

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



Patient Journey Mapping Moving Mountains: Research in the North

2 May 2014
Patricia Howard

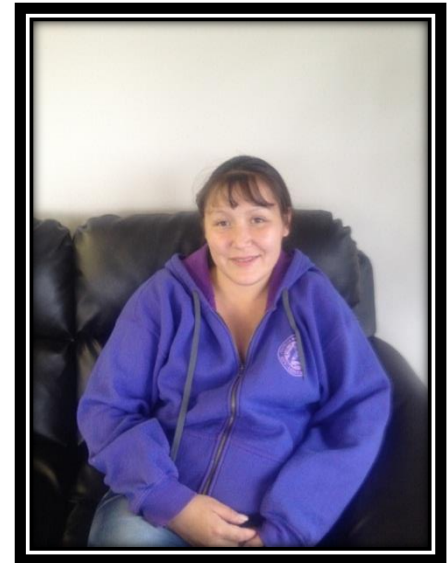
Blood Borne Pathogens Services Team



Acknowledgements

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Patricia Howard, MA
Principle Researcher

Bareilly Sweet, MEd
Collaborating Research Support

Dr. Theresa Healy, PhD
Collaborating Research Support

Dr. Tina Fraser, PhD
Collaborating Research Support



northern health
the northern way of caring

Background -STOP HIV Pilot Project Goals

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



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



ARV Stats

June 2013 FN only ARV Stats

BC - on ARVs

705/6403 (11% Aboriginal)

705/837 (84% on treatment)

NH Region

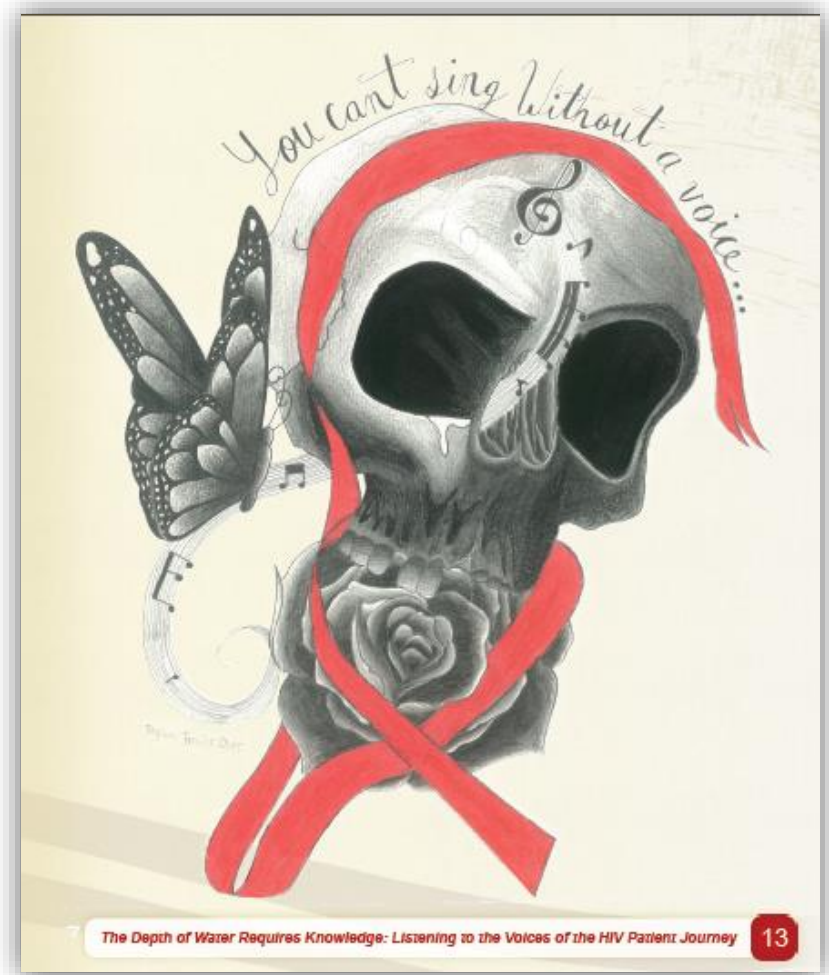
85/248 are alive (35% Aboriginal)

73/180 on ARVs (41% Aboriginal)

