Vancouver Coastal Health
Promoting wellness. Ensuring care.

Community Engagement

Community Engagement Report

Seek and Treat to Optimally Prevent (S.T.O.P.) HIV/AIDS

March 2012

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Table of Contents

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Mary Clifford, Aboriginal Health Strategic Initiative, Vancouver Coastal Health

Boys R Us Drop-in Program

BC Centre for Disease Control Outreach Program

BC Positive Living Society

Downtown Eastside HIV/IDU Consumers' Board

Health Initiative for Men (HIM)

HUSTLE Men on the Move

Impact BC Patient Voices Network

Maximally Assisted Therapy (MAT) Program at VCH Downtown Community Health Clinic

Pacific AIDS Network

Portland Hotel Society and the Life Skills Centre

Positive Women's Network

Vancouver Area Network of Drug Users (VANDU)

Vancouver Coastal Health Community Engagement Advisory Network

Vancouver Native Health Society

WATARI Youth Community and Family Services

Executive Summary

Seek and Treat to Optimally Prevent (STOP) *HIV/AIDS* is a pilot project funded by the BC Ministry of Health to expand HIV testing, treatment and support services in BC. Vancouver Coastal Health is committed to ongoing community involvement throughout the STOP project until its completion in March 2013. Community discussions have been conducted since 2010 (www.vch.ca/get_involved/community_ engagement/reports/). This phase, conducted in January and February 2012, gathered feedback about people's experience of STOP services and their priorities for 2013 and beyond. 221 people participated in focus groups, interviews and online survey.

Public Awareness Campaigns

- Lessening stigma about HIV testing has been effective in select neighbourhoods but the stigma associated with being HIV positive is an important direction to consider in future campaigns.
- Media campaigns should continue to focus on educating the public about the 'new reality' of living a long and healthy life with HIV.

HIV Testing and Diagnosis

- Participants reported that the rapid HIV test has greatly improved uptake of testing.
- Testing provided at public events is considered particularly effective when: peers and nurses check with people for other health needs while they wait in line; when peers provide support and referrals; and when people can choose whether to be tested by a medical professional or a peer.
- Concerns were reported with regard to testing in doctors' offices, including consistency in follow-up with test results, and continued stigma.
- Routine testing for HIV in hospitals is new, and there was no general consensus between participants on this topic: some felt it is a vital part of public health responsibility; others were concerned about the patient's experience of being asked to take a test.

Linkage to Care

- Participants reported that services seem better organized and linkages are more visible and seamless from one service to the next. Many of these services have existed for many years but it is the STOP project that has linked them together, to the benefit of the client experience.
- Peer navigation and peer-based support projects have been key factors in the success of increasing testing and linking people to care, helping people to prepare for the HIV test, providing emotional support, and accompanying new patients through the system so they can become confident in managing their health.
- For members of the Latin American community, support does not seem to have been strengthened to the same extent as in English-speaking communities. Participants currently report the same levels of isolation and distress as that reported by all participants in 2010.
- Future linkages should expand to include mental health teams, drug and alcohol teams, etc.

HIV Treatment and Retention

- Participants spoke very highly of the care received from HIV specialists in hospitals and clinics, and suggested that more screening of students and training of staff would be helpful.
- Participants gave many positive examples of being prepared and supported to start and stay on HIV medications. The healthcare provider's approach cannot be underestimated in its impact on patient willingness to start medications. Physician education should continue with regard to how to deliver medication information in ways that are positive and empowering to patients.

Ongoing Support for People Living with HIV

- HIV discussion and education groups remain important, and suggestions for the future include a wide range of interests and needs, such as HIV and aging, back-to-school/work programs, and family involvement.
- Participants also suggest that a funding mechanism be created so that HIV+ people and medical/professional allies can apply for grants to run community empowerment project.

1. 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, with the overall goal of reducing HIV incidence. Project partner organizations include Northern Health, Provincial Health Services Authority, the BC Centre for Excellence in HIV/AIDS, Providence Health Care (PHC) and Vancouver Coastal Health (VCH).

The Vancouver (VCH/PHC) STOP HIV/AIDS Project is committed to ongoing community involvement throughout the length of the pilot project. In partnership with community representative Kath Webster (STOP HIV Provincial Leadership Committee), the VCH Community Engagement (CE) department facilitates public consultations about HIV services, with people living with or at risk for HIV, in a model of semi-annual report-back and discussion, so that:

- Vancouver STOP leadership and members of the public maintain an ongoing dialogue throughout the length of this project;
- The 'public voice' of people living with HIV, those living at risk for HIV, and their loved ones can inform and influence decision-making for pilot project priorities.

Reports for each phase of public consultation are available on VCH's website (www.vch.ca/get_involved/community_engagement/reports/). See Appendix One for detailed listing of all consultation phases.

Members of the Vancouver STOP leadership team have begun looking ahead to how HIV services can be sustained after the pilot project is completed in March 2013. They requested that the current phase of public consultation gather feedback about people's experience of STOP services, and their priorities for 2013 and beyond. This report summarizes ideas and recommendations gathered in January and February 2012.

2. Methods

In keeping with recommendations from participants in earlier consultation phases, discussion groups were used in this phase, and where a formal group process was not possible (due to participant needs), facilitators conducted interviews. Participants in earlier consultation phases also suggested that an online survey should be available for those who cannot or do not wish to participate in groups, and this method was added for the 2012 phase.

