

Community Engagement



Community Engagement Report

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

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Kath Webster, STOP Leadership Committee Community Representative, Vancouver; Community Facilitator

Lyanna Storm, Community Facilitator: Positive Women's Network and Dr. Peter Centre

Boys R Us Drop-in Program

BC Centre for Disease Control Outreach Program

BC Persons with AIDS Society (BCPWA)

Bute Street Clinic

Dr. Peter Centre

Healing Our Spirit BC Aboriginal HIV/AIDS Society

Health Initiative for Men (HIM)

Helping Spirit Lodge

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

Portland Hotel Society

Positive Women's Network

QMunity Queer Resource Centre

Settlement Orientation Service (SOS)

Vancouver Coastal Health Aboriginal Wellness Program

Vancouver Native Health Society (VNHS)

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. The pilot project focuses on individuals living with multiple barriers to care, including addiction, mental health issues, homelessness and other social or environmental factors. Community representatives worked with Community Engagement staff of Vancouver Coastal Health to conduct discussion groups with members of the public to identify:

- Elements of current service that hinder or facilitate access to HIV testing, follow-up and treatment
- Potential strategies to improve the current system of care

Key challenges face HIV services:

- **Stigma** still has profound impact on people's willingness to be tested, acknowledge HIV status or engage with healthcare providers.
- **Prioritising resources:** HAART medications are key to reducing transmission and illness progression, and accordingly resourced. However effective these medications are, participants expressed concern regarding recent funding cuts to community-based organizations (CBOs) which are essential to facilitate patient uptake of health services.

Current services:

Testing/diagnosis

- It is helpful when nurses performing HIV tests are specially recruited and trained to provide services in a manner that is appropriate and welcoming of community norms.
- Participants spoke highly of the new rapid Point-of-Care (POC) HIV test and saw many advantages.
- The delivery of test results, *whether HIV positive or negative*, is a sensitive issue for most participants: people want results in person, and to be encouraged to bring a friend with them (as appropriate).
- It is helpful when healthcare providers are sufficiently skilled to give referrals and emotional support..

Encouraging follow-up/check-ups

- Healthcare providers' encouragement and guidance is key to help people build resilience and self-management skills.
- Participants spoke highly of clinics and centres that offer information workshops – similar to chronic disease management workshops facilitated at many CBOs
- 'Emotional assessment' is as important to many participants as the 'physical assessment', e.g. screening for depression and anxiety, asking about disclosure and family concerns.
- Hours of service are an important factor. Some participants had not been able to attend appointments due to specialist hours, because their jobs offered no sick leave.

Starting and Staying on ARV Treatment

- Wide variety of models to deliver medications is key to adherence.
- Accompaniment to medical appointments, for transportation, advocacy and 'translation' of medical information is critical to adherence for some participants.
- Medication information workshops increase awareness and informed choice.
- Many programs already run over-capacity and group participants expressed a wish to see these programs expanded.

Factors that hinder follow-up and/or ARV adherence

- Pressure from their healthcare practitioner to start or stay on medications
- Screening tests (e.g. biopsies) are not sufficiently explained before or during the test
- Not understanding medical language or medical information so they could share in decision-making
- Not feeling confident or supported to share their own knowledge or research with doctor
- Fear of others discovering HIV status (e.g. nurses identifying their home-clinic location when visiting hotels; stand-alone HIV services)
- Services perceived as conditional on ARV adherence

Over-arching factors that impact access to care

Housing: key strategy in reducing risk of illness progression.

- HIV+ group participants want non-HIV-specific housing maintained as an option, to reduce risk of being identified as HIV+.

Non-clinical locations for services - Participants would like to see HIV services offered:

- In community-based locations (e.g. shelters, food programs, libraries, drop-in centres) and at community events
- In combination with other less stigmatized health conditions/medical care, such as screening for blood sugar and TB, flu vaccinations, etc.

Language and immigration needs:

- Free, non-nominal testing that requires no personal information is particularly important for illegal immigrants, due to strong fears of immigration tracking.
- Testing and healthcare services need to be coordinated with outreach workers who are recognized and trusted by this population.
- Few clinics provide free primary healthcare services for people who do not have medical insurance. People need more information about these services, especially those open evenings and weekends.

