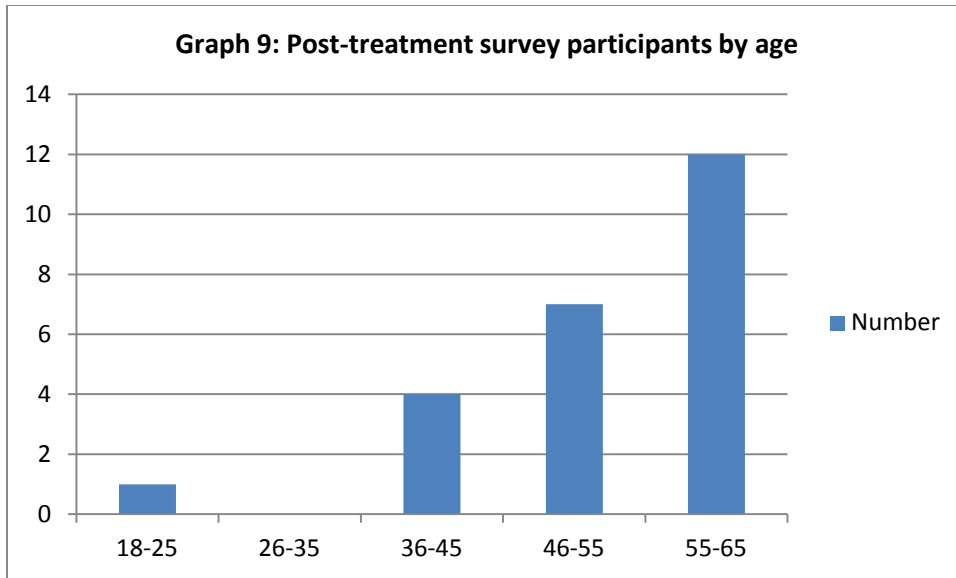
A final set of questions for the start-of-treatment survey asked open-ended questions related to HCV treatment, SHC’s services, and service improvement. The first question asked participants to provide information about what led them to start HCV treatment. Most of the respondents related their decision to health and/or loved ones; for instance, one respondent wrote that “[I’m] just worried about my health and would like to live a long time for my kids.” One individual noted that not having to pay for services guided their decision.

The second qualitative question asked participants about the barriers they perceived would prevent people from seeking treatment. Their responses primarily fit into two categories: lack of education (i.e. “Uneducated about Hep C and treatments available”); and fear of treatment/disease acknowledgement (i.e. “Scared to face treatment, not ready”). When asked about what could be done differently by SHC, participants had very little to add. Most responded either that they didn’t know (40%, n=4), or that they were happy with current services (30%, n=3). Similarly, no additional feedback was provided by respondents.

### Post-Treatment Survey

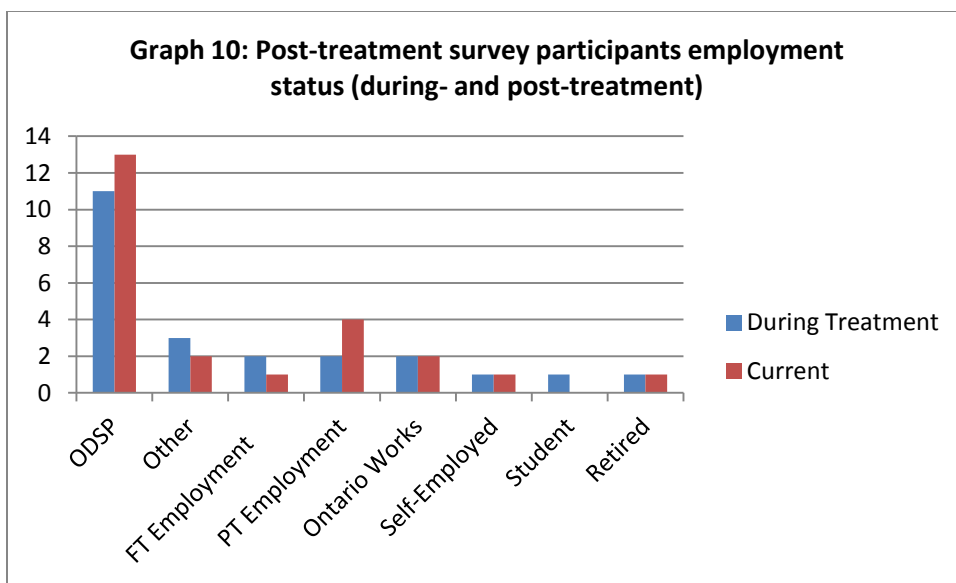
#### ***Who are the people that SHC has treated for HCV?***