A graphic poster was used to guide discussion groups (see Appendix Two), and participants were asked:

1) What services do you think have improved over the last year or two?
2) What services do you think have really made a difference for people, and in what ways?
3) Which services still need improvement, and how could these services be improved?

For the online survey (see Appendix Three), participants were asked to complete specific questions on services for testing, diagnosis, support and treatment.

128 people participated in 13 discussion groups (see demographics in Appendix Four), including one group conducted in Spanish. 93 people completed the online survey (see demographics in Appendix Five). All participants were asked for demographic information about their gender, age-range, city and neighbourhood of residence. Due to conditions of anonymity, survey participants were also asked questions about sexual orientation and HIV status. It is interesting to note that, when asked for neighbourhood, some survey participants withheld this information, perhaps due to concerns about being identified. As can be seen, a wide diversity of people participated, and their experiences and ideas are summarized below.

2.1 Limitations

A variety of methods was utilized in order to ensure this public involvement process would be accessible to the most vulnerable members within the HIV infected and affected populations. Due to stigma, many will not attend discussion groups or complete an online survey. Due to poverty and chaotic life situations, many cannot access online surveys. As well, some community partners from previous phases were unable to participate in this phase of consultation. The CE team will continue to pursue maximum participation in its next phase of consultation for the STOP HIV project.

3. Prevention: Public Awareness Campaigns

The STOP HIV project has put significant effort and resources into social media and advertising campaigns to de-stigmatize and increase public acceptance of HIV testing. Examples of these testing campaigns include *'It's Different Now'* (bus shelters and website), *'Know Your Status'* (buses and posters in the Downtown Eastside) and *'What's Your Number'* (websites and posters in the West End).

3.1 Impact on stigma has been a key theme of concern reported by participants through all community consultations. Although this was still discussed by many people in this phase, there seems to be some improvement in public awareness and acceptance of HIV testing in the neighbourhoods targeted in the STOP HIV campaigns.

"Stigma is getting better in some ways: more people are educated, and more people have HIV."

"I got tested because I saw lots of help in the community and saw posters for a support group – and I know people are testing HIV+ everyday."

The problems with stigma still reported by people are predominantly about others' reaction to their disclosure of HIV status:

"As soon as I tell people, they stop talking to me."

"People who have kids - when they find out you have HIV, they disappear."

Lessening stigma about testing has been effective in select neighbourhoods but the stigma associated with being HIV positive is an important direction to consider in public education and social media campaigns.

3.2 Educational messages

Many participants felt that popular perception has not caught up with the 'science' of HIV, and the following messages would be key in helping to reduce stigma:

- Education about HIV transmission (misinformation about transmission is still common);
- Improved treatments weaken the virus, and reduce the chance of passing it on;
- People with HIV can have a long healthy life, can have relationships, can have children.

It was emphasized that media campaigns now need to focus on educating the public about the 'new reality' of living with HIV. Articles like the recent front-page feature in Metro newspaper *("HIV proves no obstacle*", March 2, 2012) is a wonderful example of helpful, reassuring messages for the general public.

3.3 Other suggestions for future education and awareness campaigns include:

- Locations: posters in hotels, community centres and other non-clinical locations;
- A blitz of public education similar to recent hand hygiene campaigns, with a clear 'brand' and representation in hospital lobbies involving senior healthcare leaders – these made a strong impression on the general public;
- HIV testing and education campaigns will be increasingly effective if they utilize community-specific leaders, are guided by community values, and expand geographical scope, for example:

"Our system needs to adapt to the reality of many cultures – many are clan-oriented, and fear spreads and is maintained by 'elders' – what they say, 'goes'."

"Rural areas need to be included (in these campaigns*). There is lots of migration between Vancouver and small towns, and there's no information going in or coming out about HIV."*

4. HIV Testing and Diagnosis

4.1 The Rapid Test

Participants reported widely that the rapid HIV test has revolutionized testing. Access to testing is widely available, non-invasive, can be done on the street and results are fast. For those who need a confirmatory test, support is often available during the waiting period. A concern was expressed about how the rapid test result is reported to the person being tested. Some felt it is more helpful to use the phrase 'Non-negative', rather than 'Preliminary Positive', as people experience much distress at hearing the word 'positive' and may not return for the confirmatory test.

4.2 Testing at public events

HIV testing has been available at many large public events in Vancouver. Participants addressed many specific events they attended, identifying the factors they felt would encourage the public to get tested:

- While people are waiting in line, have peers and nurses check with people for other health needs, such as wound care and other infections;
- Before and after the test peers give counseling, information, support and referrals, encouraging follow-up;
- Incentive-gifts are a good way to draw people to testing in the Downtown Eastside (e.g. the $5. gift card) but numerous participants believed it is equally if not more important to have a caring, professional approach – that peers and staff demonstrate warmth, genuineness and empathy;
- Offering fruit and snacks at testing events;
- Doctors and nurses '*in white coats'* were very important for a sense of credibility and trustworthy professionalism, as well as the choice to be tested by a healthcare professional or a peer;
- Having tables or booths with many different tests or types of information (as relevant to the community), so that there is a 'norm' for people to be in line-ups without singling out the HIV test – it is just one of many offerings in a larger event;
- Partnering with a variety of organizations to set up the testing event, so that their guidance informs how the event can be tailored to their community's needs.