Incentives for patients:

- Should we pay people to access health services early and take care of their health?
- Considerable discussion and debate in some groups
- Highlights need for VCH to develop consistent policy on financial incentives for clients/patients

New Strategies to improve access to services

Transforming public health messages - To transform stigma and increase testing:

- New ad campaigns that express positive messages about getting tested and treated, focusing on healthy lifestyle choices, courage, community responsibility/self-care, as appropriate to community.
- Local community-specific celebrities appear in ads, encouraging testing.
- Encourage testing as a regular part of one's health routine, *'like visiting the dentist'*.
- Objective educational messages about the consequences of HIV and benefits of medication.

Public education - Expand HIV testing and education to:

- Staff at non-HIV CBOs and institutions (e.g. ESL schools, churches, recovery houses), basic HIV/Hepatitis/STI testing and workshops. These staff are some people's only source for health information.
- Community events: workshops presented as health info. for the whole community, within a range of health conditions, and combined with health literacy training exploring topics such as self-advocacy, knowing your body, knowing your medications.

Peer Involvement:

- *Greatly* expanded role recommended for peer volunteers/workers, e.g. facilitating health education workshops for public and healthcare providers, medical accompaniment, testing, 1-1 coaching and support
- Requires appropriate resources for screening, training support and coordination of peers

Patient-provider communication - To improve patient-provider communication:

- Handouts for providers to give patients information about websites and CBO resources
- Doctors to provide simple, clear explanation and handouts on medications, side effects and solutions
- Medication workshops for patients, co-facilitated by HIV specialist, nurse practitioner, HIV+ person
- Workshops for healthcare providers to look at provision of care for multi-barrier populations

1. Introduction

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

The STOP project has five goals:

- Ensure timely access to high-quality and safe HIV/AIDS care and treatment
- Reduce the number of new HIV/AIDS diagnoses
- Reduce the impact of HIV/AIDS through effective screening and early detection
- Improve the patient experience in every step of the HIV/AIDS journey
- Demonstrate system and cost optimization

Phases of this pilot project have been launched in Prince George and Vancouver's inner city, identified as priority sites as they represent a majority of BC's HIV cases and display increasing rates of HIV/AIDS. As well, the pilot project focuses on individuals living with multiple barriers to care, including addiction, mental health issues, homelessness and other social or environmental factors¹.

From its initial stages, the STOP project has identified community partnership as critical to an accountable, responsive and effective pilot project. The STOP Leadership Committee recruited four community representatives to inform the planning process and to support the engagement of the community. For the Vancouver arm of STOP, the recruited community representative worked with Community Engagement staff of Vancouver Coastal Health to plan and conduct discussion groups with members of the public to identify:

- Elements of service that hinder or facilitate access to HIV testing, follow-up and treatment
- Potential strategies to improve the current system of care

The STOP project is committed to community involvement throughout its four-year period (2010 – 2013), and further plans are offered in the *Next Steps* section of this report (page 15).

2. Methods

In collaboration with community partners and VCH staff, key priority populations were identified for consultation. They include Aboriginal people, youth, people with mental illness and/or addiction, immigrants and refugees, marginalized populations of men who have sex with men, homeless persons and injection drug users. Discussion groups were chosen as the methodology for this consultation so that people would share and build on each other's ideas for improved models of service.

We sought to capture the experiences of both people living with and at risk for HIV. It was recognised that, for some groups, it would be potentially harmful to ask participants about their HIV status, or to ask them to comment on services specific to HIV treatment. Therefore, two simple discussion guides were developed (Testing Services only; and Testing, Follow-up and Treatment Services), and both discussion guides asked the same two essential questions:

- 1) What is working or not working in these services?
- 2) How can we improve access to these services?

Community Engagement (CE) staff met with representatives from community-based organizations (CBOs) and co-facilitators before each group in order to adapt the discussion guide to meet the specific group's needs. Each discussion group was co-facilitated by CE staff, and the STOP Community Representative, Kath Webster and/or a representative of the partner CBO. Two discussion groups were also co-facilitated by Lyanna Storm, Community Facilitator. Some discussion groups were scheduled to coincide with an already-existing group-slot. Other groups were recruited via posters, phone calls, personal contact and online outreach.

The 13 discussion groups were conducted in June and July (see Appendix 1), including two groups conducted in Spanish. The 113 participants reflected a wide diversity of age groups and neighbourhoods in Vancouver (see Appendix 2) and the content of these discussions is summarized below. A meeting was also held with CBO service providers and their feedback is included in this summary (see Appendix 3 for list of participating organizations).

