

# Pilot Process Evaluation of the Sanguen Health Centre Hepatitis C Program

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Prepared for: Sanguen Health Centre



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## **EXECUTIVE SUMMARY**

**Rationale.** The pilot process evaluation was carried out on behalf of Sanguen Health Centre (SHC) to collect information from their clientele on strengths and limitations of their hepatitis C program.

**Methods.** Focus group (FG) methodology was selected for collection of information for the pilot evaluation. Two focus groups were carried out, one at each of SHC's two locations. Participants were individuals who utilize services offered by Sanguen, and were recruited by Sanguen staff. FGs were audio taped with permission of all participants. Participants completed a short background questionnaire to supply demographic information. Following the sessions, audio from the FGs was transcribed. Findings were examined using thematic analysis.

**Main Findings.** Three themes common to both FGs were identified through analysis: peer support network, comprehensive services, and approach to service delivery. These themes illustrated that participants were extremely satisfied with the program due to such features as the peer support group, the multidisciplinary nature of the services, and the comfortable, non-judgemental atmosphere fostered by the staff.

**Conclusions.** Sanguen should continue to use a caring, non-judgemental approach. Participants had difficulties identifying weaknesses in the program. More exploration into potential barriers to access is needed, possibly through communication with less involved clients.

**Suggestions for Further Evaluation.** Further FGs should be conducted until saturation of information is achieved. Clientele who are less involved in the services and programs offered should be sought out for FGs, which should be carried out in the absence of more involved clients. Additional methods of evaluation can be explored to conduct a more thorough process evaluation.

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## **BACKGROUND**

Sanguen Health Centre (SHC) is an organization dedicated to meeting the needs of those living with or at risk for hepatitis C. With two locations, one in Waterloo and one in Guelph, Sanguen Health Centre offers medical care, individual counseling and advocacy, support groups, outreach services, education, and more.

Hepatitis C is characterized by inflammation of the liver caused by the hepatitis C virus (HCV). HCV is spread through blood-to-blood contact, most commonly as a result of sharing needles when using illegal street drugs. It is estimated that 69% of individuals who inject drugs in Canada are living with this disease (CATIE, 2013). Inflammation of the liver can lead to cell death, swelling, and build-up of scar tissue in the liver, known as fibrosis. Fibrosis reduces blood flow, resulting in hardening and shrinking of the liver, known as cirrhosis. Eventually this damage may lead to liver cancer or liver failure, which can occur at differing rates. Many people have no physical symptoms, even when there is damage to the liver (CATIE, 2013).

When SHC was founded in 2007, it consisted solely of the clinical team comprised of one doctor and one nurse. However, as services and demand for comprehensive care increased, Sanguen expanded in 2011 to a multidisciplinary team to incorporate social workers and provide additional services. SHC's main roles currently include medical care, support programs, and outreach programs. Each of these main areas consists of several client-centred services offered by a specialized team of staff members (refer to Table 1 for details on the next page).

The mission, beliefs, and approach employed by SHC are consistent with the mandate outlined in the *Proposed Strategy to Address Hepatitis C in Ontario 2009-2014*. This strategy was a call to action emphasizing the importance of providing education, treatment, prevention,

and support for populations at high-risk for hepatitis C, particularly those who use illegal street drugs (Ontario Hepatitis C Task Force, 2009). The strategy also recommends that hepatitis C treatment should align with key principles (Ontario Hepatitis C Task Force, 2009). These principles include such concepts as:

- Equitable access to high-quality treatment, prevention, education, and support for all people
- Employment of harm reduction principles, which emphasize reduction in the transmission of blood-borne pathogens without requiring that individuals abstain from drugs (e.g. by dispensing clean needles)
- Reduction of stigma and discrimination which can act as barriers to accessing hepatitis C services

**Table 1.** Main roles of service teams at Sanguen Health Centre

<b>Service Area</b>	<b>Team Members</b>	<b>Roles</b>
<b>Medical Care</b>	<ul style="list-style-type: none"> <li>• Infectious disease specialist: Dr. Chris Steingart</li> <li>• Clinic coordinator: Michelle</li> <li>• Two hep C treatment nurses: Tracy and Martine</li> </ul>	<ul style="list-style-type: none"> <li>• Provide information about treatment and hep C, in the clinic and in the community</li> <li>• Screening for hep C, treatment, monitoring</li> <li>• Assistance with obtaining medication coverage</li> </ul>
<b>Support</b>	<ul style="list-style-type: none"> <li>• Support Coordinators: Estera and Abby</li> <li>• Community Coordinator: Jan</li> <li>• Peer support group co-facilitators</li> </ul>	<ul style="list-style-type: none"> <li>• One-on-one counselling (substance abuse, mental health, trauma, relationships, etc.)</li> <li>• Facilitate peer support group</li> <li>• Advocacy; help with arranging government financial assistance; crisis support.</li> </ul>
<b>Outreach</b>	<ul style="list-style-type: none"> <li>• Manager of outreach, education and prevention: Violet</li> <li>• Peer outreach volunteers</li> </ul>	<ul style="list-style-type: none"> <li>• Workshops and presentations</li> <li>• Distribution of harm reduction supplies</li> <li>• Connect with people in the community through permanent locations/mobile outreach</li> </ul>