- If testing is offered at community celebrations, it must be done in a manner that is integrated with community norms and needs.

4.3 Testing at community clinics

In groups and surveys there were many, many glowing reports from people about their experience of being tested at the Bute Street Clinic and the HIM clinics (both in the West End and on Commercial Drive). The Three Bridges Youth Clinic was also cited as a supportive and friendly location, as were the VIDUS clinic, the Watari clinic, the testing station at VANDU (perceived as a 'community clinic'), and the availability of a nurse at the BoysRUs drop-in.

4.4 Testing at a doctor's office

As with all testing locations a range of experiences was reported, but a few concerns were raised in this category, particularly by survey respondents:

- Consistency of informed consent and information about the option to test non-nominally;
- Process for follow-up with test results;
- Misinformation about the virus and medications;
- Continued stigma:

"When I received the HIV result last year it was a great shock. There was no warning. He told me in front of my wife – she didn't understand at first, so he pointed at me and just said 'AIDS'!"

In order to support routine HIV testing in doctors' offices, it is strongly recommended that physician education be continued.

4.5 Testing at the bathhouse

Gay men in this consultation spoke very highly of their experiences of being tested by a nurse in the bathhouse, observing that many people are getting tested in this environment. It is a positive experience, especially for populations where being gay is particularly taboo and they would likely not ask for or consent to a test in any other environment. As well, it is perceived as a trustworthy and cost-effective testing method.

4.6 Testing in hospitals

Routine HIV testing for all adults admitted to Vancouver hospitals was phased in through Fall and Winter 2011. As of January 2012, all Vancouver hospitals have started offering an HIV test to all patients at admission.

Vancouver STOP leadership felt that many participants in earlier public consultations are largely aware of HIV testing and services, and asked that a specific focus group be conducted with members of the public who have little or no exposure to HIV issues. Nine members of the public, invited through the VCH Community Engagement Advisory Network and Impact BC Patient Voices Network, met in a two-hour focus group to discuss this new form of testing. None had been offered a test in hospital. As well, other focus groups discussed hospital-based testing, and only one person in the online survey had experienced testing in the hospital.

There was no general consensus within or between groups about routine testing in hospitals:

- Some felt it is a vital part of public health responsibility to ensure that testing and treatment are accessible to all, and hospitals are the most practical location to offer the test, as there are many routine blood tests and patients expect them.

- Some were concerned about privacy in a hospital and wondered if the offer of a test is done in a location and manner that preserves privacy..

- Cost-effectiveness of the test was also a question, given the large number of tests being administered *(note: Vancouver STOP data has recently confirmed this testing method is highly cost-effective).*

- Posted information in admissions should be improved and made clearer. Currently, a poster in Admissions lets patients know they will be asked – this poster was widely perceived as unclear and overly directive. Participants wondered if it should be phrased instead as an invitation to take the test.

- An information sheet is available about the test. Although this sheet has been written for low-literacy needs, participants felt it was somewhat overwhelming, with a lot of print to read.

- Concern was expressed about the patient's experience of being offered a test, particularly for people who have low literacy or do not speak English. This testing method is efficient and effective, but do patients feel confused or unclear about what is being asked?

Patient experience of hospital testing may be an important area for evaluation in the future.

4.7 General suggestions for future HIV testing:

It was understood by participants that STOP HIV testing campaigns focused on the West End and the Downtown Eastside because of high rates of HIV in these areas. To increase awareness of and testing for HIV, and to further 'normalize' HIV testing in our society, participants suggested it is important to now take testing to many other neighbourhoods, parks and community festivals.

Other suggestions included:

- Client access to online checking of results;

- Hold testing events at more housing facilities in the Downtown Eastside (e.g. supported housing, single-room occupancy hotels, etc.), coordinated with their staff;

- Continue expanding the offer of HIV testing to a wide range of locations, such as detox and recovery facilities, and include education for staff;

- Some felt it is important for 'informed consent' to include clear discussion on HIV criminalization;

- When a person is newly diagnosed, a video of HIV information may be more easily absorbed than paper-based information.

5. Linkage to Care

"LINKAGE is the 'meat' of the success of STOP, and this is not just about linking clients to doctors, but also linking clients to peers, to community resources, and linking community organizations to each other."

Numerous clients brought forward examples of how quickly they have been linked to care, from the rapid HIV test, to diagnosis and follow-up by a nurse or doctor, the very quick (or sometimes immediate) link to a peer navigator, then connected into appropriate health and community services and onto support groups. For some, this whole process has taken a matter of two weeks – a dramatic contrast to the many stories from participants in our first phase of consultation (Summer 2010) who spoke of isolation and lack of information over many years before they were connected to care.

Participants widely reported that services seem better organized, and linkages are more visible and seamless from one service to the next. It was also remarked that most of these services have existed for many years but it is the STOP project that has linked them together, to the benefit of the client experience.

5.1 Peer Navigation and Support Projects

"If I turn HIV+ my life changes forever. What will my life look like? I need this information before I'm going to get tested."

"When an HIV+ person does this work, it does change people's attitude. They see I'm HIV+, strong, healthy, and respected."

