The Depth of Water Requires Knowledge: Listening to the Voices of the HIV Patient Journey

Innovation and Development Commons
Brown Bag Lunch
27 November 2014
Patricia Howard, MA
Agenda

- What is HIV?
- STOP HIV Pilot and From Hope to Health
- BC HIV Statistics
- Acknowledgements
- Purpose of PJM
- Background
- Methodology
- The River Journey
- Introduction of Report
- Discussion of Findings
- Recommendations
- Next Steps

First item on the agenda for our upcoming meeting:

Sex.
What is HIV?

- HIV is a virus that attacks the immune system, resulting in chronic, progressive illness that can leave people vulnerable to infections.

- Fortunately, the virus is also frail: it cannot survive long outside the human body and does not transmit easily aside from some very specific behaviour.

HIV cannot be transmitted by:

- mosquito bites
- shaking hands or hugging
- coughing or sneezing
- using toilet seats or door knobs
- sharing eating utensils or at the water fountain
HIV and Silence

69% believe that people would be unwilling to tell others they have HIV/AIDS because of the stigma associated with this disease.
Background
STOP HIV Pilot From Hope to Health

1. Timely access to high-quality and safe HIV/AIDS care and treatment
2. Reduce the number of new HIV/AIDS diagnosis
3. Reduce the impact of HIV/AIDS through effective screening and early detection
4. **Improve the patient experience in every step of the HIV/AIDS journey**
5. Demonstrate system and cost optimization

1. Reduce the number of new HIV infections in British Columbia
2. Improve the quality, effectiveness, and reach of HIV prevention services
3. Improve the quality, effectiveness, and reach of HIV prevention services
4. **Improve quality and reach of HIV support services for those living with and vulnerable to HIV**
5. Reduce the burden of advanced HIV infection on the health system
BC HIV Statistics

In BC there are approximately 12,000 people living with HIV

Each year it is estimated 200 - 300 people ranging from 13-81 years old are diagnosed with HIV infection

June 2013 FN only ARV Stats
BC - on ARVs
705/6403 (11% Aboriginal)
705/837 (84% on treatment)

NH Region
73/180 on ARVs (41% Aboriginal)
73/85 (86% on treatment)

NI Region
45/49 (92% on treatment)
First and foremost, I have to acknowledge and thank our experts.

This PJM Report would not have been possible without the assistance of our participants:
Allan Mousseau, Christina Tom, Gay-lene Collison, TW, MR, CA, CW, SD, RL, CF, KL, BK, ML, MR, FM, CT, LS, JS, MW.
Purpose of PJM

Improve the patient experience in every step of the HIV/AIDS journey

- Be culturally safe and appropriate
- Reduce stigma & discrimination
- Listen to the experts
- Address barriers
- Identify areas of need
Background

Prince George (Northern Health) was utilized as one of the two locations (Vancouver’s inner city, the other) within British Columbia to be involved with the Provincial Seek and Treat for Optimal Prevention (STOP) HIV/AIDS Pilot Project from 2010 - 2013. The HIV+ population in Prince George has been identified as a priority site since the region represents a majority of BC's HIV cases and displays increasing rates of HIV/AIDS. The STOP Project has clear mandates and guidelines and it was because of these goals, this report was written.

Project 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

The project's strategic goals are supported by the following initiatives:

- We must transform how we screen for HIV
- We must streamline HIV/AIDS diagnosis and linkage to care
- We must continue to develop site-specific programs to consistently deliver high-quality services across participating pilot sites
- We must deal with the determinants of health that are negatively influencing the health of people living with HIV and AIDS
- We must engage in a highly collaborative process that will allow us to learn from each other and turn knowledge into practice

The STOP Goals allowed this Patient Journey Mapping (PJM) Report to be developed and under the direction of Barellt Sweet, Northern Health's Regional Coordinator, Blood Borne Pathogens Services, Patricia Howard, Northern Health’s Aboriginal Coordinator, was able to take this project on as the Principal Investigator. We were also fortunate enough to have the assistance of Dr. Theresa Healy, Northern Health’s Regional Manager for Healthy Community Development, along with Dr. Tina Fraser, LIRBC Assistant Professor and Aboriginal Education Coordinator, both of which offered Collaborating Research Support.

