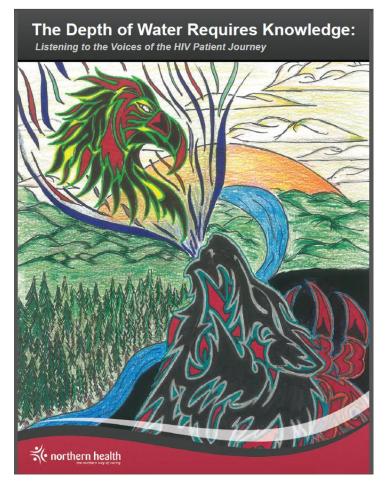
The Depth of Water Requires Knowledge: Listening to the Voices of the HIV Patient Journey





Innovation and Development Commons

Brown Bag Lunch 27 November 2014 Patricia Howard, MA



Agenda

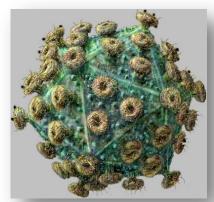
- o What is HIV?
- STOP HIV Pilot and From Hope to Health
- BC HIV Statistics
- Acknowledgements
- Purpose of PJM
- Background
- Methodology
- The River Journey
- Introduction of Report
- Discussion of Findings
- Recommendations
- Next Steps





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

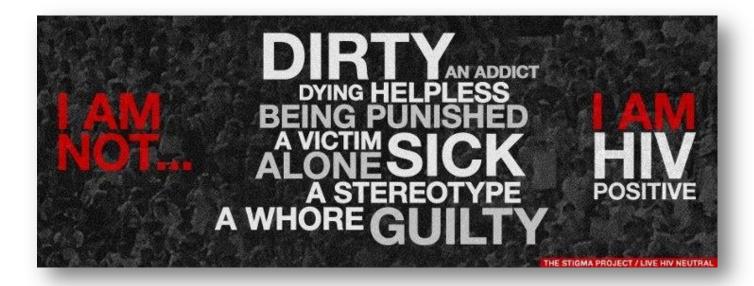






HIV and Silence

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

northern 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

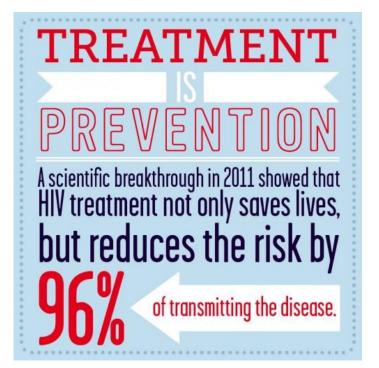
In BC there are approximately 12,000 people living with HIV

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)





Acknowledgements



Patricia Howard, MA Principle Researcher



Dr. Tina Fraser, PhD Collaborating Research Support



Dr. Theresa Healy, PhD Collaborating Research Support



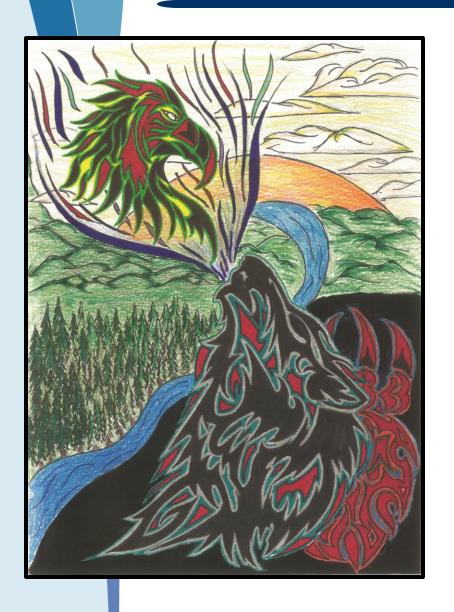
Bareilly Sweet, MEd Collaborating Research Support