Peer navigation and peer-based support has been a key success factor in reducing stigma, increasing testing and providing support, particularly with marginalized populations. A variety of models has been used to teach about HIV testing and staying healthy with HIV, providing services such as:

- Helping people to prepare for the HIV test
- Providing emotional support, accessible on the street or after normal business hours;
- Accompanying clients to lab tests, community services, support groups, doctor's appointments;
- Providing in-depth and repeated explanations about medications and other health information, at client pace of absorption;
- Helping long-term homeless to adjust to living in an apartment, including new activities of daily living;
- Counseling families, and/or assist client to prepare to disclose;
- Supporting the client to become confident and independent in managing their health, with a wide support network.

"My peer navigator is getting me connected now – they are very informative and they always have time for me."

Peer navigation and support projects also provide workshops at shelters, detox and recovery centres, community centres and many other locations, reportedly with great success, due to several factors:

- Peers 'translate' HIV education into language that is easily understood by their listeners.
- Peers are people living with HIV and/or Hepatitis C, speaking openly about living a healthy life with these conditions – they serve as inspiring role-models of good health after diagnosis.
- A nurse is often available during workshops to provide testing and treatment information, providing a community-positive role-model for peers and professionals working in partnership.

- Peers speak about a wide range of health concerns in addition to HIV, tailoring workshops to community interests so that listeners are motivated to learn about how to start taking care of their health in general.

- Peers include spiritual and emotional health in their workshops, providing positive reinforcement for groups who often feel labeled solely as a 'social problem' by mainstream society.

Peers who participated in these focus groups reported benefits to themselves and also to the broader community:

- Highly marginalized people are learning new skills and feeling more confident in many aspects of their life, providing more motivation to stay healthy.

- Being involved in positive community-building work is healing for the peers as well as their communities.

- Peer involvement gives people a sense of meaning and purpose, and a healthy mechanism for social connectedness.

5.1.1 Expansion of peer navigator and support programs

"Peer navigators are the glue that has held STOP together."

Due to the volume of requests they are receiving, it is strongly suggested that the peer navigator and support programs be expanded:

- Greater number of peer navigators, to support other clinics and services that are now requesting their support (beyond referrals from the STOP team);

- Expand the peer navigator program to specific vulnerable populations, such as the Latin American and First Nations communities.

- Increase the length of time that peer navigators can work with newly diagnosed clients, e.g. up to two years, so that the client is sufficiently confident and connected to services.

- Provide peer navigators for clients who may not be newly diagnosed but who are not aware of new services, support and treatment.

- Embed the peer navigators within neighbourhood or population-specific clinics and agencies, so that they are part of local networks and connected to many relevant services.

5.2 Concerns expressed in the Latin American community

- In two discussion groups conducted with members of the Latin American community, post-diagnosis support does not seem to have been strengthened to the same extent as in English-speaking communities. Participants currently report the same levels of isolation and distress as that reported by all participants in summer 2010.

- Although Spanish-speaking staff have been hired for the Vancouver STOP HIV project, these staff do not seem to be designated specifically for Spanish-speaking clients, and perhaps have full-case loads with English-speaking clients?

- HIV positive group participants and their spouses had not heard of or met Spanish-speaking HIV support workers, aside from three community staff who have provided services to the Latin American community for many years.

- This was perceived by group members as a strong concern, given the unknown number of 'undocumented' Latin American people living with high risk behaviors in the Downtown Eastside.

- Concerns were expressed about frequent lack of interpreter services, and interpreters who were inappropriate and insensitive with regard to HIV.

- Spanish-speaking staff and peers, situated within services that are Latin American-specific, may be vital to increasing the acceptance of testing, reducing stigma, and linkage & retention with treatment.

5.3 Expanded linkages between community organizations

- Participants observed that many staff who do not work in the HIV field are not aware of STOP HIV services.

- Future linkages should expand to include mental health teams, drug and alcohol teams, housing staff and many related services.

- Some participants reported long waits for mental health services, and/or their GPs misdiagnosing and misprescribing psychiatric medications. Linkage with mental health teams, and with mental health peer support workers may provide innovative new partnerships.

6. HIV Treatment and Retention

6.1 Medical monitoring

Participants spoke very highly of the care received from HIV specialists in hospitals and clinics but specific concerns were raised with regard to:

- Long waits between appointments with specialists. It is understood this is a common concern across the health system and many disease conditions.

- Lack of discretion about the sensitivity of disclosing HIV status in hospital labs and admissions, e.g.
    - Lab technician announcing 'viral load!" in the hospital hallway
    - Emergency department doctor writing 'HIV' in large letters on the admission form when the patient is visiting for non-HIV related matters

- Lack of sensitivity in medical residents and students, e.g.
    - asking patients how they got HIV after the attending physician has stepped out of the room;
    - appearing embarrassed, ashamed or judgmental with patients.

Respondents suggested that more screening of students and training of staff would be helpful.

6.2 Uptake and adherence with HIV medications

As with medical monitoring, respondents gave positive examples of how they had been prepared and supported to start and stay on HIV medications:

"My team of doctors have treated me with respect, and preparation for starting medications was detailed."

It's good to have places where you can be anonymous and get meds where people don't know."