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Methodology

- Literature Review/Best Practices
  Process for patient mapping

- Engagement with ASO’s to identify participants
  Cultural Safety and confidentiality

- 2 focus groups with HIV+ individuals
  (14 participants) one group women specific

- Key informant interviews with HIV+ individuals
  (5 participants)

- Broad representation
  (age, gender, newly dx, long term survivors)

19 people total living with and affected by HIV
84% Aboriginal representation
The River Journey

Designed to improve the Health Care System by listening to the voices of the patient
One story

“My journey began in October of 1984. This doctor I used to go and see took a blood test. We used to call him the “vampire” because he always took blood from everyone. He went and got me tested without telling me. And then he said “make an appointment, come back” so I went back, kept my appointment. He told me, “I have some good news and some bad news.” I asked, “What’s the good news?” He said, “There is no good news really, I just said that to cheer you up. The bad news is you’re HIV positive; you have five years left to live.” Right away he knew how long I was going to live and that was 28 years ago when he said that and I’m still here.”

(KI 12-12-12-05)
Discussion of Findings

Findings

I know I’m not alone in having that feeling of rejection and having a hard time with asking for help for that fear of not being able to receive it and in a way that almost sounds like being spoiled or something but it’s not that way.

We had a very rich set of data and began to process of analyzing by identifying common themes. Our first cut of the data resulted in 3 themes and x sub-themes. Our second cut enabled us to condense and synthesize and finally we had the 3 themes and xx sub-themes discussed here.

General observations

One of the central themes that emerged throughout the STOP HIV/AIDS Pilot Project has to be, despite the many obstacles in place, the incredible amount of strength and resilience within this population. It was an honour and privilege to work with such an amazing group of individuals.

Shame discrimination and stigma

In the focus groups, the major finding related to silencing. The common experiences around stigma, discrimination and shame all created a perfect storm that swamped any attempts to engage in the health care system and be heard. There were also experiences that were related to how they were treated, and which also highlighted the implications and outcomes of this treatment.

You're a joker... you always will be. That's what they're saying.

Some implications and outcomes reported in the sub-themes were: lack of compassion, lack of knowledge, lack of HIV knowledge, lack of knowledge of the determinants of health. These were all embedded in the service provided.

At the hospital I kind of felt like their attitudes are different... The nurses... Like I can tell when somebody’s talking about you, type of thing. They're talking about you but they're just... you can sense it from you know.

Systemic barriers

In addition, to the stress of dealing with individual service providers who failed to offer compassionate service, participants identified additional stress that was imposed by the system itself. Policies meant they were told things like:

- You can only talk about one thing to the doctor
- He said, that's something we'll get into at another time.

Late for an appointment told to come back next week

I just wish it wasn’t such a long wait period to see a doctor. Like, if I want to make an appointment, because on a daily basis I have different things I have to do, like, I go to my groups and things like that. So it’s not like I can just hang out in a doctor’s office all day waiting for an appointment, right? Like, I understand that they’re very, very busy here but maybe they should get another Doctor or two or something you know. So they can meet the needs of the patients a lot better.

- You are not asked for important information that could impact treatment and care

They just track you once you’re in there. Once you see the doctor or whatever they just track you, they don’t ask you proper questions. I don’t see results that I want to see... I want to see who’s going on with my blood work. I didn’t get to see that, that was just rather broke my little heart. Cause I like to know I’m the type of person who wants to know the numbers. Cause once the numbers go down I have the ability to change that, not the medical worker.

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Recommendations

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Believe You Can

No, I don't like groups. I'm not a group person. I stay by myself. I don't even see my spouse anymore. I'm so scared. I am in need of counselling. My mom doesn't know I'm not the kind of person to open up.

Best Practice principles

During the individual interviews, the consensus emerged around best practice principles for care. These included:

• Reduce Shame – ensure the least amount of people know they are HIV+

I don't tell anybody anymore because of negativity.

• Highest regard for confidentiality – ensure accessing services does not become a broadcast of a status that should be private.

As soon as I found out my whole family just right away it was on Facebook. And it was all my mum. The one person that I'm supposed to love and she fucking hurt me so hard. I still love her. I just can’t respect her the way I used to. Oh my daughter’s dying she got HIV. If I’m dying I’m like why am I still here? I havent talked to a whole about this to anybody.

• Address ignorance and lack of respect proactively and effectively.

At the hospital I kind of feel like their attitudes are different, yeah I just face so much of it [injection] in my life that I really don't need it from people that are supposed to be a professional and those supposed to be helping you.