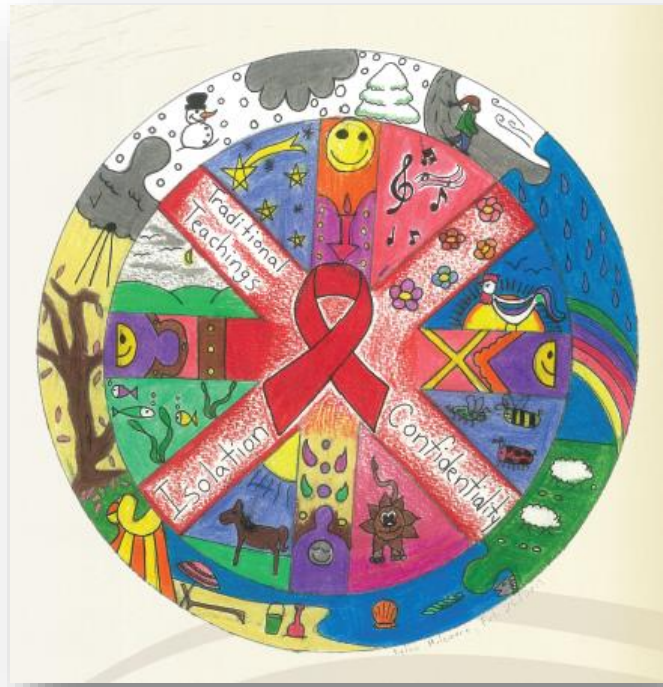
73/85 (86% on treatment)

NI Region

45/49 (92% on treatment)



Process for Completion of Needs Assessment



- Literature Review/Best Practices
- Engagement with ASO's to identify participants and share vision
- 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)

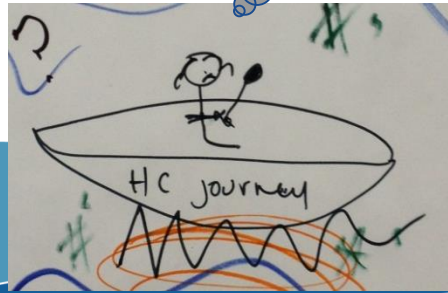
**19 people total living with and affected by HIV
84% Aboriginal representation**



The River



I am all alone



I know what my body needs too



General Feedback From Engagement

I am tired of hearing I am a junkie

Lowered capacity in spiritual, cultural and mental health

- Patients/clients feel unimportant, lonely, uncared for, and angry.

And I just feel like one of those people that is starting to fall between the cracks type of thing, you know?

(KI 26-11-12-01)



- Recognition that resource and advocacy needs impact an individual
 - housing
 - food security
 - income security
 - education
- Themes identified from consumer engagement align with literature and key informant feedback



Themes from Engagement

“ But they need to understand me, where I'm coming from. Cuz I'm the one who's positive and they're not. They don't live inside me, I do. ”

(KI 12-12-12-05)

Theme	Description of Gap
1. Access to HIV knowledgeable and culturally competent providers and staff	<ul style="list-style-type: none">• Finding HIV knowledgeable providers who are culturally appropriate• Need more Aboriginal liaison workers/advocates
2. General awareness of Services	<ul style="list-style-type: none">• Not all providers or clients are aware of Services or how to access• Address Social Determinants of Health
3. Access to Peer Services	<ul style="list-style-type: none">• Include us - part of Positive Prevention Group• Keep us educated and informed

Themes from Engagement

“
*I've been in my body [xx] years, okay? I know when something is wrong...
don't put me in a box and say, 'Well, no, it can't be this because this is
what the book says...'*

*I need to have a
say in my care*

(KI 26-11-2012-01)

Theme	Description of Gap
4. Mentorship opportunities for long term survivors	<ul style="list-style-type: none">• Mentoring of newly dx individuals• Access to individuals who are HIV + and have a positive outlook• Mentorship as part of healing journey
5. HIV education opportunities	<ul style="list-style-type: none">• Education needs to reflect reality of today's epidemic and the challenges HIV + individuals are facing:<ul style="list-style-type: none">• HIV and aging• Disclosure• Criminalization• Understanding blood results etc.• Medication adherence and interactions

Themes from Engagement

I keep my head
down - people
talk

At the hospital I kind of feel like their attitudes are different, yeah. I just face so much of it [rejection] 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.