Limitations

This consultation is one of many steps being taken by the STOP project and Vancouver Coastal Health to learn about the full complexity of community experience of HIV services. Due to resource limitations, it was not possible to conduct some population-specific discussions, and group locations were therefore chosen in order to capture the greatest possible range of experiences of barriers to care. In this way, experiences of sex trade, immigration, mental illness, injection and other drug use, age, gender and many other concerns were raised in discussions. But it is inevitable that some aspects of community experience could not be fully explored in mixed groups. Published research or consultation documents specific to HIV services for specific populations (women in sex trade²; street-involved youth³; men in sex trade⁴; injection-drug using women⁵) were also collected and utilized in the formation of this report. A question was also raised during consultations regarding the role of families in HIV care, with suggestion that this be a target group for future consultations.

Future phases of community involvement could be planned in order to take into account diverse communities' needs. Factors which could be considered include various social determinants of health (e.g. income, education, social support, gender, culture), geographical location (e.g. by neighbourhood, service use) and preferences for participation (e.g. surveys, interviews, group discussion), so that the 'voice' of service-users continues to take a prominent role during implementation of this project.

3. Key challenges face HIV services

Stigma and Fear

Many participants stated that stigma and its consequences remain significant barriers to people's willingness to get tested, attend follow-up appointments or pursue treatment. Many would prefer to not know or acknowledge their HIV status rather than experience shaming, fear and judgment. The following points emerged from group discussions:

- Despite three decades of public health campaigns, participants stated that many myths are still widely believed regarding the origin, transmission and disease progression of HIV, contributing to the ongoing shaming and judgment associated with HIV.
- In each of the 13 discussion groups, the same identical phrase appeared in some form, '*HIV is a death sentence*'. This entrenched belief continues to have significant and damaging impact on people's perception of diagnosis and treatment.
- There is substantial and reasonably-based fear of other people discovering one's HIV status, due to reactions of rejection, abandonment, public shaming and physical violence. Willingness to engage with service providers is sometimes tied to the risk of disclosure, and acceptance of the potential consequences.
- HIV disproportionately affects people who already experience strong judgment from health and other institutions, and high barriers to accessing services (e.g., lack of formal employment and/or education, social isolation, experiences of cultural and personal trauma, etc.). Many do not have the skills to overcome these barriers alone and require extensive support, particularly for a stigmatized and life-threatening condition.

Prioritising Resources

- Highly Active Anti-Retroviral Treatment (HAART) medications are perceived by some as the 'silver bullet' to reduce illness progression and transmission, and this approach to HIV prevention and treatment is accordingly resourced.
- However effective these medications are, HIV+ participants felt strongly that community-based organisations (CBOs) are essential to facilitate patient uptake of health-related services (of which medication is one of many options).
- In our efforts (local, provincial and national) to preserve essential elements of our socialized healthcare system, CBOs face continued cuts in funding and services, such as education, support, case management and medical accompaniment. As pointed out by HIV+ participants, many clients require extensive and long-term support to access care. CBO services are also 'essential elements' of our healthcare system.

These observations are not intended to prescribe how resources should be prioritized, but instead pointed out by participants across many groups regarding the necessary balance required between clinical/medical services (e.g. testing, medical check-ups, treatment) and community/social services (e.g. education, outreach, support) so that all people living with and at risk for HIV can achieve optimal health.

4. Findings: Elements of current service

4.1 Testing and Diagnosis

It is helpful when nurses performing HIV tests are specially recruited and trained to provide services in a manner that is appropriate and welcoming of community norms

- Group participants spoke of avoiding certain clinics or clinic-times when they knew an insensitive or inappropriate nurse was on duty – sometimes not returning for testing.
- This observation was repeated in a number of groups, and not specific to any one clinic.

Participants spoke highly of the new rapid Point-of-Care (POC) HIV test and saw many advantages:

- The pin-prick method is physically easier, especially for injection drug users, and preferable for many people who don't like needles.
- Test-kits can be carried to outreach locations - particularly helpful for people who cannot or do not wish to come to clinics.
- Results are available within minutes (instead of the one or two week waiting period) making it more likely that patients will receive their results.

The delivery of post-test results, *whether HIV positive or negative*, is a very sensitive issue for most participants.