### Previous Evaluation Studies

In 2012 – 2013, an outcome evaluation was completed by the Centre for Community Based Research (CCBR) for SHC in order to evaluate the outcomes of the hepatitis C program. Data was collected using four different surveys, each one specific to a branch of services offered

by Sanguen: outreach, screening, start-of-treatment, and post-treatment. The evaluators collected demographic information, as well as program-specific information such as how the respondents were referred to Sanguen, reasons to avoid hepatitis C screening, awareness of services offered by SHC, and suggested improvements. Based on the survey results, the evaluators concluded that “participants contacted through outreach, screening, start-of-treatment, and post-treatment were satisfied and enthusiastic about the services offered by SHC.” They went on to suggest that Sanguen should continue to collect data using these surveys in order to obtain a larger sample size which will provide increased information about clients, outcomes, and opportunities for improvement (Centre for Community Based Research, 2013).

## **RATIONALE OF PILOT EVALUATION PROJECT**

There are approximately 100, 000 individuals in Ontario who have hepatitis C without even knowing they have contracted the disease (CATIE, 2013). The long term impacts of HCV on the health care system are severe as many individuals go on to develop cirrhosis, cancer, and failure of the liver when without proper monitoring, treatment, and management (CATIE, 2013). As one of few hepatitis C focused health centres in Ontario, one of the goals of SHC is to minimize the potential future impact of HCV. Given that SHC has been operating for over five years and has never conducted a process evaluation, the program is interested in knowing the strengths and limitations of program usage, delivery, and operation from their current clientele through a process evaluation.

A process evaluation for the pilot project was selected as the program was interested in knowing how they can improve their services and if there are any unmet needs from their current clientele. They also wished to answer answering the following questions:

- What are the key things that Sanguen does well?
- What and how does SHC keep their clientele engaged?
- Do participants come to and use the support groups? Why? What makes them come back?

A focus group (FG) methodology is useful in bringing together several users of the program simultaneously to gain their insight and viewpoints on the programs activities (Myers, 1999). A small group of participants between 6 to 12 individuals gather, allowing for an enriching discussion from multiple perspectives. This type of setting allows participants to interact and exchange ideas as well as to understand and stimulate each other's viewpoints (Balch & Mertens, 1999). The depth and richness of the qualitative data obtained through FGs cannot be achieved in other methods such as an individual interview or survey. The knowledge obtained about the program depends on the participants to share their experiences in a group setting. The focus group method is also less demanding on the individual as they are not required to answer all questions if they are uncomfortable or lack knowledge in that particular area (Myers, 1999). At the same time, participants can hear what others are saying which may lead them to think of different suggestions or provide alternative insight. In addition, participants have the opportunity to answer any question they may have missed at a later point in the focus group. The use of FGs requires time, commitment, and funding, but is an economical method of gathering data on multiple participants simultaneously, as compared to interviews and surveys.

## **METHODS**

### **Participant Profile**

The target audience for the pilot process evaluation of the FG were individuals who utilize the services offered by SHC, especially the support group, one-on-one support, and medical care. Since these services are directed to anyone who is living with or at-risk for 4



hepatitis C in the two regions, all individuals using the program were eligible to participate in the FG discussion. In addition, the services are also open to the family members and the loved ones of those with hepatitis C, such as their caregivers, so these individuals were also encouraged to join and share their experiences. All participants must speak English as the services provided at SHC are given in the English language.

### **Recruitment and Sampling**

Recruitment for the focus group was carried out by program staff during the weekly support services. This was ideal for approaching this sensitive population since current clientele interact with staff members on a regular basis and have a trusting relationship with them. Staff members highlighted the rationale for the group discussion, inviting and encouraging clients to join. Approximately 6 – 12 participants was the recruitment goal in order to obtain depth and detailed responses from all individuals and to avoid social pressures often present in large group settings. Individuals from all age groups and stages of hepatitis C development were invited who utilize SHC services. No program staff were invited to the FGs to avoid power struggles.

Monetary compensation of a \$20 Tim Horton's gift card was offered to participants of the FG along with a variety of snacks and beverages during the discussion. The gift card was purchased and offered by SHC while the evaluators acquired refreshments and equipment.

### **Personnel**

There was one facilitator and one assistant-moderator for each FG and both individuals served as the evaluators for the pilot project. One team member had previous contact with SHC as a volunteer and one was external to SHC in order to have a neutral and unbiased viewpoint on the program. During the FG, the facilitator was responsible for introducing the topic, leading the

discussion, and covering all questions. The assistant was responsible for ensuring all consent forms were complete, arranging all appropriate equipment, taking notes of non-verbal gestures, identifying speakers sequentially for transcription of the audio recording, creating a seating chart, and closely monitoring the time.

### **Evaluation Tool: Focus Group**

**Planning and Preparation.** Two focus groups were suggested for the pilot project as a starting point in conducting evaluation and obtaining feedback from program users. One FG was conducted at the Waterloo location and the other at the Guelph location in order to examine differences in user experiences with the program. Although two groups are sufficient for a pilot analysis, with more time, budget, resources, and participants, a larger project with additional focus groups should be conducted at both locations until saturation of information is achieved. In addition, a focus group with staff members could be conducted to determine their perspective.

The FG was conducted at SHCs community locations so that participant would be comfortable due to familiarity and to ease access to the location. Parking at these locations is free for program users and bus routes are nearby for those utilizing public transportation.