(KI 26-11-2012-01)



6. Stigma

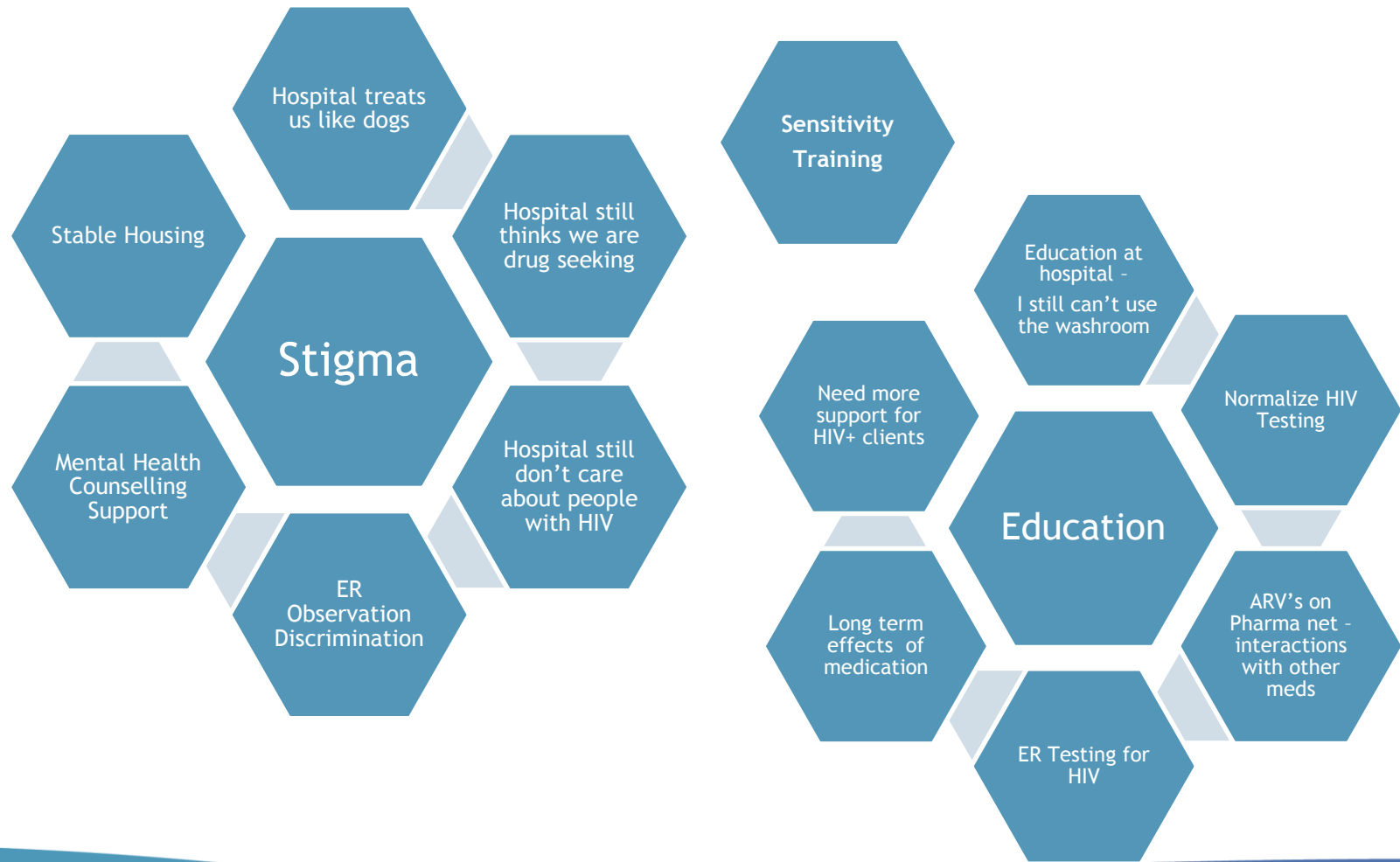
- Remains a significant issue
 - Need for positive sexual messaging
 - Need to look at cultural issues
 - Desire to start to decrease stigma by dealing with it internally
 - Identity formation
 - Confidentiality
 - Sensitivity training