- In the case of blood-draw tests, though several participants acknowledged being tested on a regular basis (every 3-6 months), many reported that the actual day of test results is very difficult. This impact should not be under-estimated, and examples of good delivery of test results include:
 - Results are given in-person (some reported recent test results by phone).
 - The healthcare provider has been appropriately trained to give referrals and emotional support.
 - The patient has been encouraged to bring a support person with them, as appropriate

Participants' examples of helpful information when receiving an HIV positive diagnosis:

- Clear, simple information about the condition (instead of technical information about the virus and/or medications), and empowering messages about disease self-management and normal life expectancy
- Referrals to CBOs, emotional support, and HIV specialist
- A list of responsible websites for further information
- Sufficient time to offer emotional support (e.g. 30-60 minutes), or referral to emotional support that is immediately available
- An offer to book a return-visit the next day or week for a follow-up meeting
- An exploration of the patient's further needs (e.g. information, emotional support, peer support, medications, alternative therapies, etc.), according to his/her interest
- Handouts to be discussed at the follow-up appointment, and/or with a support person of their choice

4.2 Medical Follow-up/Check-ups

Participants identified a range of models available for HIV medical follow-up, including daily or monthly visits, or home-care visits when it may be a few months or years (if ever) before a patient may be willing to visit a clinic. Participants made the following observations about encouraging follow-up:

- **Healthcare practitioners' encouragement and guidance is key to helping people** find the information and supports they need to build resilience and self-management skills. A number of qualities engender trust in the patient-provider relationship, influencing patient ability, willingness, motivation and confidence to engage in their health plan.
- **Participants spoke highly of clinics and centres that offer information workshops**, looking at nutrition, exercise, medications and other topics – similar to chronic disease management workshops at many CBOs.
- **Many participants found they became more committed to participating** in their healthcare as they learned more about their disease, and could take a greater role in their self-management.
- **Some centres also offer meals, outings and other opportunities for social networking and support.** Low-access/high barrier populations find these services beneficial for numerous reasons (e.g. giving structure to the day, meeting peers, learning new information), and are therefore motivated to attend health appointments.
- **'Emotional assessment' is as important to many participants as the 'physical assessment'.** Screening for depression and anxiety, asking about disclosure and family concerns are examples to include in a whole-person assessment, in addition to blood tests for CD4s and viral load.
- **Hours of service are an important factor in people's ability to see HIV specialists.** Some participants expressed concern that they had not been able to attend appointments due to specialist hours, because their jobs offered no sick leave. If they left for an appointment they would lose that day's pay, or lose their job. There are few options for clinical care in evenings or on weekends.

Several patients also gave examples of practitioner approaches that had hindered communication, and sometimes resulted in the patient's withdrawal from service:

"My doctor advised me to go on medications at my second appointment, and because I was not interested, I was sent to his resident instead. The message was that I'm not worth his time if I'm not on medications. The resident pushed the medications too. When I still refused, she became very condescending and wouldn't make eye contact. If I had a better doctor, I may have been willing to return and even just get blood counts done: now I just don't see doctors."

- Pressure from their healthcare practitioner to start medications
- Doctor perceived as judgmental about the patient's personal activities
- Patient is seen as 'HIV' and nothing else: all symptoms are seen through the lens of HIV disease, ignoring other possible causes of symptoms (such as aging or non-HIV related conditions) and bypassing other important health screening tests
- Screening tests (e.g. biopsies) are often not sufficiently explained before or during the test
- Not understanding medical language or medical information so they could share in decision-making
- Not feeling confident or supported to share information they have heard or researched

4.3 Starting and Staying on Anti-Retroviral Treatment

There is a wide variety of models to ensure medication adherence, tailored to suit client skills and life situation. Participants identified some of the following examples:

1. Hotels/residences have staff trained to dispense medication
 2. Outreach nurses bring medications to clients in their homes or other locations
 3. Clinic-based programs offer social support, meals, counseling and education
- These and other models are key to medication adherence for those who experience high barriers to healthcare, allowing clients to build trust with staff, moving from one model to the next, if possible, as their needs and comfort-level change, increasing their social and self-care skills.
 - Some centres offer opportunities for client involvement in education and outreach programs (much like CBO models), giving people a sense of pride, purpose and meaning. Many people spoke of this work as key to their disease self-management strategy, and willingness to adhere to medication.
 - Some clients prefer to have HIV medications available at their local pharmacy or clinic rather than HIV clinics, due to convenience, reduced stigma, and/or established relationships with staff. Some clients find hospital-based pharmacies present obstacles to medication access (e.g. several appointments required for each refill).
 - Accompaniment to medical appointments, for transportation, advocacy and ‘translation’ of medical information is critical to adherence for some participants.
 - Medication information workshops increase awareness and informed choice.
 - Many programs already run over-capacity, and group participants expressed a wish to see these programs expanded so that more people could share these benefits.

