

**Community Engagement Report: October 15, 2012
Seek and Treat to Optimally Prevent (STOP) HIV**

Fall 2012 – Evaluation of Client Experience of Vancouver STOP HIV Services

Introduction

Seek and Treat to Optimally Prevent (STOP) HIV/AIDS is a four-year (2009-2013) pilot project funded by the BC Ministry of Health to expand HIV testing, treatment and support services in BC. The pilot project focuses on individuals living with multiple barriers to care including addiction, mental health issues, homelessness and other social or environmental factors. From its initial stages, the STOP project has identified community consultation as critical to an accountable, responsive and effective pilot project.

For the Vancouver portion of STOP HIV/AIDS, the Community Engagement department has coordinated public consultations throughout the length of the STOP project to ensure client experience would inform service planning. In partnership with the Vancouver-based community representative from the provincial STOP Leadership Committee, Kath Webster, discussions have been conducted in Summer 2010, Spring 2011, Fall 2011 and Spring 2012. Reports for these consultations are available at www.vch.ca/ce/reports.

For Fall 2012, client evaluations were conducted for Vancouver STOP HIV services in support of the project's evaluation team and the STOP HIV Regional Patient Experience Working Group.

Many contracted service providers funded by STOP already include client evaluation in their work plans. In order to avoid overlapping evaluations, CE staff agreed to conduct client surveys for the following services, asking clients about their experience of:

- HIV testing in Vancouver hospitals, women's centres and bath houses
- Intensive case management and peer support

Methods

Survey questions and methods were tailored to specific populations, as follows:

- HIV testing in hospitals: in-person interviews were offered in English, Punjabi and Chinese
- HIV testing in women's clinics: a paper-based survey was offered to all clients who had accepted an HIV test, available in English, Punjabi and Chinese
- HIV testing in bathhouses: clients were offered the option of online survey or paper survey after each visit with the nurse, available in English
- Intensive case management and peer support: in-person or telephone interviews were offered to clients, available in English and Spanish

In all settings, patients/clients were offered the opportunity to participate or not, with assurance that their responses would not affect their care in any way.

Results

Client population	Number of Respondents
Hospitals	45 (26 male, 19 female)
Women's Clinics	108 female
Bathhouses	6 male
Case management/peer support clients	21 (16 male, 5 female)
Total	180

Testing

Is testing acceptable to members of the public?

- For surveys across all settings, patients were asked how they would rate their *level of comfort with being offered an HIV test in the facility* (i.e. hospital, women's clinic, bath house), as a proxy for the theme *Acceptability*
- For hospital patients, there was no apparent pattern to patient responses by gender, age or language with regard to test acceptability
- Due to a range of patient debilities (e.g., acute physical distress at time of admission, hard of hearing but appeared to understand questions), some patients expressed surprise they had been offered an HIV test. Ongoing training may be indicated for healthcare providers who offer the test, with regard to how and when to offer the test.
- Patients expressed a range of opinions on how or if testing should be offered. For example,

"This is the best thing – every country should do this!"

Or

"I would not agree to be tested for HIV. It is personal information and I would not participate."

- Privacy when being offered a test was important to some patients, and confidentiality of results was mentioned frequently as an important concern from many hospital respondents
- 92% of respondents from women's clinics stated that they were comfortable with being offered an HIV test, and were supportive of HIV testing being offered in these settings
- Respondents from bath houses all had positive experiences of HIV testing, and expressed strong hope that nurse services would continue in these settings
- Suggestions for improvement focused on the need for greater public education about HIV in order to reduce stigma about the associated risk factors for transmission, and to increase public awareness about HIV transmission, testing and treatment

Intensive Case Management and Peer Support

Since 2010 the Vancouver STOP HIV project has had a specialized clinical outreach team for newly diagnosed and highly vulnerable HIV+ clients, offering support from doctors, nurses, social workers, case managers, outreach workers and peer navigators. As well, Vancouver Native Health Society has been funded to offer a similar intensive case management model, including peer support workers. These models of care focus not only on HIV-related tests and medications, but also cover a broad range of client needs, such as finding housing, food, doctors; providing medical accompaniment, translation and interpreting, linkages to alcohol and drug services; transitioning out of prison or off the street.

The following quotes and themes illustrate the unique achievements of this model of care. For some clients, the network of services meets many practical needs. For example, it was common to hear from clients, "I don't know what I would do without the workers..."