As reported in previous consultation reports, the healthcare provider's approach cannot be underestimated in its impact on patient willingness to start medications. The readiness to start medications is affected by many complex factors, including confidentiality, disclosure to family and at work, interaction with other medications, and concern about the long-term affects of these medications. Concerns were expressed by a few clients and their loved ones about perceived pressure to start HIV medications, without discussion about client readiness, other health-enhancing alternatives or details about side effects.

"My husband is scared! There's no permission to talk about side effects or other methods of medicine. He comes back from appointments crying, always treated like a failure: 'I see you haven't done anything since we last met…' *They're not saying,* 'I see you've had HIV for five years and your viral load is very low. WOW! How have you done this?' *Now when he does need medications, he won't start."*

"'Why aren't you on the meds? When are you going on the meds?' *It's hard to hear this at every appointment. This is all they go on about."*

These examples point to the need for continued physician education on how to deliver medication information in ways that are positive and empowering to patients, as well as the importance of linkage to peer support, so that people are making informed healthcare decisions with confidence and trust.

Finally, there was concern expressed in one group about elements of the HIV movement re-directing stigma onto those who are not on medication. It was felt by some participants that this message is already creeping into medical and community education –

"If you're not taking the meds, YOU are the problem!"

For some members of the gay men's community especially, this message has worrying overtones of former stigma, and indicates the continued need for leadership in compassion and social change.

6.3 Concerns about interactions between HIV and non-HIV medications

- As HIV medications help people to live longer lives, we are now seeing the normal effects of aging in people in their 50's, 60's and even 70's.
- Chronic diseases such as arthritis, diabetes, heart disease and hepatitis C all require their own complex medication regimes.
- Participants report reluctance from various specialists to recommend medications, as they do not know how these may interact with HIV medications, or impact the immune system of HIV+ people.
- This will be an important area of research to consider in the future.
- Medical specialists are also encouraged to work in partnership with their clients in this new and emerging field of care, as many participants report informal exchange of information among peers in support groups and retreats.

7. Ongoing Support for People Living with HIV

7.1 Housing

Housing has clearly been another great success story for the STOP HIV project.

"My new apartment got me on my feet enough to re-group myself and carry on living with HIV."

"Housing really is the base for it all – without this you can't get started with anything."

- Due to the expense of living in Vancouver, several participants requested that portable housing subsidies be increased, as well as supported housing units.

- It was also suggested that a group-home model may be helpful for those living with serious mental illness or who cannot live on their own, as current conditions in SRO hotels and some other facilities are not safe or healthy for these individuals.

7.2 HIV discussion and education groups

Many models of discussion, support and education groups have continued to develop since the last phase of public consultation. It remains important to participants that these are facilitated by healthy peers who act as strong role models, and topics include education about the virus, holistic and complementary therapies, diet and nutrition, when and whether to start medications. Side effects are a particularly important topic for many respondents.

"I did the support group before treatment. I needed to talk about the impact and fear of treatment, and it was important to make me more comfortable for preparing for treatment."

Interestingly, a number of people reported that they do not want a traditional support group model in which the group focuses on emotional sharing. Some felt that an unstructured therapeutic approach is not productive or inspiring, and had many creative suggestions for the future of HIV groups:

- More community kitchens (as is being used now in some HIV groups)

- Community gardens

- Incorporating other group models that focus on living a healthy life with a long-term chronic disease (as is also used in some current groups)

- Personal awareness and growth

There were also suggestions for groups targeted to specific demographics and interests, such as people living with HIV and hepatitis C, aging and HIV, online gamers, outdoor enthusiasts, straight men and long-term survivors.

7.3 Back-to-school and back-to-work programs were also significant topics of discussion in groups and surveys, though with varying responses:

"This would be important, especially for the Downtown Eastside – training people to provide healthcare services."

"We should be preparing people to return to the work force and contribute. It's very do-able with the meds now. People should be encouraged to continue their lives working and not stay stuck in victim mode."

For others, the return to work seems a great deal to overcome:

"Back to work programs are ineffective. The job market is too competitive, especially having been unemployed for so long, and training (with adequate support) for skilled jobs is unavailable."

This will clearly be a strong trend of discussion in the future HIV movement as people remain healthy and live longer.

7.4 Family Support

Another new and prominent theme in this consultation is that of family involvement. Participants from every population raised the issue of families in some form, and many suggested it would be helpful to include families more in

every stage of HIV support. Of course, the definition of 'family' includes the individual's chosen members of family, and included parents, friends, children, spouses, immediate and extended family.

Peer navigators and service professionals already provide counseling and support to family members, and participants suggested that enhanced family support could include:

- Group HIV education for families to attend (with the HIV+ family member if desired);
- Opportunities to learn about general HIV health and medications;
- Developing and providing information for children and families who live in other cities;
- Detailed information about transmission: questions about fear of transmission to children were mentioned a few times in this consultation.

"It's helpful to make space for families to take part – it's reassuring and gives us hope."

8. Innovative Next Steps

As the Vancouver STOP Project winds down its final year, STOP leadership members will prioritize services with input from stakeholders for implementation after March 2013. Participants had several suggestions that would combine the best elements of the STOP legacy with upcoming trends in the HIV field, for example:

- For front-line work, continue and expand the peer navigator and peer support work.
- Provide a funding mechanism (similar to VCH's SMART Fund, www.smartfund.ca) whereby HIV+ people and medical/professional allies can apply for grants to run community empowerment projects.
- Allocate funding to community agencies and clinics to hire HIV+ peers for education and navigation work.
- Encourage cross-training of staff and peers from organizations that serve different populations (e.g. the Downtown Eastside and West End) to continue strengthening linkages and provide an increasingly integrated safety net for HIV+ people.