Many people in the Downtown Eastside appreciate having their HIV doctor and support program in the same location, but for others, stigma and fear are barriers to service if the service is identifiable as HIV-specific. Participants suggested:

- It is helpful when HIV-specific programs are located *within* a general healthcare clinic.
- Outreach staff and nurses should not identify where they work when they visit hotels:

“The nurse came to the hotel and told them where she was from, so everyone figured out I’m HIV. There’s lots of stigma on the street – the nurses need to stop telling people where they’re from.”

Many patients addressed the importance of simple, clear discussion with their healthcare practitioners, without judgment or pressure, with regard to medication issues: the decision of when and why to start, what each medication is for, daily schedule, side-effects, benefits and risks. These discussions increase client understanding, willingness, ability and self-agency in disease self-management.

“The doctor just gave me a big bag of pills and sent me off – no information – I left them in the garbage on my way out.”

When provision of health services is conditional on medication adherence, this presents a barrier for clients who cannot adhere or choose to stop medications. As well, some clients stated they felt judged for stopping medications, and/or using complementary therapies. People identified the subsequent loss of services (and bond with healthcare providers) as having significantly damaging impact. Clients need to have continued support and services if they change their decision, particularly as this may likely impact their willingness to return to medication.

5. Over-arching issues that impact access to HIV care

5.1 Housing

Provision of social housing for people living with HIV is a key strategy in reducing risk of illness progression.

- Suggestions made by CBO staff to better coordinate services include:
 - Housing societies could be resourced to employ an HIV services coordinator who sets up services for all patients in their hotels/residences (rather than each housing manager forming individual relationships with service providers).
 - Women-only housing, with palliative care beds are important for safety and security.
 - The STOP project could consider approaching BC Housing to advocate for more HIV housing.
- It was also noted that some HIV+ group participants want non-HIV-specific housing maintained as an option, to reduce risk of being identified as HIV+.

5.2 Medical services in non-clinical locations

Due to concerns about disclosure and stigma, participants had many suggestions for increasing uptake of HIV clinical services through provision in locations perceived as ‘neutral’, and where people have established trusting relationships with staff and peers.

- **HIV testing could be offered:**
 - in community-based locations (e.g. shelters, food programs and community kitchens, libraries, drop-in centres, neighbourhood houses) and at community events, where people are already gathered and have support
 - with free needles and condoms available
 - in combination with other less stigmatized medical care, such as screening for blood sugar and TB, flu vaccinations, etc., so that others do not know what kind of test the person has requested
 - where appropriate, testing could also be accompanied by an HIV/STI discussion so that people can ask questions and learn harm reduction information
 - for youth, in an informal community setting, in combination with other sexual health screening and information
- **Medical follow-up and medications could be offered:**
 - in women-only locations such as shelters and drop-in centres
 - at any community-based location or clinic that is convenient to the patient, where he or she already has trusting relationships with staff
- **Training for staff:**
 - Non-clinical staff require training to provide information and support, and to properly dispense medication.
 - Concerns were expressed by group participants about a small number of staff in medical outreach teams who do not seem comfortable in the Downtown Eastside.
- CBO staff also identified many benefits to patients when medical services in non-clinical settings are developed and co-managed as partnerships between VCH and CBOs, so that community needs are addressed at all stages of health service planning.

5.3 Language and immigration needs

Two discussion groups were conducted for Spanish-speaking people, including one group for youth who are illegal immigrants. The following suggestions were offered:

- Free, non-nominal testing that requires no personal information (e.g. a BC Medical number or social insurance number) is particularly important for illegal immigrants, due to strong fears of immigration tracking, police and possible deportation.
- Testing and healthcare services need to be coordinated with outreach workers who are recognized and trusted by this population.
- Services available in Spanish, or with a translator present, are needed so that patients can ask questions and, if necessary receive emotional support.
- Few clinics provide free primary healthcare services for people who do not have medical insurance. People need more information about these services, especially those open evenings and weekends.
- Printed information about HIV and other health conditions could be sourced in Spanish from several reputable U.S. websites.
- Questions arose about what types of service would be available if an illegal resident is diagnosed HIV+. The STOP project may need to consider providing funds to support lab tests and medications for this population as well, so that access to treatment is possible for everyone, regardless of immigration status.

5.4 Incentives for patients

- Should we pay people to access health services early and take care of their health, given the possibly greater costs if they must later enter the health system in an acute care crisis? This is an ongoing question for chronic disease management across several health conditions.⁶
- There was considerable discussion and debate in some groups, with questions arising such as: Do all people at risk and living with HIV get paid? How is it decided who gets paid? For what services? For how long? What about other incentives?
- This highlights the need for VCH to develop a consistent policy on financial incentives for clients/patients.