A post-treatment survey was completed by 24 respondents. Individuals identifying as male and female were equally represented with 12 each, and most of the respondents (79%, n=19) were aged 46 or older. Four respondents (n=17) reported that they were aged 36-45 years and one respondent (4%) was aged 18-25. The vast majority (87%, n=21) identified as Caucasian/white, and the remaining 3 identified as Aboriginal/First Nations.



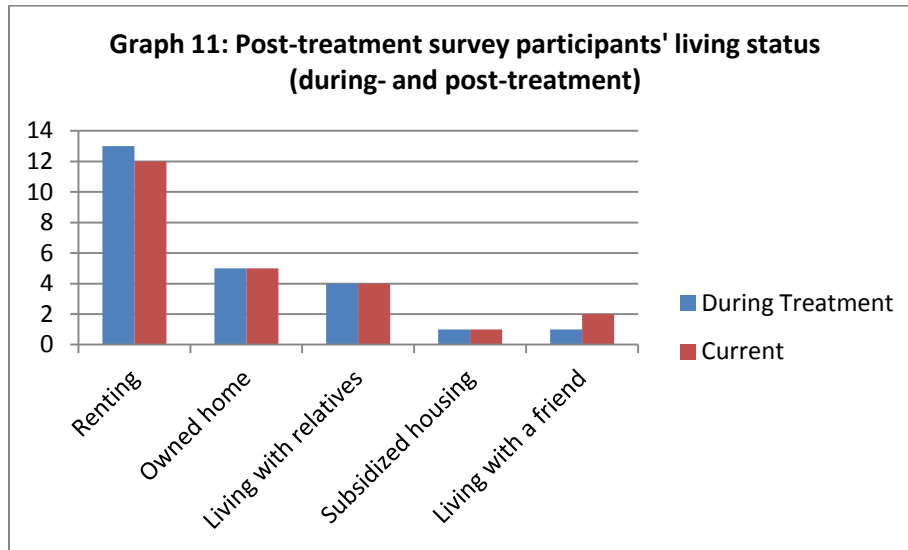
Questions about the employment status of participants were framed according to status during treatment and status after treatment. Most respondents (54%, n=13) indicated that they were receiving some sort of government support during treatment. Part-time and full-time employment was represented by two individuals each (8%), and one each reported either self-employment, student status, or retirement. Three individuals indicated “other” for their employment status.

There was some variation when participants indicated their current employment status. Again, most participants (62%, n=15) indicated that they were receiving some form of government support; however, fewer reported full-time employment (4%, n=1) and more reported part-time employment (17%, n=4). Additional comparisons are illustrated in graph 10 below.



Questions about housing were also framed according to status during treatment and post-treatment. Generally, participants indicated that they were in stable housing during treatment; most (54 %, n=13)

indicated that they had rental housing or owned housing (21%, n=4). Five participants (21%) indicated that they were living with friends or family during their treatment, and one was living in subsidized housing. There was little variation in post-treatment housing; only one person indicated a change from renting to living with a friend. Eight participants (33%) indicated that they had been homeless in the last 5 years. Additional housing comparisons are illustrated in graph 11 below.



Respondents were also asked about previous diagnoses. They were presented with a list of mental and physical ailments and asked to indicate all that applied. Many of the respondents indicated some form of mental health concern and some indicated other health issues. This information is presented in table 11 below.