The next phase of public consultation will likely take place in Fall 2012. This current phase and previous phases have been designed to serve community dialogue and provide a conduit for 'public voice' in this project. It has been suggested that it may be helpful to gather more rigorous patient experience data about specific STOP services in the next phase, and we look forward to continued community participation as well.

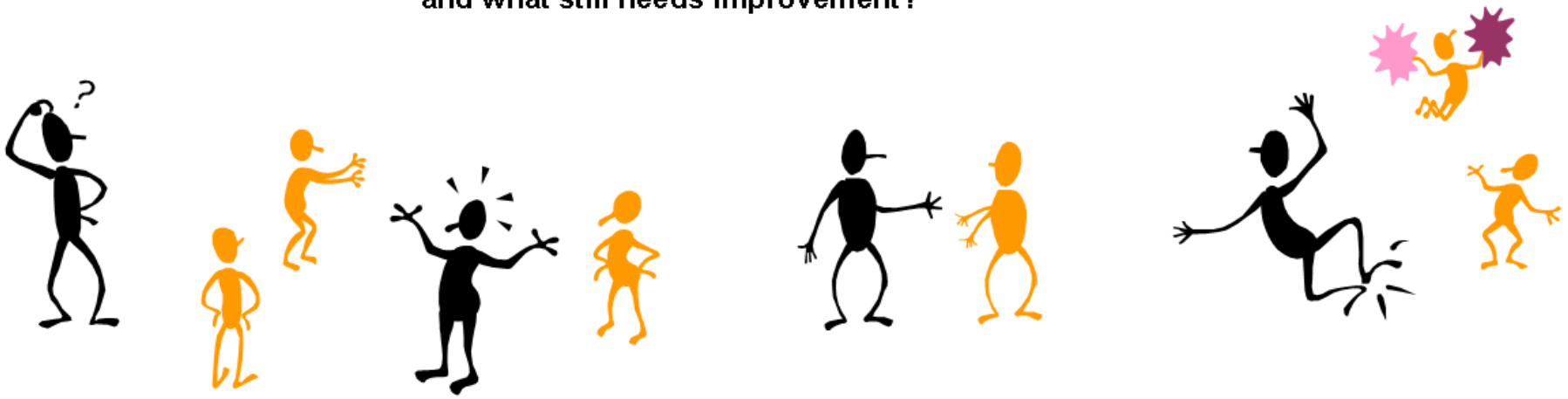
Appendix 1 - Focus Groups by Date, Location & Attendance

Group	Summer 2010	Spring 2011	Fall 2011 – Update only	Spring 2012
Vancouver Native Health	11 7 male; 3 female; 1 two-spirited	10 9 male; 1 female	N/A	10 8 male; 2 female
Positive Women's Network - All members	8 7 female; 1 transgendered	9 female	16 female	4 female
Positive Women's Network - Aboriginal women	9 8 female; 1 transgendered	N/A	N/A	10 female
Downtown Community Health Clinic Maximally Assisted Therapy (MAT) Program	10 4 male; 6 female	8 4 female; 4 male	6 5 male, 1 female	9 5 male; 4 female
BC Positive Living Society	11 male	6 male	17 16 male, 1 female	19 16 male; 3 female
Portland Hotel Society Life Skills Centre	10 male	15 13 male; 2 female	N/A	15 13 male, 2 female
Latin American families	18 14 male; 4 female	25 18 male; 6 female; 1 transgendered	N/A	10 7 male; 2 female 1 transgendered
Latin American youth group	16 9 male; 7 female	17 7 male; 10 female	N/A	N/A
Latin American peer workers				8 5 male; 3 female
Health Initiative for Men	3 male	3 male	N/A	N/A
Dr. Peter Centre	3 male	N/A	N/A	N/A
Helping Spirit Lodge	5 female	N/A	N/A	N/A
Youthco AIDS Society	5 male	5 4 male; 1 transgendered	N/A	N/A
BOYS R US (Male sex-trade workers)		7 6 male; 1 transgendered	N/A	4 male
DTES Consumers' Board		14 10 male; 4 female	N/A	11 7 male; 4 female
Healing Our Spirit	N/A	11 7 male; 2 female; 2 two-spirited	N/A	N/A
VANDU Peer Educators			7 5 male, 2 female	8 5 male; 3 female
HIV+ service providers	4 3 male, 1 female			11 8 male; 3 female
HIV testing – general public				9 2 male; 7 female
Total	**13 groups** **113 participants** 69 male; 41 female; 3 two-spirited / transgendered	**12 groups** **130 participants** 87 male; 38 female; 5 transgendered / two-spirited	**4 groups** **46 participants** 26 men 20 women	**13 groups** **128 participants** 80 men 47 women 1 transgendered

Appendix 2 – Graphic poster used to guide discussion groups

STOP HIV has provided money and resources to strengthen HIV services and treatment support.

What do you think has really made a difference for people – and what still needs improvement?