Both FGs were scheduled to be on the same day as the regular support groups at SHC. This was planned to ease participant burden since they would already be present at the facility to attend the focus group. The Waterloo focus group was conducted on a Wednesday afternoon while the Guelph discussion occurred on a Thursday afternoon.

Development of all materials were completed by the evaluators and confirmed by the program staff contact. Materials included a consent for participation, audio recording, and follow-up contact as well as a background questionnaire. In addition, a protocol was developed

outlining the process the evaluators should follow on the day of the FGs. Lastly, a script was developed with appropriate questions and probes to guide the discussion.

Both the facilitator and assistant arrived at least 30 minutes prior to the start of the session to set-up materials (copies of all forms, refreshments, nametags, and audio recorder). Chairs were previously set-up in an open circle by the support group users and the set-up was used to allow for observation of body language and gestures. A small table was placed at the centre of the circle for the audio recorder to capture all voices at an equal distance.

**Conducting the Focus Groups.** Individuals indicated interest in the focus group by showing up at the designated time and place mentioned during the announcement made at the support group session. Individuals were also reminded to stay for the focus group discussion during the support group session that was immediately prior to the focus group discussion. Steps taken once participants arrived are outlined in table 2.

After arriving, the facilitator and assistant explained the protocol, expectations for the discussion, and all consent forms. Individuals were welcome to obtain refreshments during this time or at a later point in time. One consent form was directed at obtaining general consent for participation in the group discussion. The second consent form explained the reason for audio recording the sessions (see Appendix A for these consent forms). All individuals provided written consent for participation as well as audio recording. Participants were also provided with a background questionnaire to obtain basic demographic information on those present at the focus group (see Appendix B).

**Table 2.** Procedure undertaken by evaluators prior to start of discussion

<b>Steps before beginning focus group discussion</b>
1) Facilitator will explain protocol, expectations for discussion, and all consent forms
2) Participants complete general consent and audio recording consent (see Appendix A for all consent forms)
3) Participants offered refreshments
4) Background questionnaire completed by participants (see Appendix B)
5) Assistant ensured all consent forms were signed in order to begin the discussion

After all required consent forms were obtained and checked for signatures, the evaluation team members (DD and KS) began the group discussion.

The evaluators introduced the session by explaining the rationale and the intentions of conducting a FG. Ground rules were established to highlight that all opinions are appreciated and welcomed. Prior to turning on the audio recorder, participants were provided with the opportunity to ask questions and clarify the purpose of the session. After the audio recorder was turned on, the facilitator dictated questions from the script (for complete script, see Appendix C). The assistant recorded names of all participants present in a seating chart and the beginning of each response provided to ease transcription that would occur afterwards. The assistant closely monitored timing of the session. The assistant was also offered an opportunity to ask any questions they felt were important. At the end of the discussion, summary remarks were made by the facilitator to confirm the responses discussed and a follow-up consent form was distributed to contact participants at a later date to confirm findings (see Appendix D). All individuals were thanked for their participation and were encouraged to obtain their gift card from SHCs receptionist as they were leaving.

**Debriefing and Transcription.** Immediately after each FG session, both the facilitator and moderator engaged in a debriefing process. This process is essential in order to discuss the participant interactions and impressions of the session (Myers, 1999). Topics covered in the debriefing included concepts such as level of participation in the conversation, differences of opinion between participants, and indications of strong opinions or emotions regarding a certain issue. General feedback about the FG preparation, set-up, and interaction with clients was discussed to make notes of how to improve. All debriefing comments were written down in detail for further review during report writing.

After all FGs were conducted, transcription of the audio recording was performed. The assistant of each session was the one to carry out the transcription, as they were the individuals observing all non-verbal gestures and taking note of the speakers. After transcription, both members reviewed the full, non-abridged transcripts.

**Analysis of Focus Group Data.** Data sources for analysis included the seating charts, field notes, debriefing notes, completed background questionnaires, and the transcripts.

Since the majority of the data obtained was qualitative in nature, the evaluators proceeded with a thematic analysis. The transcripts of the FGs were searched to identify the overlying themes and ideas that were discussed within each topic and through the whole discussion. Multiple reviews of the transcript were conducted to see how ideas tied together and if any opinions changed as the discussion progressed. Possible quotes that identified themes and sub-themes were highlighted for further use in the written report. Both evaluators conducted all of these steps separately to ensure confidence in findings. After findings were confirmed, a comparison between the Waterloo and Guelph groups was conducted to identify any differences

in group composition and if the themes that emerged were similar. Some questions on the background questionnaire were categorical and were able to be explored through frequency analysis. Microsoft Excel was utilized for frequency analysis and to display any graphical representations of the findings.

## FINDINGS

Two focus groups were held, one in SHC’s Guelph location and one in Waterloo.

### Demographics

The Guelph focus group had nine participants, five female and four male. All nine participants identified their ethnicity as white. The Waterloo focus group had eleven participants, nine male and two female. Almost all participants (n = 10) identified as white while one identified as African American. The HCV status of participants is visualized in Figure 1 below.

