



Visioning Health II

Shifting the Narrative: A Health-Focused Approach to Research with HIV-Positive Indigenous Women Across Canada

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Presenters



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Introduction / Opening

- Land Acknowledgement
- Opening Prayer
- VH Women who have gone before



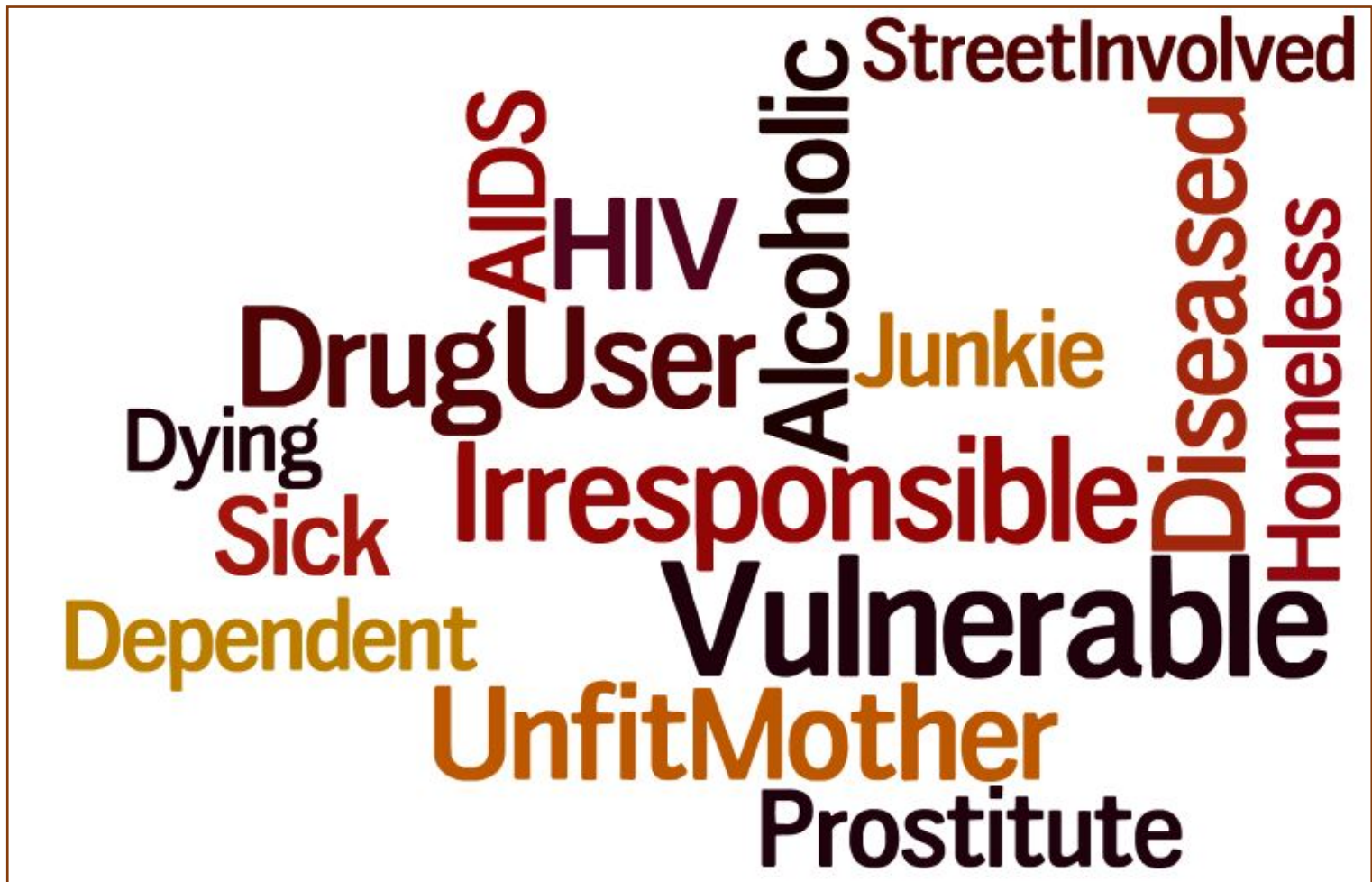
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- **Research Team:** Tracey Prentice, Doris Peltier, Charlotte Loppie, Renee Masching, Cathy Worthington, Randy Jackson, Mona Loutfy, Denise Spitzer, Alex Wilson, Kim McKay-MacNabb.

Why Visioning Health?

A Pathogenic Perspective



Why Visioning Health?

The *way* researchers acquire knowledge in indigenous communities may be as critical for eliminating health disparities as the actual knowledge that is gained about a particular health problem (Cochrane et al. 2008, p.22)