I keep my head down – people talk.
Themes from 6 January 2014 follow up

Improvements Suggested

- Education to peers re: drug interactions and health needs
- Need to coordinate discharge planning to assist family

Support Service Satisfaction

- Normalize PLN to include supports and family members
- Maximize disability services
  - Housing
  - Rent
  - Floating Subsidies

Grief Counselling

Men’s support groups

Women’s support groups

Support groups For family and Peers

Happy with MASP

Happy With Needle Exchange
Themes from 6 January 2014 follow up

Stigma
- Hospital treats us like dogs
- Hospital still thinks we are drug seeking
- Hospital still don't care about people with HIV

Mental Health Counselling Support

ER Observation Discrimination

Stable Housing

Sensitivity Training

Education
- Need more support for HIV+ clients
- Education at hospital - I still can't use the washroom
- Long term effects of medication
- ARV's on Pharma net - interactions with other meds
- ER Testing for HIV

Normalize HIV Testing
Knowledge to Action - Top Three Priorities

1. Address stigma and discrimination through education and awareness
2. Community engagement and supports to build community capacity
3. Improve the experience for those living with and affected by HIV

Key Message: Nothing about us - without us
Regional Testing Initiative - Jan 2014

- Prince George
- Vanderhoof
- Ft. St. James
- Fraser Lake
- Lakes District

Next:
- Quesnel
- Mackenzie
- McBride
- Valemount
Tools & Resources: Integration for Wrap around Services

Patient information — Routine HIV testing at UNBC

Why is an HIV test being offered?

We are offering an HIV test to all patients in hospital.

Knowing your HIV status is important for your health and health care. People with HIV often have no symptoms for many years. During this time, your health may be affected without you knowing. The only way to know for sure is to have an HIV test.

As HIV blood test is simple, it can be done with all your blood tests while you are in the hospital.

HIV is treatable with medication. The medication will keep your immune system strong. People with HIV who are treated can live long and productive lives.

What you need to know

The Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system. The immune system helps your body fight off infection.

HIV infection is a chronic illness that can be treated with medication. Like diabetes, there is no cure for HIV. But people with HIV who are treated can stay healthy and are less likely to pass the virus onto others. This is because the amount of virus in the body can be controlled by medication.

HIV can lead to Acquired Immunodeficiency Syndrome (AIDS). If you are not treated with anti-HIV medication.

HIV can spread from one person to another during unprotected sex (vaginal, anal, and sometimes oral) or by blood contact (such as sharing needles) with someone who has HIV.

You have the right to refuse to be tested for HIV.
Purpose of Environmental Scans

The primary objectives of the environmental scans are to:

1. Examine existing services and supports
2. Map existing services in communities
3. Identify gaps and challenges
4. Implement potential solutions
## Environmental Scan Sample Questionnaire

### Community Name:  
Contact Name:  
Date:  

<table>
<thead>
<tr>
<th>Things to keep in mind when answering questions below:</th>
<th>Green</th>
<th>Orange</th>
<th>Pink</th>
<th>Red</th>
</tr>
</thead>
</table>
| Do you have the service on site?  
If not on site, do your community members have access to services off site?  
Is there an active, functioning referral process?  
Are services accessible and provided with adequate access, easy to reach? | Access/availability is good/acceptable | Access/availability is there, but with quality issues needing improvement | Service gap: insufficient service or capacity or limited access | Service gap: no service in the community or accessible |

### Questions

<table>
<thead>
<tr>
<th>Questions</th>
<th>Check as appropriate: ✓</th>
<th>Comment Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Do your community members have access to contraception (other than condoms)?</td>
<td>✓</td>
<td>Community Health Nurse comes to clinic one day each week. Gap: need more hours on site.</td>
</tr>
<tr>
<td>Has your community participated in any HIV stigma reduction activities (i.e. AIDS Walk, Around Kitchen Table, community HIV education event/health</td>
<td>1</td>
<td>2 individuals came previously - not health care professionals; should be done door to door, one on one meetings - more personal and confidential; community tells us what they need</td>
</tr>
<tr>
<td>Do your community members have access to HIV prevention information materials?</td>
<td>1</td>
<td>written materials are ineffective as there are literacy issues - photos more appropriate - engage the community members via photo novella - photo voice</td>
</tr>
<tr>
<td>Do you incorporate traditional cultural practices (TCP) into your HIV program?</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Do you provide any formal HIV education for your community?</td>
<td>1</td>
<td>some education - health days</td>
</tr>
<tr>
<td>Do your community members have access to peer-based programs for HIV prevention or support?</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Do you have condoms to distribute to clients at your institution/health centre in your community and/or First Nations community?</td>
<td>1</td>
<td>distribution is limited; health canada supplies limited kind; improvement needed</td>
</tr>
<tr>
<td>Do your community members have access to HIV post-exposure prophylaxis (i.e. after sexual assault or needle stick/occupational exposure)?</td>
<td>1</td>
<td>extremely limited - people don't disclose - confidentiality issues</td>
</tr>
<tr>
<td>Do you have a needle and syringe exchange program at your health centre/in your First Nations community?</td>
<td>1</td>
<td>confidentiality issues pose problems</td>
</tr>
<tr>
<td>Do your community members have access to Mental Health &amp; Addiction services (counselling, detox, treatment)?</td>
<td>1</td>
<td>2 workers for entire nation - need more</td>
</tr>
</tbody>
</table>