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

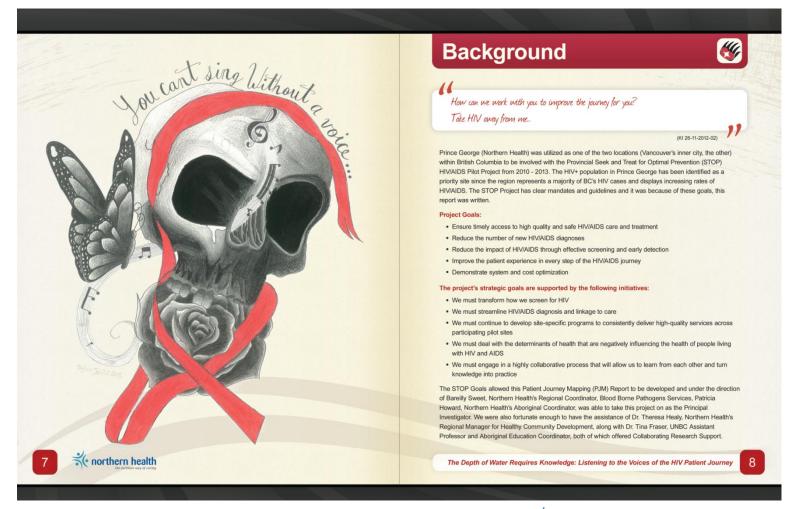


Improve the patient experience in every step of the HIV/AIDS journey

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

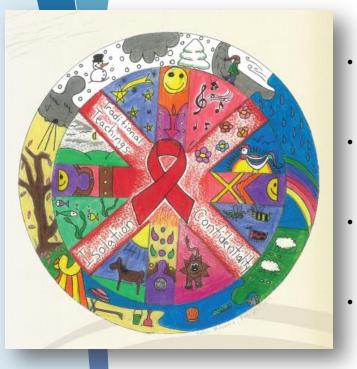


Background





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



I am all alone





I know what my body needs too



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



Introduction of Report

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 Im 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 5 themes and xx subthemes. Our second cut enabled us to condense and synthesis 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 engage in the health care system and be heard. There were also experiences that were "dangerous blood.

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 related to how they were treated, and which also highlighted the implications and outcomes

You're a junkie you always will be. That's what their esaying.

Some implications and outcomes reported in the subthemes were: lack of compassion, 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 feel 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 their just you can sense it you know.

northern health

Stay away from her - shes got AIDS

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

. You can only talk about one thing to the doctor

He said that's something we'd get into at another time

(KI 26-11-2012-01)

appointment told to come back next . You have to wait to see the doctor, long beyond the appointed time, with no recognition of the cost to the HIV patient (rides that are no longer available, meals that were skipped, medication regimes that have been disrupted, other appointments they have.)

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 theire 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 bit better.

(KI 26-11-2012-01)

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

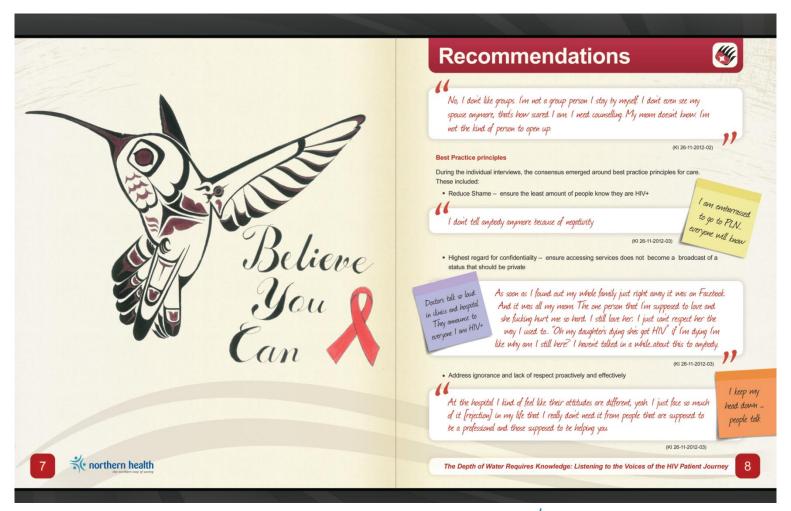
They fast track you once you're in there. Once you see the doctor or whatever they fast track you, they don't ask you proper questions. I don't see results that I want to see _I want to see what's going on with my blood work I didn't get to see that, that was just rather broke my little heart. Cuz, I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