6. Strategies to improve access to HIV services

POC testing and one-pill-per-day treatments were discussed with enthusiasm by many group participants, but it was also agreed that innovations like these will be utilized to their maximum benefit only if the following themes inform the services we provide.

6.1 Transforming our public health messages

Stigma and myths still form much of the public perception of HIV, which participants attribute to television, movies and other popular information sources, contributing significantly to people's reluctance to find out or acknowledge their HIV status. Some group participants suggested that the formats of current public health testing and ad campaigns also contribute to the myths and stigma, for example:

- Some participants see public health messages that still imply HIV is a 'death sentence'.
- Some people experience the questions used in pre/post test counseling as an accusation that they did something 'wrong' to risk catching HIV.
- Some healthcare providers address HIV as a dire and frightening condition.

To transform stigma and increase testing, participants suggested:

- New ad campaigns and questions for pre/post test counselling could express positive messages about getting tested and treated, focusing on healthy lifestyle choices, courage, community responsibility and self-care, as appropriate to the target population.
- Local community-specific celebrities could appear in ad campaigns, encouraging testing and helping to reduce stigma.
- Additional messages in ad campaigns could include:
 - Testing is free, quick, anonymous and easy
 - Encouraging testing as a regular part of one's health routine, like visiting the dentist
 - Acknowledging family/community roles in maintaining health, regardless of HIV status
 - Objective educational messages about the consequences of HIV and benefits of medication
 - Living healthy with HIV is possible for all

6.2 Maintaining and Expanding Public Education

- **For non-HIV-specific CBOs and institutions** (e.g. ESL schools, churches, recovery houses), basic HIV/Hepatitis/STI testing and workshops could be offered, as these staff are some people's primary source for health service information.
- **For elementary and high schools**, education could be renewed by introducing the Canadian AIDS Society's new K-12 curriculum (available August 2010).
- **For community events**, workshops could be presented as health information for the whole community, relevant to a range of health conditions, and combined with health literacy training exploring topics such as self-advocacy, knowing your body, knowing your medications.
 - CBO staff identified that this model could be run in partnership with current initiatives, e.g. the Carnegie Learning Centre uses a community development approach and has run health literacy projects in the Downtown Eastside.
 - Public forums on HIV and Hep. C innovations could be held in popular community settings, inviting experts to give presentations, led and introduced by community leaders.

- It is important that educational workshops be developed and delivered in partnership between health authorities, CBOs and other partner agencies to ensure messages are community appropriate, provide opportunity for shared learning, and encourage messages of shared community responsibility for health.

6.3 Peer Involvement: HIV+ people and other peer volunteers/workers

Introduction

“There is this whole new tone with HIV now, with the medications: don’t give up! Don’t give up on yourself, don’t give up on HIV.”

“I want to volunteer. Let us get trained! Let us do something, contribute. We are not ‘down and out’ – we have knowledge too.”

A particularly strong, united message came across at all discussion groups with regard to the importance of new roles for peer volunteers/workers, both as a method of reaching the ‘hard-to-reach’ and as a direction for new energy and vision for people living with HIV.

After diagnosis or a meeting with one’s doctor there are many questions and fears, and many people agreed that they want to speak with someone from their own community, however a ‘peer’ is defined. For HIV+ participants, most felt it was very important to meet and speak with healthy role models who give hope, support and guidance. It was also felt that if more peers are involved in HIV and health work, open about their HIV status and doing strong support work in their community, this would create a momentum that could have significant impact in overcoming stigma.

Many of the following examples of peer roles exist in different forms in various AIDS service organisations, and across chronic disease conditions. There are many elements to choose from in expanding and coordinating peer support programs, adapted to various communities’ needs and traditions. As well, this strengths-based approach offers people the opportunity to learn new skills and develop a new vision of their post-diagnosis future:

“I’ve spent 25 years waiting to die. What do I do now? Can I return to my dreams before I got HIV?”

“I’ve gone through the organisation’s peer training. They included me in the peer research, I go on hospital visits, I’ve been trained in chronic disease management work and counseling other people. I give to others, and I receive a lot from the organisation too. On the hospital visits I’ve seen people in different paths or choices... it has been a spiritual awakening.”