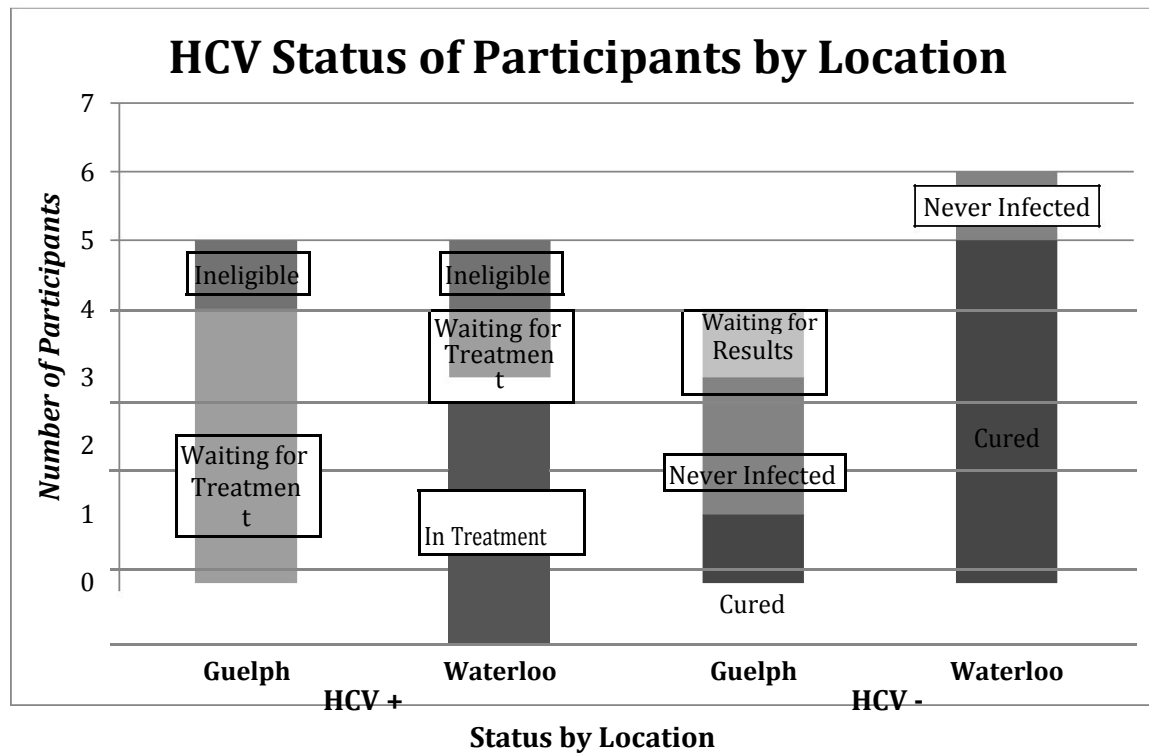
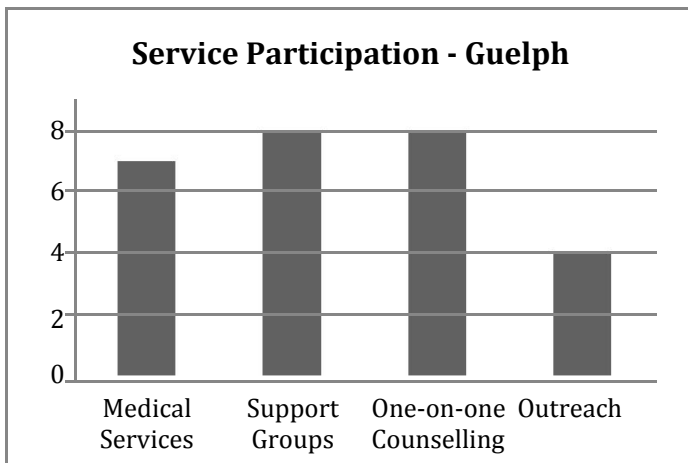


Figure 1. HCV Status of Participants by Location

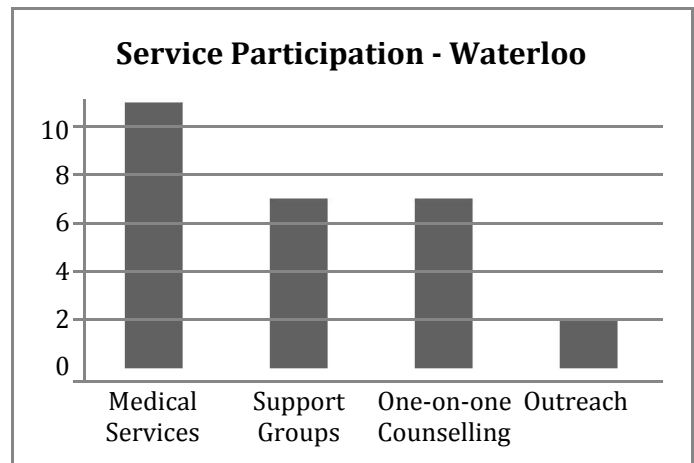


One of the participants in Guelph was waiting to access medical services and was not yet aware of the other services offered by Sanguen. The presence of this participant added some difficulty to the focus group, as she would frequently interrupt the discussion to ask questions about the services and how she could access them. Of the two participants in Guelph who had never been infected by HCV, both attended one-on-one counselling for support external to hepatitis C and one also volunteered with outreach services. All participants were actively involved in conversation and shared their opinions openly. Both groups included one individual who was infected with HCV but did not qualify for treatment. For both participants, this is because individuals are not eligible for HCV treatment if their liver is considered healthy. In both focus groups, the peer co-facilitators from the support group occurring prior to the focus group remained to participate in the discussion.