(KI 26-11-2012-01)

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

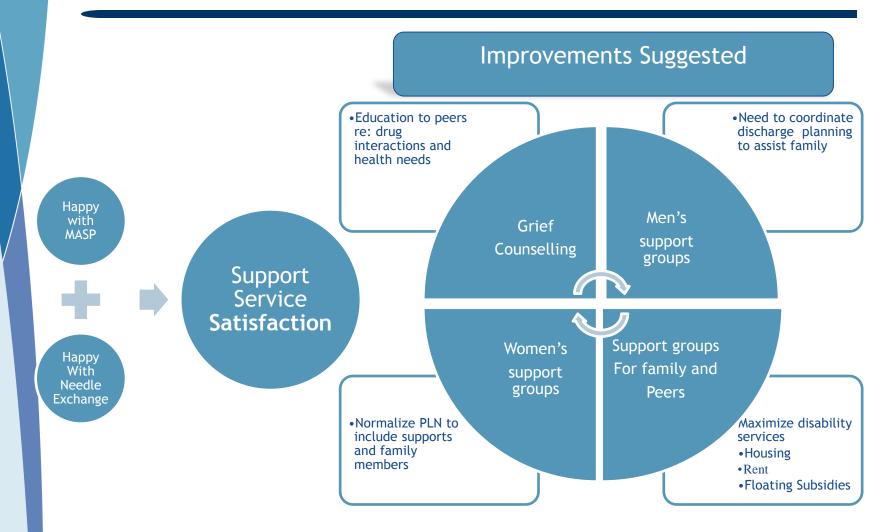


Recommendations



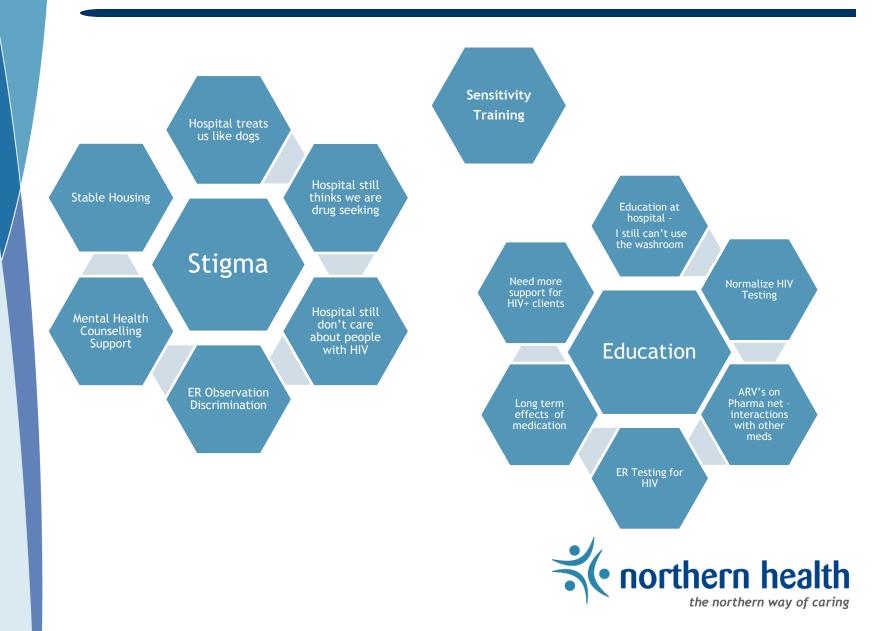


Themes from 6 January 2014 follow up





Themes from 6 January 2014 follow up



Knowledge to Action - Top Three Priorities

Improvements, there's always room for improvement.