**Table 11: Post-treatment survey participants' previously diagnosed physical and mental health conditions**

Pre-existing diagnoses	N	%
Anxiety	11	46
Depression	11	46
No answer	4	17
Other mental health concern	4	17
Diabetes	4	17
High blood pressure	4	17
Post-traumatic stress disorder	3	13
Bi-polar	3	13
Cardiovascular disease	2	8
Arthritis	2	8
ADHD	1	4
Multiple sclerosis	1	4
Blocked air passage heart	1	4

The respondents were asked about their history of treatment at SHC. Most (92%, n=22) had commenced treatment after 2008, with starting dates in 2009 (21%, n=5), 2010 (33%, n=8), and 2011 (29%, n=7) most frequently cited. Most participants (92%, n=22) reported completing their treatments in 2010 or later; nine (37%) had completed in 2010, ten (42%) had finished in 2011, and 3 (13%) had finished in 2012. One each completed their treatment programs in 2008 and 2009.

Two-thirds of the respondents underwent 24 weeks of treatment or greater; eight respondents had undergone 48 weeks, ten respondents completed 24 weeks of treatment, and six respondents had had less than 24 weeks of treatment. Most (92%, n=22) of the respondents had taken or were taking a combination of Peg-interferon and Ribavirin, and the remainder had an additional dosage of Victrellis along with the other two drugs. A large majority of respondents (73%, n=19) indicated that their treatment had been successful (i.e. sustained virologic responses)

As a follow-up, participants were asked to respond to three Likert-scale questions about treatment. The first statement read “I take my medications regularly as directed by my doctor,” and all participants either agreed (21%, n=5) or strongly agreed (79%, n=19). Similarly, the second statement that “I take my medications on time as directed” was met with total agreement by residents. Six respondents (25%) agreed with it and eighteen (75%) strongly agreed. The third statement read “I attend my appointments at Sanguen Health Centre regularly.” Again, all participants were in agreement with one (4%) indicating that they somewhat agreed with it, six (25%) agreed with it, and seventeen (71%) strongly agreed with it.

Participants were asked about challenges that they faced during treatment, including side effects from medications and other medical complications. These symptoms are detailed below in table 12 below.

**Table 12: Side effects endured during treatment experienced by post-treatment survey participants**

Side effects during treatment					
Symptom	N	%	Symptom	N	%
Fatigue	15	63	Mood swings	8	33
Trouble sleeping	13	54	Skin problem/rashes	8	33
Depression	12	50	Impaired memory	8	33
Loss of appetite	12	50	Stomach problem	7	29
Flu-like symptoms	12	50	Headache	7	29
Low red blood cells	10	42	Dizziness	7	29
Weight loss	10	42	Impaired concentration	7	29
Irritability	10	42	Other (hair loss, nausea, loss of patience)	7	29
Confusion	8	33	Suicidal ideation	4	17
Anxiety	8	33			

**Table 13: Other outcomes from treatment experienced by post-treatment survey participants**

**Other outcomes from treatment**

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Not drinking and smoking anymore  
 Coughing of around six months. Pneumonia  
 Kidney problem  
 Drug withdrawal  
 Bed ridden. Not understanding thing. Scared  
 Dehydration  
 Complications involving multiple sclerosis  
 Loss of daughter 4 years ago  
 Makes you feel strange

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Most participants (79%, n=19) indicated that they successfully completed their treatment at SHC. The five respondents that did not (21%) provided some feedback as to their reasons why, which included “side effects” (13%, n=3), “liver conditions” (n=1), and that “the doctor stopped treatment” (n=1). All of the participants (n=19) that had successfully completed treatment indicated that they had reached sustained virologic response.