Testing

Community events

Hospitals

Community agencies

Clinics

Linkage to support and treatment -
Helping people start or reconnect with services, and to stay healthy

STOP outreach team (nurses, doctor case managers)

Peer teams

Support and Treatment

Medical treatment in new and non-clinic locations

Peer support

Housing, food, etc.

Discussion groups & self-management education

Appendix 3 – Online Survey

Welcome to our survey about your experience of services from the Vancouver STOP HIV project.

- The Vancouver STOP HIV project has been running since Spring 2010, and there have been many changes in services that you may have noticed over the last year or two. For example:
- Testing is now offered at community events, in hospitals, in community agencies and at community clinics.
- When people are diagnosed, we hope they are being quickly connected to care, support and treatment.
- The STOP outreach team provides a doctor, nurses, outreach workers and case managers that specialize in HIV support.
- Peer navigators help people learn about the health care system and other supports available.

These and many other services have been funded by the STOP HIV Project. We want to hear what you think has really made a difference for people – and what still needs improvement.

About this survey

We are asking about services provided by the STOP HIV Project in Vancouver since 2010. Therefore, this survey is for people who have been tested or received HIV services in Vancouver since 2010. The survey will guide you through a series of questions based on your HIV status, where and when you were tested and whether you receive services in Vancouver. Depending on your answers, this survey may be shorter or longer but all input is greatly appreciated. This survey is completely anonymous.

Your age-range:

- 19 and under 20s 30s 40s 50s 60s 70s 80 and over

Your gender:

- Male Female Transgendered/Two-spirited

Sexual orientation:

Please select all that apply.

- Heterosexual (straight); Bisexual; Man who has sex with men; Woman who has sex with women
- Other – please list any other ways you describe your sexual orientation

Your HIV status:

- HIV Positive; HIV Negative; HIV status unknown

Your city of residence:

- Vancouver; Richmond; North Vancouver / West Vancouver; Other (Burnaby, New Westminster, Surrey, Coquitlam and elsewhere)

HIV Testing

Have you been tested for HIV since 2010?

- I was tested for HIV in 2010, 2011 or 2012; I was tested prior to 2010; I have never been tested for HIV.

Were you tested for HIV in Vancouver? Yes No

Using the table below, please tell us where you were tested for HIV since 2010, and your experience of being tested in the location(s).

Please select Yes or No for each location listed below. If you select Yes, please tell us about your experience at that location. For example: Was it convenient to get an HIV test? Was the person who gave the test helpful and informative? Was your privacy and dignity respected?

- At a public community event; At your doctor's office; At a walk-in clinic; At a shelter; At a community centre; In your home; In a hospital
- Or other locations

Do you have any suggestions to help us further improve HIV testing in Vancouver?

HIV Diagnosis Experience

If you were diagnosed HIV+ in the last two years, please tell us about your experience of being told you have HIV. For example: What was your experience of the person who gave you the diagnosis? Was this person helpful, judgmental, indifferent? Did this person take time to explain HIV? Did this person provide emotional support? Were you given information about how to connect with care and support services?

Do you have any suggestions to help us improve people's experience of being told that they have HIV (being diagnosed HIV+)?

HIV Support and Treatment

Do you receive services in Vancouver for your HIV-related health needs?
Yes, I receive services in Vancouver; No, I receive services outside of Vancouver.
In the last two years, have you used any of the following services?

Please select Yes or No for each service listed below. If you select Yes, please tell us about your experience with that service. For example: How did you hear about this service? What helped you get connected and stay connected to this service? Did it take a short time or a long time to get connected to this service? Were there specific supports or encouragement that helped you?

- HIV medical specialists (e.g. doctors, nurses, epidemiologists); HIV case manager; HIV peer navigator; HIV outreach worker
- HIV housing; HIV self-management and/or peer support discussion groups
- Other services (please describe)

Please tell us about any improvements or challenges that you've experienced with other HIV services in the last two years. For example: Emotional support for living with HIV Information and education to improve your health Preparation and support for starting HIV medications Ongoing support to stay on HIV medications.

Do you have any suggestions that will help us further improve services in Vancouver for people living with HIV?

Appendix 4 - Focus Groups by Date, Location & Attendance

Date	*Location/Population*	*Number of people*	*Attendance by Gender*
Jan. 17, 2012	BOYS R US Drop-in for male sex workers	4	4 male
Jan. 19, 2012	Downtown Community Health Clinic Maximally Assisted Therapy (MAT) Program	9	5 male; 4 female
Jan. 24, 2012	Downtown Eastside HIV IDU Consumers' Board	11	7 male; 4 female
Jan. 25, 2012	BC Positive Living Society	19	16 male; 3 female
Feb. 6, 2012	Positive Women's Network – All members	4	4 female
Feb. 8, 2012	Positive Women's Network – First Nations / Aboriginal members	10	10 female
Feb. 9, 2012	Portland Hotel Society Life Skills Centre	15	13 male; 2 female
Feb. 15, 2012	Vancouver Native Health Society	10	8 male; 2 female
Feb. 20, 2012	WATARI – Latin American People with HIV	10	7 male; 2 female; 1 transgendered
Feb. 21, 2012	HIV Testing General Public	9	2 male; 7 female
Feb. 22, 2012	WATARI – Latin American Peer Workers	8	5 male; 3 female
Feb. 23, 2012	Three Bridges Clinic - HV + Staff	11	8 male; 3 female
Mar. 1, 2012	Vancouver Area Network of Drug Users (VANDU)	8	5 male; 3 female
TOTAL		**128**	**80 male** **47 female** **1 transgendered**