(KI 12-12-12-05)



- 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



BBP Services: Activities

Recommended actions/outcomes from "Depth of Water"

Promote testing in acute care

- 1. Develop interest
- 2. Initial training
- 3. Ongoing support

Community engagement

- 1. Environmental Scan
- 2. Community Forum
- 3. Ongoing support for community plan tailored to local needs
- & resources

Training for NH health care providers

Normalization of testing

Partner with MH&A & Ministry of Social Development at policy and service delivery levels

Support Partners'
Groups in PG & other
communities

Training for community health care providers

Specialist & Pharmacist Support

MASP (PG)

Address ignorance & lack of respect among health care providers

Protect confidentiality

Improve communication & understanding around treatment delays or difficulties

Invest in treatment services

Commit resources to address social determinants of health:

- -Housing
- -Food security
- -Life skills
- -income

Ensure well-resourced diverse & culturally appropriate ancillary services

Support patient's self-advocacy & self-care

NH Peer Advisory Council

Reduced shame, stigma & discrimination of HIV+ individuals

- -Reduced wait time for doctor
- -Promised services are actually in place
- -Internal & external outreach

Accessible, well-resourced, diverse & culturally appropriate ancillary support services

orthern health

Blood Borne Pathogens Services Team

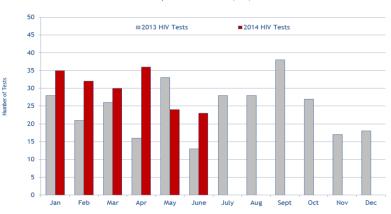


Peer Nominated Innovation Award October 2014
HIV Continuum of Care Collaborative



Regional Testing Initiative - Jan 2014



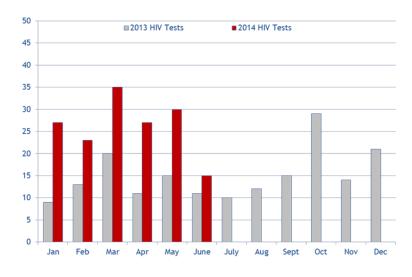


- Prince George
- Vanderhoof
- Ft. St. James
- Fraser Lake
- Lakes District

Next:

- Quesnel
- Mackenzie
- McBride
- Valemount

Comparison of Monthly HIV Test Volumes Stuart Lake Hospital 2013 and 2014 (YTD)





Tools & Resources: Integration for Wrap around Services



Patient information—Routine HIV testing at UHNBC

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.

An 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 vitat 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.

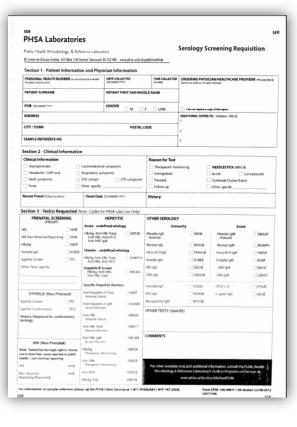
HIV can lead to Acquired Immunodeficiency Syndrome (AIDS) if you are not treated with anti-HIV medication.

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.

HIV is a 'reportable' infection. This means that positive test results are sent to the Medical Health Officer, who is a public health doctor, and an HIV Designate Nurse, who are responsible for the care of people who may have been exposed to HIV. The role of the HIV Designate Nurse is to offer you completely confidential nursing support.

You have the right to refuse to be tested for HIV.





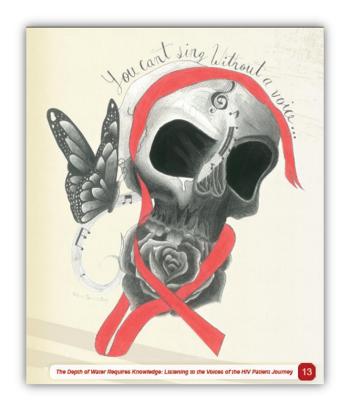
Jniversity Hospital of Northern British Columbia HIV Testing Admission Orders							
Allergies: None known Unable to obtain List with reactions:							
tate: Time:							
Admission Instructions	Time Processed RN/LPN Initials Comments						
Offered for all adult patients admitted to acute care. * Consider offering Hepatitis Test in conjunction with HIV test.*							
Patient has consented to HIV Test Yes - HIV antibody test with next bloodwork							
If no, state reason:							
Follow-up for Positive Test Results f patient requires further support around pre or post counsel, please call in this order:							
NIHU Public Health HIV Designate Nurse: 778-349-2793 & Alternate (Mon - Fri)							
Communicable Disease Team Nurses On Call Line: 250-565-7363 (Mon - Fri)							
AIDS Prevention Program: 250-53-1727 (1300 - 1900, Mon - Sun)							
Wellness Van Nurse: 250-960-9777 (1900 - 2300, Mon - Sun)							