Figures 2 and 3 below depict the services the participants of the focus groups engage in.



**Figure 2.** Participation in SHC services, Guelph



**Figure 3.** Participation in SHC services, Waterloo



## **Thematic Analysis**

Across the two focus groups, three over-reaching themes were identified from the content of the group discussions: Peer Social Support Network, Comprehensive Services, and Approach to Service Delivery.

**Peer Social Support Network.** The participants identified the peer support group as an extremely valuable component of the services offered by Sanguen, allowing participants to learn from one another, share their thoughts and feelings, and experience a feeling of community.

Common discussion points indicated that the support groups allow participants to learn from others who have lived experience with hepatitis C. For those who were preparing to begin treatment, information from group members who were in differing stages of treatment was regarded as invaluable. As one participant commented, “I didn’t know about hep C until I got it and then I started coming to the support group to find out how everyone else dealt with the program.” Another added, “I want to know what I’m up against... I listen to everybody because you don’t know when something’s going to come up. I’m always learning something new.”

On top of learning from one another, having a place to share thoughts and feelings was identified as very important. One participant notes, “Outside this room I don’t share, I don’t talk to people about what I’m going through. I don’t want to scare people away from me. And coming here lets me share a little bit more about myself.”

The participants also identified the importance of the support group in building a sense of community, and easing feelings of isolation: “[We] find out that we’re not alone, that we’re pretty much all the same... we all have our shortcomings, and to feel that and know that, you don’t feel alone.” Another comment, “I’m not as embarrassed because when I hear other people,

I see I'm not anything special", illustrates the idea that the sense of community offered in the support group has helped participants alleviate some of the stigma they face as individuals with hepatitis C.

Some participants went on to identify how the support group helps them to manage other issues in their lives, aside from hepatitis C. In regard to staying off drugs, one participant noted, "I really have to push myself to be around people, to be accountable. And that's huge, so having a place like this to come... is an incredible tool."

Of all the active participants, only two had never attended support groups. One stated that he received all of the information he needed from the clinical team and felt he had enough support within his own social circle. The other individual cited barriers in terms of a busy schedule, considerable travelling distance to reach the location, and difficulties in securing child care.

**Comprehensive Services.** Comparing the support group to the individual medical care and counselling, one participant stated, "The one thing the support group allows is we've all been there. They haven't gone through the treatment but we all have. And there's the difference. We can see from experience ... That's the one thing the support group has that they don't have."

This quote illustrates another common theme that was discussed in the focus groups; the comprehensive array of services offered by SHC. Participants discussed the value of support services and outreach in combination with medical care. The general impression conveyed by the participants was that Sanguen acts to, in all ways possible, serve the best interest of the person, not simply treat the disease.

One participant noted that after having treatment delayed for months by another doctor, he sought medical treatment at Sanguen. Dr. Steingart arranged for him to attend counselling for his mental health issues prior to starting treatment, explaining that treatment could exacerbate his mental health concerns. The participant was grateful that Dr. Steingart was interested in his overall health and not only treating his hepatitis C. Another brought up the value of support services in integrating new individuals into the program, saying, "I haven't seen Steingart yet, but I was still able to meet with Jan; I was still able to come the support group; all that while I was waiting to see Steingart." Furthermore, the importance of one-on-one counselling was discussed from the perspective of someone who had not had access to it, saying, "When I went on my treatment, there was no counselors. There was [only] Martine and Chris...My treatment was pretty tough. I was going through a lot of emotional stuff, lot of anger issues, a lot of stuff that was inside me that wasn't me. It was the side effects of the medication." This illustrates the value of Sanguen's current multidisciplinary team approach in meeting the needs of individuals that extend beyond medical care.

Lastly, participants brought up the value of the outreach services including the harm reduction strategies. One participant commented, "They're still there for the addicts that are still using... they still treat [them] as a patient." Another stated, "I've heard of a number of different scenarios where addicts would be taken down to emergency and they would be treated like shit because they were addicts. And the outreach staff would go down there and act on their behalf, because there are addicts who still need pain killers for pain....We're still entitled to fair treatment, and [Sanguen] advocates on behalf of the addict." A participant in the Guelph focus group mentioned the value of having peer outreach workers, individuals with hepatitis C and

addiction issues who volunteer with the outreach team. He stated, “I know that there are practising addicts involved in outreach and I think that that’s part of the special make up.” The group agreed that peer outreach workers improve access to individuals who are most in need of education.

**Approach to Service Delivery.** In both focus groups, conversation was largely dominated by discussion of the approach to service delivery utilized at Sanguen Health Centre. Participants agreed that Sanguen’s non-judgemental, friendly, and compassionate approach to service was a unique and valuable aspect of the program which particularly appealed to them.

One participant stated, “When I first started showing up at Sanguen, everyone was very kind to me. I thought everyone had their game-face on. And I’ve been here for over 4 years now, and this is how these people live. They’re absolutely non-judgemental, it’s safe.” The importance of non-judgemental nature of the staff members was a sentiment that was echoed throughout both focus groups. One participant provided an example of this, “I remember my counsellor being at a home visit and showing up when we were getting high... Most counsellors would be like ‘Put that away. I don’t wanna see it.’ Right? ... She just sort of stood there and waited until we finished and then we had a meeting. Which is remarkable in itself because most counsellors...won’t deal with you if they think you’re on anything...They’re not like any counsellor that I’ve dealt with...I’ve been dealing with workers and people in the system my whole life and I’ve never met anyone like the people here.”