It was also acknowledged that people still want and need healthcare professionals and CBO staff to provide services and support. Some participants spoke of being deeply private people who would only speak with their doctor or a staff person. In either case, it is the long-term relationship with a trusted contact that often initiates and sustains a person’s connection with healthcare. For many people there is no connection with staff or healthcare professionals; peers are their only possible ‘bridge’.

Peer support is no more a ‘magic bullet’ than HAART medication to reduce transmission and illness progression, but participant discussions strongly indicate that peer-based programs could play a significant role in transforming access to HIV testing, follow-up and treatment.

Possible roles for peer volunteers / workers

- Facilitating health education / health literacy workshops for the public and healthcare providers
- Outreach, in collaboration with healthcare staff to assist them with accessing new patients
- Administering/accompaniment for HIV POC tests, including pre/post-test counseling and referrals
- Same-day post-diagnosis support
- Facilitating multi-session *workshops for newly diagnosed patients* have been very successful for numerous chronic conditions, and could be adapted by local community members to specific community traditions, covering topics such as treatment options, how to talk to your doctor, supplements, nutrition, disclosure, medication and side effects
 - There is strong anecdotal evidence from other chronic disease groups that patients engage more successfully with their condition and with healthcare providers if they receive initial intensive education, followed by ongoing support to maintain health needs and continue learning new information
 - Combination of education and support has strong and significant impact on patient ability, confidence and motivation to manage disease over course of their lives
- A multi-session *chronic disease management group* co-facilitated with a healthcare provider
- Providing 1-1 coaching to prepare for medical visits
- Medical accompaniment and ‘translation’ of provider language
- System navigation and accompaniment to service organizations
- Hiring and training of medical outreach team staff and other service providers

Training, support and referrals

- Training for peer volunteers/workers should include both the task-based skills (e.g. group facilitation, peer support counseling, workshop methods, etc.) as well as process-oriented skills, such as relationship boundaries, ethics and self-care.
- Peer volunteers/workers need thorough screening, training, support and evaluation (some peer support workers had not been screened or monitored appropriately, and had breached confidentiality or were not reliable).
- HIV+ peers need to be open about their HIV status, and sober and responsible while in the peer role so they can focus on the client and help him/her cope.
- Boundaries can be especially difficult when a peer is volunteering in a community or neighbourhood where he/she has been well-known. How do peers protect confidentiality in work versus non-work contact, when they will often be working with close friends and family?
- Support and debriefing of peers is very important due to the burn-out and trauma sometimes experienced in this field.
- CBOs need to provide structured opportunities for peers to use their skills, coordinating referrals, communicating peer support services to healthcare providers, and providing networking/training opportunities for peers across organizations.
- Participants emphasized that connecting newly diagnosed patients to a peer support person should be made as important a priority as referring them to a doctor or signing them up for welfare and housing.

Coordination of peer programs

- Various peer programs are disjointed and disconnected at present. It is not recommended by CBO staff that these programs be standardized or based in one location, but they do need to be better coordinated and shared.
- CBOs and other partner organisations could be assembled to share and create best-practice guidelines for recruitment, training, support and evaluation of peer involvement programs.
- Peer involvement programs from across Vancouver, outside of HIV could also be contacted to offer training and networking opportunities.
- Information about the volunteer supplement from welfare should be made more widely available. This is extra incentive for some people, and helps them to return to a structured routine.

6.4 Improving communication between healthcare providers and patients

HIV+ participants largely agreed that it is not the length of the appointment but instead the qualities of holistic assessment, shared decision-making and openness to patient questions and knowledge that determine the degree of trust between provider and patient.

Participants suggested the following strategies to improve patient-provider communication:

- Handouts should be developed for providers to give their patients information about responsible websites and CBOs for medical, nutrition and other healthcare follow-up.
- It would be helpful for doctors to provide simple, clear explanation and handouts on medications, side effects and solutions, as a discussion tool the patient could use with the doctor or other healthcare provider.
- Detailed learning opportunities for patients about medications, (e.g. group workshops, possibly co-facilitated by an HIV specialist, nurse practitioner and HIV+ person
- Workshops for healthcare providers to look at provision of care for multi-barrier populations (e.g. people in sex trade, people living with mental illness, injection and other drug users, etc.)

7. Next Steps

This initial consultation with members of the public was designed to gather information about gaps in HIV services, and how best to meet needs of people living with or at high risk for HIV infection. This report will be combined with feedback from meetings with clinicians, CBO staff and other service providers, and a literature review, in order to develop potential strategies to meet our goals over the coming year.