***Service Knowledge, Needs and Improvements***

The questionnaire then asked service-related questions. Participants were asked first to identify how they had come in contact with the SHC. The majority (83%, n=20) reported that they had been referred to the service by a doctor; three (12%) had been recommended to the service by a friend or family and one each had heard about SHC through word-of-mouth or online. Ten respondents (42%) indicated that they used supports from SHC during treatment, including four (17%) who had used services both before and during treatment. Tables 22 and 23 below illustrate the SHC services and external services below, respectively.



**Table 14: Internal and external services used by post-treatment survey participants**

Sanguen Services	Services used		External Services	N	%
	N	%			
None	12	50	None	10	42
Support through texting/phone	5	21	Family Doctor	9	38
Referrals to community resources	3	13	Family and friends	5	21
Individual counseling	3	13	Food bank	4	17
Support group	3	13	Self-help groups	4	17
Street level support/outreach	2	8	Hospital	3	13
Harm reduction supplies	2	8	Withdrawal management (detox)	3	13
Home visits	1	4	St John's Kitchen	2	8
Practical supports	1	4	Community Health Centre	1	4
Facebook/Online support	1	4	Counseling	1	4
Other (nutrition counselor)	1	4			

A series of Likert-scale statements were presented to the participants, who were then asked to rank their agreement with statement. The statements focussed on personal support networks. Again, data extrapolation was not possible because of the small sample size but several points of interest are illustrated. For instance, most of the answers indicated that the participants had a strong network of support; however, the question about intimacy had agreement and disagreement, indicating that these personal support networks do not always include intimate partners. This information is presented in table 15 below.

**Table 15: Post-treatment survey participants responses to Likert-scale statements  
(Key: 1= Strongly disagree, 3=Somewhat agree, 5=Strongly agree)**

Statement:	Rating				
	1	2	3	4	5
I have family members who make me feel safe, secure and happy.	2	1	3	3	15
I have friends who make me feel safe, secure and happy.	2	0	7	1	13
If something went wrong, no one would help me.	14	3	3	3	1
There is someone I trust, to whom I could turn for advice if I were having problems.	2	0	2	5	15
There is no one with whom I feel comfortable talking about problems.	13	4	4	0	3
I have a feeling of intimacy with another person(s).	4	6	2	3	9
There are people I can count on in an emergency.	1	1	3	3	16
I provide support to my friends.	1	1	1	6	14
I provide support to my family member(s).	1	2	2	4	13
I have a lot of serious disagreements and	12	4	4	1	2

arguments with my family.

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The post-treatment survey concluded with three open-ended questions that allowed respondents an opportunity to provide input about the services available through SHC. The first question, which asked about SHC's helpfulness, was met with an overwhelmingly positive response. Qualitatively analyzed, two primary themes emerged: enthusiasm for the environment of Sanguen Health Centre ("The setting of the clinic is like home, comfortable."); and enthusiasm for the quality of care provided by the Centre's doctors, staff, and volunteers ("[They] listened. Open and honest. Awesome staff. Helped to understand what was going on with [co-occurring medical concerns] and the interactions between that and the HCV as well as the medication").

The third question asked respondents to provide insight into improving the services for other individuals being treated for HCV. Again, participants were mostly happy with services available, however several noted that more and easier access to information, warnings about side effects, and a broader range of counseling services (including nutrition) could be provided.

## **CONCLUSIONS**

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Throughout the analysis of survey data it became abundantly clear that participants contacted through outreach, screening, start-of-treatment, and post-treatment were satisfied and enthusiastic about the services offered by SHC. Demographic statistics collected from participants in each of the survey categories indicate that SHC is connecting with at-risk populations, and that most of these connections have been made through word-of-mouth, friends & family referrals, or referrals from community and partner agencies. Unfortunately the limited sample size prevented data extrapolation beyond descriptive analyses; in some cases, questionnaire items were completely omitted due lack of responses. Bearing this in mind, it is recommended that Sanguen Health Centre continue to use a data collection protocol which will enrich the existing data, and enable SHC to develop a deeper knowledge about their clients and opportunities for service improvement.

# Appendix A: Sanguen Health Centre Hepatitis C Program Logic Model