Another common discussion point was that participants feel comfortable around the staff and that the friendly nature of their relationship with staff helps to ease their worries. One participant stated, “[It] really helps that they’re casual, they dress casual, they’re at the same

level as us, even though they have credentials and stuff...we can feel a lot more comfortable dealing with these type of counsellors because... they're at the comfortable level with us." In regard to the one-on-one counselling, one participant notes, "It's not just about you; it's about both of you. We talk about everything... you feel like you're talking to a friend." The same sentiment was expressed in regard to medical care. One participant stated, "You're not a patient, you're not a number. You are who you are with Chris. I mean we can call him Chris. He's that close...I feel so much better when I talk to him. My nerves calm down, my head clears. That's how he is." Another participant noted, "When Tracy was drawing my blood, she was talking about her daughter...so even with the nurses and Dr. Steingart, it's like friendship. It's like they're a friend. They're not above you; they're not below you; they're only beside you"

Additional aspects of service at Sanguen were brought up by many participants including how far the staff will go above and beyond the requirements of their job. In the words of one participant, "A lot of times you'll see them out doing stuff in the community that has nothing to do with the job description. There's amazing people. We can learn about life from the people at Sanguen and how to live." An example of this was also provided by another participant from an occasion when her partner was placed in the hospital due to severe mental health issues, "I was there, Sunday morning, [my counsellor] shows up at emerg to see him, apologizing because she didn't show up Saturday night. And I'm thinking -- because I didn't know them that well at the time --

'it's the weekend; what are you doing here?' I figured she might show up Monday, but she showed up first thing in the morning, she had a card for him, she brought food. She actually got in an argument with one of the people at the hospital because they were being ignorant." Another participant provided a similar example, "There was days at three o'clock in the morning, I'd be



going to the hospital and forgot to bring my medication and forgot everything I needed. And it would be, 'Martine, I need you at the hospital. I'm at the hospital.' 'Okay, no problem,' and she talked to the nurse about everything and tell them everything they needed to know. It was really nice to have somebody there, you know."

In regards to the positive atmosphere and compassionate approach emphasized at Sanguen, one participant summarized his experience as follows, "You're almost glad you're going through this because these people are so nice. There's nothing but positive results. I mean, you can't get anything but positive results out of it. The journey is great."

**Barriers/Limitations.** As mentioned above, one participant identified barriers in accessing the support group including a considerable travelling distance to reach the location and a busy schedule during the day. This participant suggested that running occasional support groups in other locations, such as community centres throughout the region and offering support groups in the evenings may make the program more accessible to individuals with similar difficulties.

One participant brought up the challenge that there is currently a year long wait list to see Dr. Steingart for those who have been diagnosed with HCV. However, most participants agreed that it was extremely valuable that Sanguen encourages people to utilize other services while they wait to see Dr. Steingart. One individual commented, "You might be on a waiting list to see a doctor in here... But what I like about this place is, there is no wait list. If I need one-on-one, see any outreach, see street help, no wait list, come on in. Doors are always open."

Participants struggled to identify areas for improvement, indicating that the staff and services at Sanguen already exceed expectations. When one participant cited challenges obtaining child care as a barrier to attending programs, other participants assured him that

Sanguen would likely find a way to help him saying, “[Sanguen] would try to get a babysitter for you. Or even have someone upstairs watching the children while you come down and have your group. If that was an obstacle, [Sanguen] will work around that obstacle.”

## **DISCUSSION**

The overall findings from the pilot process evaluation indicate that SHC appears to be successfully providing services to their clients, keeping users engaged, and encouraging use of the support groups. Across all three themes that were identified, one key strength is evident: the staff and personnel at SHC. Every participant in the discussion felt that the attitude and approach the staff utilized was helpful for them during their journey. The friendly relationship with clients was deeply appreciated and valued as participants feel a true connection with the program and truly wish every aspect of the program to be successful. SHC should continue to use a caring, non-judgemental approach to service delivery that provides comprehensive care for the individual, not only treatment of hepatitis C.

Participants also had difficulty identifying areas for improvement since most indicated that if problems came up, whether big or small, staff members went out of their way to accommodate the clients in order to best fit their needs. Most could not imagine what improvements the program could make as they felt Sanguen already did so much more than any of their other experiences with doctors and other centres. Since only a handful of people provided any suggestions for improvement or a discussion on barriers, this area will require further probing and research. As a definite limitation of this pilot project, most of those who participated were all individuals who are very involved in SHC and who are happy and enthusiastic with the services that they receive.



Furthermore, since only two or three individuals in each group were fairly quiet, participants who were heavily involved in the services often overpowered them. This occurred when participants were asked if they had any suggestions for improvement or any potential/perceived barriers. Before the participant had a chance to fully express their view, most responses to these questions were counteracted by stronger voices defending Sanguen and providing justification for the way the programs are run. Both FGs had at least one participant who acted as a co-facilitator and who were stronger voices of the support group. These individuals are very positive and enthusiastic, while being less tolerant to any constructive criticism or suggestions. In the future, it may be useful to separate such individuals from the less involved users who may be overwhelmed and unwilling to share their suggestions.