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

C	ommunity Name:			(Contact	Name: Date:
	Things to keep in mind when answering questions below: •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	Orange Access/ availability is there, but with quality issues needing improveme nt	I	Service gap: no service in the community or accessible	
	Questions	Check as appropriate: √			2: √	Comment Section
	Example: Do your community members have access to contraception (other than condoms)?			٧		Community Health Nurse comes to clinic one day each week. Gap: need more hours on site.
G	Has your community participated in any HIV stigma reduction activities (i.e. AIDS Walk, Around Kitchen Table, community HIV education event/health			1		2 individuals came previously - not health care professionals; should be done door to door, one on one meeetings - more personal and confidential; community tells us what they need
Q	Do your community members have access to HIV prevention information materials?		1			written materials are ineffective as there are literacy issues - photos more appropriate - engage the community members via photo novella - photo voice
Q	(TCP) into your HIV program?				1	
Q	community?			1		some education - health days
Q	based programs for HIV prevention or support?			1		
Q	Do you have condoms to distribute to clients at your insitution / health centre/in your community and/or First Nations community?		1			distribution is limited; health canada supplies limited kind; improvement needed
Q	Do your community members have access to HIV post exposure prophylaxis (i.e. after sexual assault or needle stick/occupational exposure)?			1		extremely limited - people don't disclose - confidentiality issues
Q	Do you have a needle and syringe exchange program at your health centre/in your First Nations community?				1	confidentiality isssues pose problems
6				1		2 workers for entire nation - need more



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@northernheath.ca



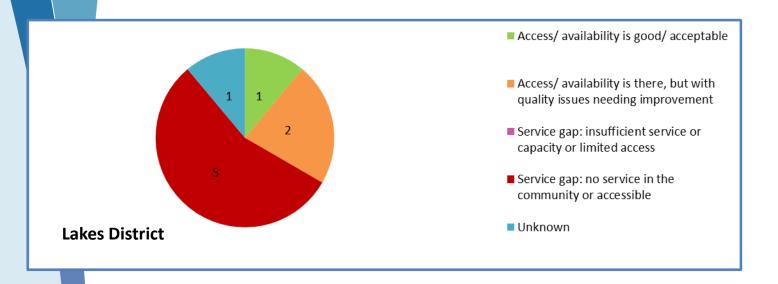
Lakes District Community Focus Group Follow Up Meeting Agenda:

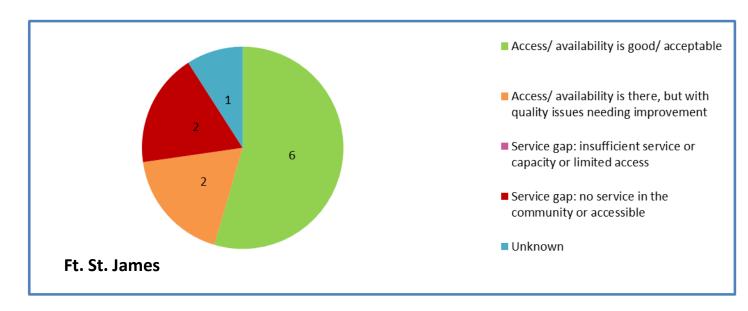
Thursday 9th October 2014 Chamber of Commerce Building 1:00 - 3:00