Focus Groups by Gender, Age and Neighbourhood of Residence

Gender	*Age*
Male (Total: 80)	20s = 3 30s = 16 40s = 27 50s = 19 60s = 15
Female (Total: 47)	20s = 4 30s = 7 40s = 13 50s = 14 60s = 7 70s = 2
Transgendered (Total: 1)	50s = 1
TOTAL	128

Age	
20s =	7
30s =	23
40s =	40
50s =	34
60s =	22
70s =	2
TOTAL	128

Neighbourhood of Residence	
Downtown Eastside =	64
Downtown Westside =	25
Vancouver Westside =	9
Vancouver Eastside =	6
Richmond =	7
North Van/West Van =	4
Outside VCH Region =	12
Not specified =	1
TOTAL	128

Note:

Downtown Eastside includes Strathcona, Hastings/Sunrise, Kiwassa, Chinatown
Downtown Westside includes West End, Yaletown
Vancouver Eastside includes Commercial Drive, East Vancouver, Mount Pleasant, Kingsway, Killarney
Vancouver Westside includes Fairview, Kitsilano, Dunbar, Kerrisdale, Marpole
Outside VCH Region includes Burnaby, Surrey, New West, Coquitlam, etc.

Appendix 5 – STOP HIV Online Survey Results

Survey Respondent Demographics (Total number of respondents = 93)

Gender & Age N = 93

Age	Male	Female	Transgender	Unspecified
20	2	9	1	1
30	11	12		
40	11	10		
50	15	14		
60	5	1		
70	1			
Totals	**45**	**46**	**1**	**1**

Sexual Orientation & Age – Males N = 49*

Age	Hetero-sexual	Homo-sexual	Bisexual	Men who have sex with men	Other	Total
20		2				**2**
30	2	7		3		**12**
40	2	9		2	1	**14**
50	2	12	1			**15**
60	1	4				**5**
70		1				**1**
Totals	**7**	**35**	**1**	**5**	**1**	**49**

* Multiple options permitted for sexual orientation

Sexual Orientation & Age – Females N = 49*

Age	Hetero-sexual	Homo-sexual	Bisexual	Woman who has sex with women	Total
20	8		2	1	**11**
30	8	1	3		**12**
40	9		1	1	**11**
50	13			1	**14**
60	1				**1**
Totals	**39**	**1**	**6**	**3**	**49**

*Multiple options permitted for sexual orientation

NOTE: Sexual Orientation: Two Queer respondents. Both HIV negative. Age: 1= 20's; 1= 40's

HIV Status & Age N = 93

Age	HIV +	HIV -	Unknown	Total
20		10	2	**12**
30	12	10	1	**23**
40	12	9	1	**22**
50	14	14	1	**29**
60	5	1		**6**
70	1			**1**
Totals	**44**	**44**	**5**	**93**

HIV Status & Age – Males N = 45

Age	HIV +	HIV -	Total
20s		2	**2**
30s	5	6	**11**
40s	5	6	**11**
50s	6	9	**15**
60s	4	1	**5**
70s	1		**1**
Totals	**21**	**24**	**45**

HIV Status & Age – Females N = 46

Age	HIV +	HIV -	Unknown	Total
20s		7	2	**9**
30s	7	4	1	**12**
40s	6	3	1	**10**
50s	8	5	1	**14**
60s	1			**1**
Totals	**22**	**19**	**5**	**46**

HIV Status & Sexual Orientation – Males N = 49*

S/O	HIV +	HIV -	Total
Homo-sexual	16	19	**35**
Bisexual	1		**1**
Man who has sex with men	3	2	**5**
Other		1	**1**
Hetero-sexual	3	4	**7**
Totals	**23**	**26**	**49**

* Multiple options permitted for sexual orientation

HIV Status & Sexual Orientation - Females N = 49*

S/O	HIV +	HIV -	Unknown	Total
Homo-sexual		1		**1**
Bisexual	3	2	**1**	**6**
Woman who has sex with women	1	1	**1**	**3**
Hetero-sexual	19	17	**3**	**39**
Totals	**23**	**21**	**5**	**49**

* Multiple options permitted for sexual orientation

City/Neighborhood or Residence for On-line Survey

Neighbourhood of Residence	
Downtown Westside =	26
Downtown Eastside =	6
Downtown Other =	6
Vancouver Westside =	10
Vancouver Eastside =	18
Richmond =	4
North Vancouver =	1
Outside VCH Region =	16
Unspecified =	6
TOTAL	93

Note:

Downtown Eastside includes Strathcona, Hastings/Sunrise, Kiwassa, Chinatown
Downtown Westside includes West End, Yaletown
Vancouver Eastside includes Commercial Drive, East Vancouver, Mount Pleasant, Kingsway, Killarney
Vancouver Westside includes Fairview, Kitsilano, Dunbar, Kerrisdale, Marpole
Outside VCH Region includes Burnaby, Surrey, New West, Coquitlam, etc.