These strategies will be brought out to members of the public in a second set of discussion groups, before implementation so that people can provide input, indicating which strategies or elements they feel will be most effective. Some pilot-tests have already been initiated over the last year (e.g. POC testing at some sites; a 10-week training group in chronic disease self-management), and other pilot-tests will have been initiated by this coming Fall. These examples will be included in Community Engagement's presentation at the discussion groups, and additional examples as developed by the Leadership Team, for feedback to shape next year's pilot test strategies. Finally, we will also ask participants to advise on possible models for ongoing engagement with the public to monitor the STOP project as it is implemented, until March 2013.

References

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- 3) Marshall BDL, Kerr T, Qi J, Montaner JSG, Wood E. **Public injecting and HIV risk behaviour among street-involved youth**. Drug and Alcohol Dependence, 2010; 110(3): 254-258
- 4) Moorhouse R, Cuddahy T. **Evaluation of Boys'R'Us Rapid Point-of-Care HIV Testing Services**. Vancouver, 2010
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Appendix 1: Focus Groups by Date, Meeting Location & Attendance

<i>Date</i>	<i>Location</i>	<i>No. of attendees</i>	<i>Attendance by Gender</i>
June 3, 2010	Not applicable	4	3 male; 1 female
June 16, 2010	Vancouver Native Health Society	11	7 male; 3 female; 1 two-spirited
July 5, 2010	Positive Women's Network – all members	8	7 female; 1 transgendered
July 6, 2010	Maximally Assisted Therapy (MAT) Program, Downtown Community Health Clinic	10	4 male; 6 female
July 7, 2010	Positive Women's Network – Aboriginal women	9	8 female; 1 transgendered
July 7, 2010	BC Persons with AIDS Society (BCPWA)	11	11 male
July 9, 2010	Life Skills Centre, Portland Hotel Society	10	10 male
July 12, 2010	WATARI – Spanish language group	18	14 male; 4 female
July 13, 2010	Health Initiative for Men (HIM)	3	3 male
July 14, 2010	Dr. Peter Centre	3	3 male
July 16, 2010	Bute Clinic: Spanish language (youth)	16	9 male; 7 female
July 20, 2010	Helping Spirit Lodge	5	5 female
July 26, 2010	Youthco AIDS Society	5	5 male
TOTAL		113	69 male; 41 female; 3 two-spirited/transgendered

Appendix 2: Focus Groups by Gender, Age and Neighbourhood of Residence

<i>Gender</i>	<i>Age</i>
Male (Total: 69)	Teens = 1 20s = 14 30s = 11 40s = 21 50s = 15 60s = 6 70s = 1
Female (Total: 41)	20s = 9 30s = 8 40s = 19 50s = 4 60s = 1
Two-spirited/Transgendered (Total: 3)	20s = 1 40s = 1 50s = 1
TOTAL	113

<i>Age</i>	
Teens =	1
20s =	24
30s =	19
40s =	41
50s =	20
60s =	7
70s =	1
TOTAL	113

<i>Neighbourhood of Residence</i>	
Downtown Eastside =	26
Downtown Westside =	20
Downtown Other =	17
Hastings Sunrise =	6
Mount Pleasant =	7
Commercial Drive =	5
East Vancouver =	11
South Vancouver =	3
Vancouver Westside =	4
Burnaby =	3
New Westminster =	2
Surrey =	1
Richmond =	1
Not specified =	7

Note:

Downtown Westside (refers to Yaletown/West End)

Downtown Other (refers to Chinatown/Strathcona/Tinseltown/Gastown)

Organisations in attendance:

- AIDS Vancouver
- Afro-Canadian Positive Net BC
- Atira Women's Resource Society
- BC Persons with AIDS Society
- DAMS: Drug and Alcohol Meeting Support for Women
- Dr. Peter Centre
- Downtown Eastside HIV/IDU Action Plan Consumer's Board
- Downtown Housing Centre
- HIM: Health Initiative for Men
- HIV Community Based Research Centre
- HUSTLE: Men on the Move Outreach and Support Services
- Lookout Emergency Aid Society
- Loving Spoonful Vancouver Meals Society
- Marble Arch Housing
- McLaren Housing
- PACE (Prostitution Alternatives Counseling and Education)
- Pacific AIDS Network
- Portland Hotel Society
- Positive Women's Network
- Rain City Housing
- Vancouver Native Health
- VANDU: Vancouver Area Drug Users' Network
- WISH (Women's Information Safe House) Drop-in Centre (including AESHA Project)
- Youthco AIDS Society