7. Access to Mental Health and Addictions Screening Tools and Support

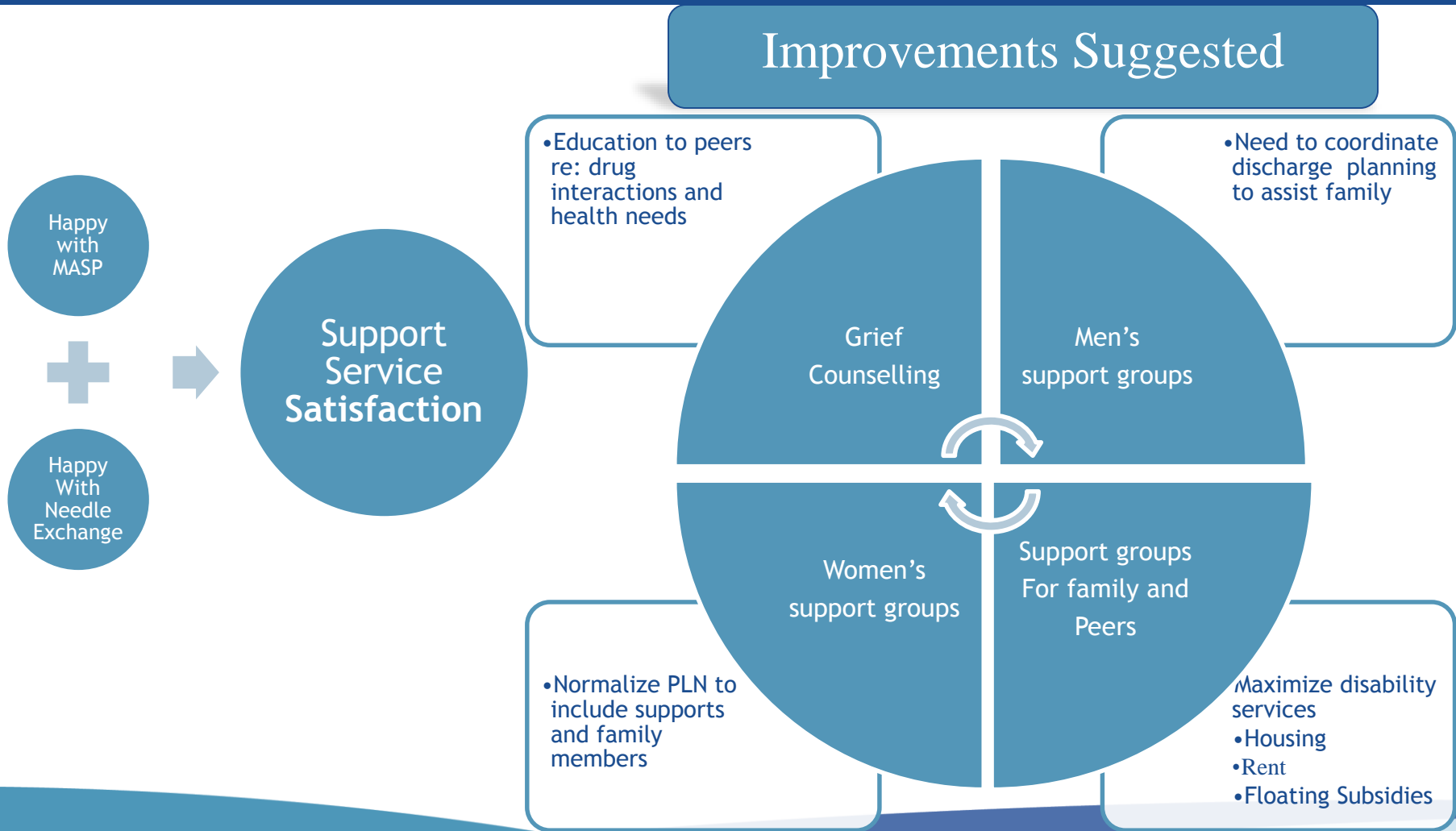
- Long standing issue
- Need to recognize the link between HIV and depression



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 within NH programs
2. Reduce community risk and build community capacity
3. Improve the experience for those living with and affected by HIV



Key Message: Nothing about us - without us

“*And as soon as they found out I was HIV-positive it's just like, everybody didn't even want to come near me, not even the nurses. I was just like what the hell is up with this, like, you know. I'm trying to live a life, I work. I make my own money and all of sudden society just turns their back on me.*”

How can things improve if the health care providers are not listening to me

(KI 26-11-2012-04)

Avoid stereotypes and assumptions!

Full report available on our HIV101.ca website

Any questions please contact:

Patricia.Howard@northernhealth.ca



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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)