Lastly, another limitation is that participants for the FG were obtained through program staff advertising to ease the process of recruitment. Therefore, participants were selected by the program, which may be a factor in response bias, where those who have more positive experiences to share are the ones interested in participating. Those individuals who are less involved with SHC and who are likely not as excited were not represented well in these FGs so their perspectives are missing from the results.

An overall drawback of the FG in Waterloo was that the group was fairly large which was unexpected. The result was that the room a tight fit for all the participants and evaluators. In addition, the number of participants was difficult to manage by the first-time evaluators, and it became challenging to draw out the opinions of the quieter participants. Lessons for further focus groups include capping the maximum number of participants depending on the size of the facility.

## **SUGGESTIONS FOR FURTHER EVALUATION**

Given that this was a pilot process evaluation, the following are some guidelines for further exploration into evaluation at Sanguen.

### **1. Conduct additional focus groups**

This suggestion is advised since there is potentially more useful information that can be obtained from the clientele. FGs should be continued until saturation of information is achieved where the users discuss no new information.

### **2. Attempt to recruit clients who are less involved with the services at SHC in future focus groups.**

This would aim to encourage participants who may not be as happy with the services to share their opinions and suggestions for improvement so the program may become more aware of where future efforts should be directed.

### **3. In future focus groups, separate more involved users from less involved clientele to encourage discussion from all parties.**

It is important to separate different types of participants to allow all individuals an opportunity to share their experiences without interruption or fear of their ideas being dismissed.

### **4. Proceed with a large scope of project to conduct a more thorough process evaluation.**

As this paper highlights the results of a pilot process evaluation, a more thorough full-scale process evaluation should be conducted to determine the program's usage, delivery, and operation. Methods that should be considered at this stage include an administrative file review, a program documentation review (including logic model) and a literature review.

## References

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## APPENDIX A: Group and Audio Recording Consent Forms

### Sanguen Health Centre Group Discussion: Consent Form

**Background and Purpose:** Sanguen Health Centre is committed to assisting individuals living with Hepatitis C to manage their disease condition through medical care, individual counseling, support groups, outreach services, education and more. This focus group will be used to assess if the program is meeting the needs of the users.

**Group Discussion:** You are asked to participate in an hour-long group session, with 6 – 12 other users of the services at Sanguen Health Centre. In the session, we will ask you to take part in a group discussion about the strengths and weaknesses of the program. This will be done so we can understand what your needs are, how you are involved in the program, and what keeps you coming back. Whether you choose to make any comments will be your decision.

**Participation and Confidentiality:** Your participation in the group discussion is completely voluntary and will not affect any services you currently receive or may receive. To thank you for your participation, we will be offering a few refreshments and a Tim Horton's gift card provided by Sanguen valued at \$10. All information you provide will be kept strictly confidential with any identifying information removed.

**Questions:** If you have any questions about this focus group, please contact Darly Dash (E-mail: [ddash@uwaterloo.ca](mailto:ddash@uwaterloo.ca); Phone: 647-537-6177) or Kate Stock (Email: [kjstock@uwaterloo.ca](mailto:kjstock@uwaterloo.ca); 519-654-8788).

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The purpose of this project has been explained to me, and I have had the chance to ask questions. I understand that I solely will decide what information I wish to share. I will receive a copy of the consent form and I freely give my consent to participate in this group discussion.

Participant's Name: (please print) \_\_\_\_\_

Participant's Signature: \_\_\_\_\_

Date (mm/dd/yyyy): \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

## **Sanguen Health Centre Audiotaping: Consent Form**

To ensure that we do not miss any valuable discussion points made during the focus group, we would like to audio-record the session. We need the permission of all participants to audiotape the conversation. The recording allows us to go back and analyze the information you have provided more thoroughly. Specific comments may be directly quoted, but we will not identify any individuals. The recording will be kept secure and destroyed after analysis.

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The reason for audiotaping has been explained to my satisfaction. I understand that everyone in the group has to agree before any audiotaping can take place. I freely give my consent to audiotaping by signing below.

Participant's Name: (please print) \_\_\_\_\_

Participant's Signature: \_\_\_\_\_

Date (mm/dd/yyyy): \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

## APPENDIX B: Background Questionnaire

Name \_\_\_\_\_ Date Completed (mm/dd/yyyy) \_\_\_\_\_

**Please answer the questions below based on the best available answer.**

If you have any questions, please do not hesitate to ask.