People like my son can't access services on their own. He lives with me, and it's a real fight for caregivers. The people (STOP outreach nurses) were just great. They come to take his blood, to take him to appointments. She is gentle – she has a nice manner and isn't afraid to touch him. He's now taking meds for HIV, they've got him to take surgery for his teeth. There's a kind of help there that people like my son need - without them he would die of AIDS.

There were also examples of peer navigators who would likely be irreplaceable for particularly vulnerable clients:

The main assistance he has received from peer navigators is housing. He says the moral support from the peer navigator really helps and it's good to have an empathetic ear. He likes the fact that they are also HIV positive and have a better understanding of him as a result. He is very grateful for the furniture they got him.

The peer navigator takes me to the doctor to help explain. She helped me talk to the doctor, to give me tablets for joint pain – I don't know what caused the pain but I take tablets and pain stops! It was helpful to start HIV pills -- I was getting so small – now I know I'm strong again!

However, most clients reported that it was the combination of these practical services with a remarkably caring approach, including a focus on client empowerment and skill-building, that was truly transformative for them, resulting in greater self-efficacy and a sense of hope and future. It is new in this phase of Community Engagement involvement to hear several new themes from clients themselves.

Connecting or re-connecting to medical care

Client has been HIV positive for 11 years. He had never been on meds before connecting with the STOP team. Until he connected to the STOP team he hadn't received health care (including blood work) for 6 years. He feels that the biggest thing the STOP team has done for him was improving his standard of living overall.

Client tested positive in 2011. He spent 13 of the last 16 years in different prisons. Connecting with the nurse and the doctor was a life-saver – they gave him hope that he could live with HIV. He is now happy to have an undetectable viral load. Other than a doctor who only prescribed methadone, this is the first doctor he has ever seen.

Nurturing client independence

When staff came to the shelter, I said, "I'm not ready, I'm high and you need to be patient. I need to be able to do this on my own." The outreach worker supported me with my addiction issues, got me into temporary housing and took me to appointments – but he also helped me start planning out my whole life. Now I've been clean 4 months, I'm living in a house in Richmond and commuting every day to DPC. I'm also going to the sweat lodge every week, re-connecting with family – it was important that I do it myself.

The peer navigator is helping me get back to work. I go for construction work each morning now and I'll be going back to do grade 12. They're going with what I need and giving me that little push to make changes.

When I'm on Vancouver Island, I'm healthy, walking, eating right, happy. The whole STOP team is trying to help me arrange to move there. My doctor, my housing worker, the case managers -- they are connecting together. They see I've made a difference to better myself and my health, and I keep pushing, keep fighting for my life. They are helping me, and I push too -- I want a long life.

This last quote also points to a new theme of **hope and belief that clients can make change, over a long lifetime:**

Now everything in my life is about the blood tests. The biggest change for me is knowing I'm not going to die of HIV; I'll die of old age."

What has made biggest difference? I have a sense of hope. I can do better, like the peer navigators have. I can go forward instead of backward. I'm going to university and I start in September.

Staff and peers seem to be working with clients to create a plan toward independence and self-management, and clients are now also talking about how they will take steps to turn around their future -- a theme not heard in earlier phases of consultation. It is the combination of many elements that contributes to these changes:

- Having clean, secure housing brings calm, and a potential for looking beyond immediate needs
- On-call workers provide much-needed and highly skilled emotional support when clients may be at risk for drug relapse or suicide
- Outreach workers, case managers and nurses can focus on specific client needs and tailor their approach to each client, providing as much or as little support as needed at various steps of client journey
- Peer role-modelling shows clients they can 'give back', do volunteer work, facilitate support groups, return to school or work
- The sense of caring from staff and peers leads to clients' increased sense of social connectivity and increased confidence, and then to better self-management skills
- Messages that 'You can have a long life' have significant and long-lasting impact on clients, changing their sense of responsibility to their health in general, including alcohol and drug use, fitness and exercise, developing health plans for other chronic conditions, desire to heal family and other social relationships
- Constant availability of HIV education and counseling from peers means that even the most vulnerable clients start to understand medication management

Next Steps

Current funding commitments for the STOP HIV pilot-projects end in March 2013. Staff at Vancouver Coastal Health and Providence Health Care have started planning for HIV services beyond this date, and results of these client evaluations have been submitted to inform their planning. We extend our sincere thanks to everyone for their contribution and support of our efforts over the last two years.