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**northern health**  
*the northern way of caring*
List of Invitees and ES Scan Participants

1. NH Health Services Administrator
2. NI NHA Rural Public Health
3. NH Public Health Nurse
4. Tachie First Nation
5. Mental Health & Addictions
6. Nak’azdli Health Center Health Nurses
7. Yekochee First Nation Health Nurse
8. Fire Weed Safe House
9. NH Fort St. James Home Care Nurse
10. Stuart Lake Hospital - Head Nurse
11. Nezul Be Hunuyeh Child and Family Services Society Manager
12. Nak’azdli Health Center NP
Community Engagement Invite and Agenda

Lakes District Community Focus Group

Follow up Meeting

HIV/Hep C Impacts EVERYONE
Partnership for Healthier Communities

We value your input as we work collaboratively to enhance and develop HIV/Hep C & Harm Reduction services

Community Focus Group
Chamber of Commerce – Heritage Room
9 October 2014
1:00pm – 3:00pm
Please join us in a public forum for further information contact:
250.565.7398
Or e-mail Trish at Patricia.howard@northernhealth.ca

Lakes District Community Focus Group
Follow Up Meeting Agenda:

Thursday 9th October 2014
Chamber of Commerce Building 1:00 - 3:00

1:00 Welcome and Opening prayer
1:05 ice breaker and Introductions
1:30 Review notes from August 12 meeting
1:45 Action Planning - Team charter and vision
2:45 Wrap up – challenges and TOR – Next Steps
3:00 Adjourn

First item on the agenda for our upcoming meeting:
Sex:

your3cards.com
Q8 Do you have a needle and syringe exchange program at your health center/in your FN Community?

**Lakes District**
- Access/availability is good/acceptable: 5
- Access/availability is there, but with quality issues needing improvement: 1
- Service gap: insufficient service or capacity or limited access: 2
- Service gap: no service in the community or accessible: 1
- Unknown: 1

**Ft. St. James**
- Access/availability is good/acceptable: 6
- Access/availability is there, but with quality issues needing improvement: 2
- Service gap: insufficient service or capacity or limited access: 2
- Service gap: no service in the community or accessible: 1
- Unknown: 1
Q12 Do you have a process for confirmatory HIV testing and linkage to care and treatment if you diagnose someone at your site?

Lakes District

- Access/ availability is good/ acceptable: 1
- Access/ availability is there, but with quality issues needing improvement: 1
- Service gap: insufficient service or capacity or limited access: 1
- Service gap: no service in the community or accessible: 6
- Unknown: 1

Ft. St. James

- Access/ availability is good/ acceptable: 1
- Access/ availability is there, but with quality issues needing improvement: 1
- Service gap: insufficient service or capacity or limited access: 2
- Service gap: no service in the community or accessible: 4
- Unknown: 1

*the northern way of caring*
Q11 Do you offer point of care (POC) rapid HIV testing at your institution / health centre/in your community and/or FN community

- **Ft. St. James**
  - Access/availability is good/acceptable: 5
  - Access/availability is there, but with quality issues needing improvement: 3
  - Service gap: insufficient service or capacity or limited access: 2
  - Service gap: no service in the community or accessible: 1

- **Lakes District**
  - Access/availability is good/acceptable: 8
  - Access/availability is there, but with quality issues needing improvement: 1
  - Service gap: insufficient service or capacity or limited access: 1
  - Service gap: no service in the community or accessible: 1

- **Ft. St James Aboriginal Specific**
  - Access/availability is good/acceptable: 3
  - Access/availability is there, but with quality issues needing improvement: 1
  - Service gap: insufficient service or capacity or limited access: 1
  - Service gap: no service in the community or accessible: 1

- **Lakes District Aboriginal Specific**
  - Access/availability is good/acceptable: 6
  - Access/availability is there, but with quality issues needing improvement: 6
  - Service gap: insufficient service or capacity or limited access: 6
  - Service gap: no service in the community or accessible: 6
Community Engagement - Focus Groups
Community Forum Goals

Top 3 goals:

1. *Education and Relationship Building*
   - *Incorporating consistent message*

2. *Asset Map*
   - *Resource guide*

3. *Determine what do clients need?*
   - *Consent with mapping*
Next steps: Partner Education/Training

Two sessions:
Specific pathway/ process map

Community education with BBP training

- How do we support clients?
  - Mapping

- Identify community champions
  - Including physicians/specialists

- Process pathway developed
  - “What to expect when you receive diagnosis”
Thank you - Questions?

"Is there one thing that you think service providers or anybody needs to know about your journey? Just that I'm hopeful that things do change, in the system."

(KI 26-11-2012-01)

Any questions please contact: Patricia.Howard@northernhealth.ca