1. With what gender do you identify?

Male                       Female                       Other                       Prefer not to say

2. What is your date of birth? \_\_\_\_\_ (mm/dd/yyyy)

3. With which ethnic group do you identify?

White                       Black                       Aboriginal                       Latin American  
 Asian                       South Asian                       Other (please specify \_\_\_\_\_)

4. What is your highest level of education obtained?

Did not complete high school                       High school diploma  
 Some college (no degree)                       College diploma  
 University degree                       Post-graduate studies/degree

5. How long have you been coming to Sanguen Health Centre for any of the services offered? \_\_\_\_\_ (Select one: days / months / years)

6. Which of the following services do you use?

Service	How long have you been involved? (I.e. # of days/months/years)	How often do you attend this service? (i.e. daily/weekly/biweekly/monthly)
Medical services		
Support groups		
Outreach services (i.e. harm reduction supplies)		
One-on-one support with the social workers (I.e. Estera, Abby, Jan)		

7. What is your primary means of transportation for accessing the programs and services offered by Sanguen?

- Walking                                       Driving by car                                       Public transit  
 Bicycle                                       Other (please specify \_\_\_\_\_)

8. With your main method of transportation, how long does it take you to get to Sanguen? (Please specify # of minutes/hours) \_\_\_\_\_

9. Do you have Hepatitis C?       Yes       No       Not sure

a. If yes, when did you first learn that you had hepatitis C?  
\_\_\_\_\_ (Select one: days / months / years) ago

10. Are you currently in treatment for Hepatitis C?       Yes       No

a. If you answered 'No' above, what are some reasons you are not receiving treatment?

- I've already finished treatment  
 My liver is healthy, so I don't qualify for treatment  
 I don't feel ready to start treatment  
 My doctor did not recommend treatment  
 I'm getting ready to do treatment, but have not started yet  
 Other (please specify): \_\_\_\_\_

b. If you answered 'Yes' above, how long have you been receiving treatment? \_\_\_\_\_ days / months / years

c. If you answered 'Yes' above, what treatment options are you currently receiving?

- Pegylated Interferon                                       Ribavirin                                       Incivek  
 Victrelis                                       I'm not sure/I don't know  
 Other: \_\_\_\_\_

11. What are your personal reasons for coming to this focus group?

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Thank you for completing this background questionnaire.  
The information provided will assist the evaluators in understanding group composition of you and your fellow participants.

## APPENDIX C: Focus Group Script

Phase	Specific Questions
<b>Purpose of evaluation project</b>	To gain insight on the strengths and limitations of Sanguen Health Centre's program delivery, usage, and operation, so that the program can make suitable adjustments.
<b>Icebreaker</b>	Let's go around the table and introduce ourselves. How long have each of you been involved with Sanguen?
<b>Introductory question</b>	<p>How did you first hear about Sanguen?  <i>Probes: was it through the Outreach services? Family doctor? Hospital? Friends/family?</i></p> <p>Which services do you currently use or have used in the past?  <i>Probes: medical care, individual counseling/support, support groups, outreach services, education</i></p>
<b>Transition question</b>	<p>You're all connected with Sanguen in some way, so we'll move towards discussing what Sanguen does well and how they can improve.</p> <p>What is the most helpful aspect about Sanguen that attracts you to the programs offered here? <i>Probes: how does this program compare to any other services you've used? What keeps you engaged? What do you like best?</i></p>
<b>Key questions</b>	<p>What made you get tested for hepatitis C?  <i>Probes: what kept you from testing? Were there any barriers? Was there any particular resources (or outreach services) that helped you get tested?</i></p> <p>What encourages you to start/continue/finish the treatment?  <i>Probes: support groups, counselling, outreach contact with Sanguen staff, health concerns, social network</i></p> <p>What interests you about the support group? What keeps you coming back to them?  <i>Probes: social support, a chance to discuss feelings/troubles/etc.</i></p> <p>What are some reasons you don't attend certain programs or you don't attend regularly? <i>Probes: things you don't like, transportation difficulties, timing, financial, doesn't cater to my needs, don't like sharing in public</i></p> <p>Keeping in mind that Sanguen is here to provide you with individual support, support groups, information, and medical care related to hepatitis C, are there any needs in these areas that have not been met or any steps Sanguen can take in order to improve the programming?  <i>Probes: what would increase your involvement? Timing of any activities? What's</i></p>



	<p><i>discussed at the activities? Who's at the activities that you wish to speak to?</i></p> <p><i>If people start focusing on factors external to Sanguen: "Thank you for your input. Does anyone else have any suggestions that relate to issues that Sanguen could change?"</i></p>
<p><b>Summary</b> A great deal of useful information was discussed today. I think the main points the <b>question</b> group feels strongly about are ...</p>	<p><i>(highlight some points discussed). Do you agree that these were the main points? Is there anything else you would like to add regarding the program?</i></p>

## APPENDIX D: Follow-up Contact Consent Form

### Sanguen Health Centre Follow-up Verification: Consent Form

Thank you for taking part in the discussion group today. The information provided will help Sanguen Health Centre in improving their current program. When we analyze the data provided, we will search for themes or any issues that arise from each group. All information will be summarized to get a detailed, overall picture.

To verify the information we have collected during this session, we would like to contact a few participants in the next week or two. You would be contacted via telephone for a 10-minute follow-up to verify the themes identified, if you agree with the major points, and if you have any additional thoughts or feelings to add.

If you provide permission, you may be randomly selected to be contacted by one of the facilitators you have met today. A convenient time will be set up and you would only be contacted once. All forms will be kept secure and destroyed after we have contacted you or after we have enough respondents. Your name and number will not be shared or used for anything other than this project. Do you have questions?

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Printed Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Signature: \_\_\_\_\_ Date (mm/dd/yyyy): \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Convenient day to call: \_\_\_\_ Mon \_\_\_\_ Tues \_\_\_\_ Wed \_\_\_\_ Thurs \_\_\_\_ Fri

Best time to call: \_\_\_\_ Morning \_\_\_\_ Afternoon \_\_\_\_ Early Evening