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

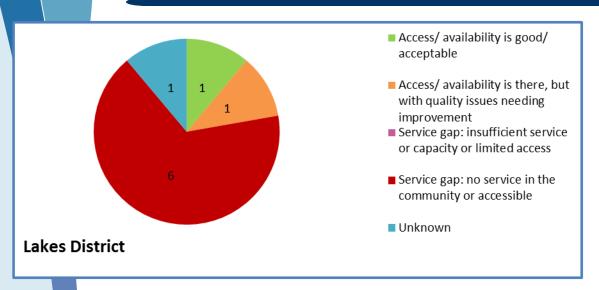


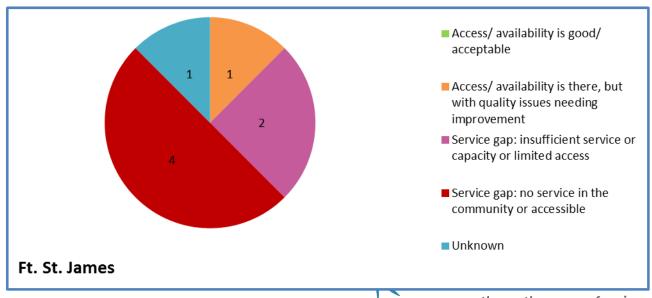
Q8 Do you have a needle and syringe exchange program at your health center/in your FN Community?



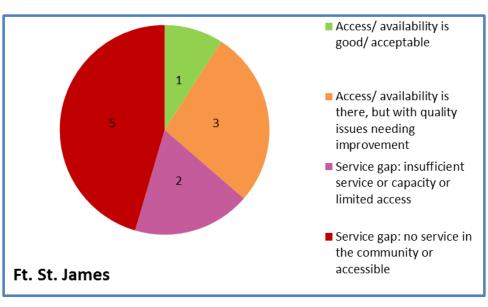


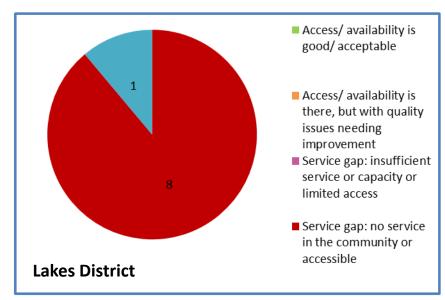
Q12 Do you have a process for confirmatory HIV testing and linkage to care and treatment if you diagnose someone at your site?

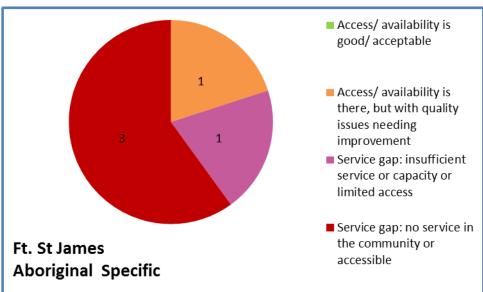


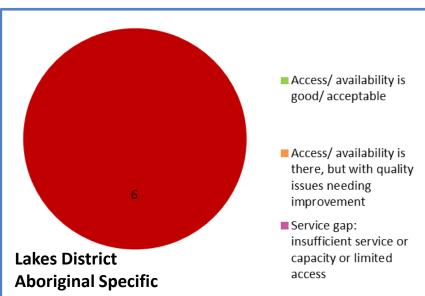


Q11 Do you offer point of care (POC) rapid HIV testing at your institution / health centre/in your community and/or FN community









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





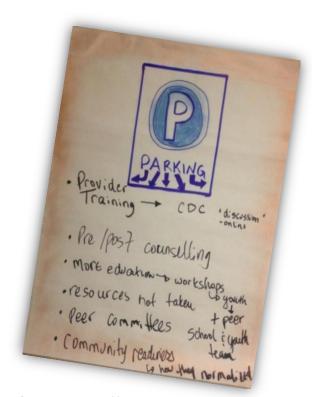
Next steps: Partner Education/Training

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 (m hopeful that things do change, in the system.

(KI 26-11-2012-01)



the northern way of caring



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