Visioning Health II - Background

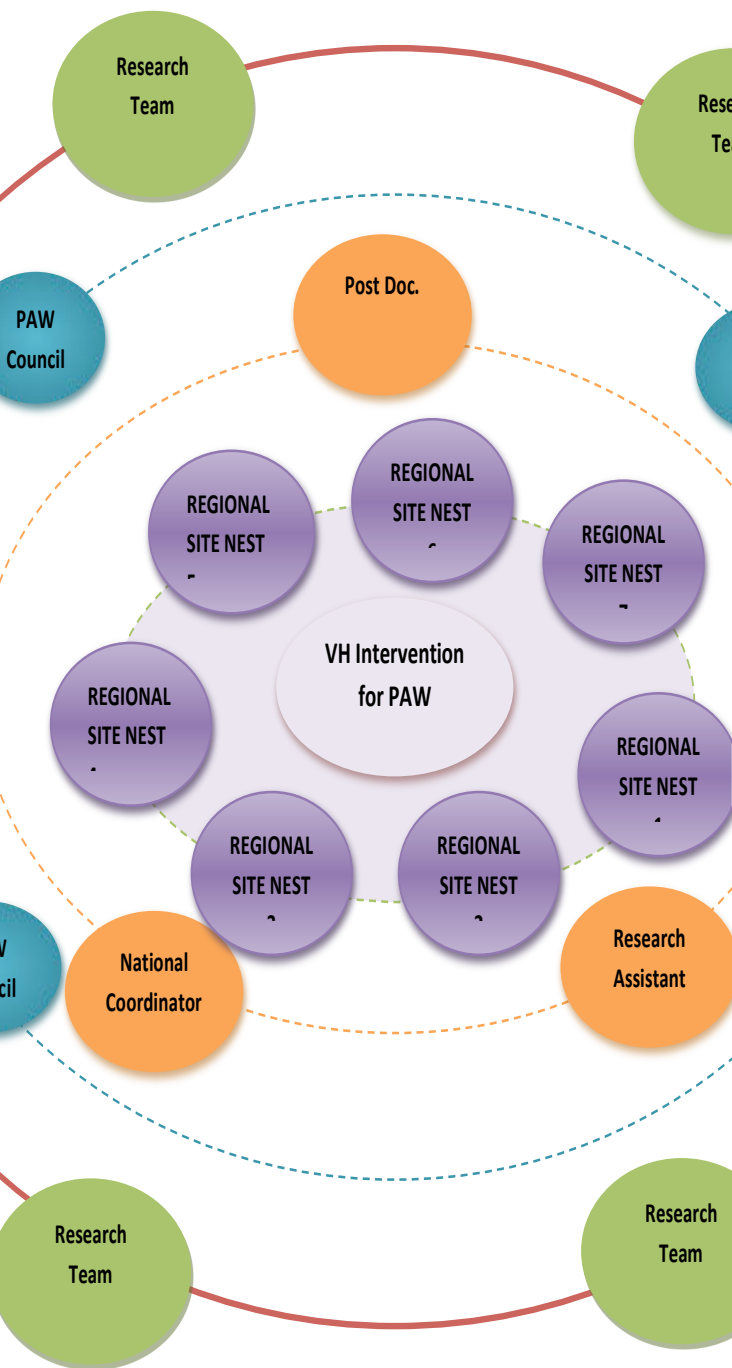
- Emerged from VH I pilot study (health, culture, gender; n= 13)
- Findings indicated that research can be healing for participants, when done with attention to:
 - ✓ MEIWA
 - ✓ Strengths
 - ✓ Indigenous knowledges
 - ✓ Cultural traditions
 - ✓ Ceremony
- Request from community to develop national study with even *greater emphasis on MEIWA*
- Inclusion of quantitative tools



Visioning Health II

VH as **nested** intervention study (Funded 2015)
with **2 goals**:

1. To co-create new knowledge about the meaning of health and how it intersects with gender and culture for ~70-90 HIV+ Indigenous women from across Canada.
2. To develop and assess the VH Model as a health intervention for Indigenous women living with HIV – *with leadership by Indigenous women living with HIV.*
 - Research team members, Women's council, CRCs/CRAAs, Peer Mentors
 - Mixed methods



Study Design

- Group research process: culturally-grounded, strengths-based, arts-informed, women-centred, CBPR
- 8 sites across Canada
 - Regional Teams – CRC, Elder/KC, Community Partner, Researcher
- 2 engagement styles
- Assessment and Evaluation
- Culture as intervention



VH II Model

- Group Orientation
- *Demo, VH Wellness Questionnaire (T1)*
- Sharing Circle #1 – Health, Culture, Gender
- Art-Making
 - hand drums, birch bark baskets, regalia dolls, medicine bundle items, recycled or upcycled Art Box, tapestry
- Sharing Circle#2 – Meaning of Artwork
- Art Narrative
- *VH Wellness Questionnaire (T2)*
- *Evaluation Surveys/*Sharing Circle
- Celebrate
- *Three-Month Follow-Up (T3)*

VH II REGIONAL TEAMS TRAINING 1 & 2





Retreat-Style

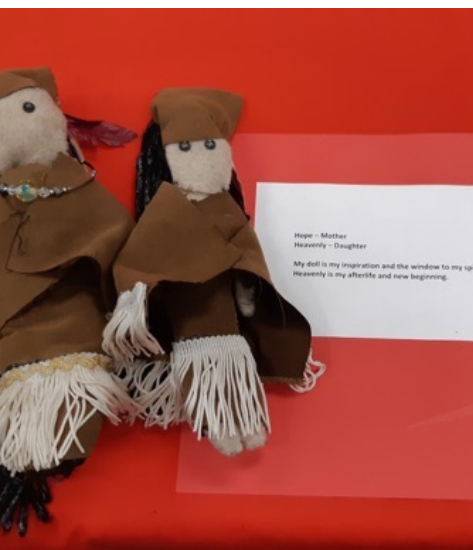
- 5-day retreat; on the land
- **TB** = Art boxes, homecoming; **BC** = birch bark baskets, letting go; **SKN** = talking sticks, water ceremony; **AB** = capotes & drums, fashion show
- I feel like every essence of my being from within has been touched. ... I just feel like I'm taking a lot with me, and I feel like I even grew taller. I know I probably didn't, but I feel taller. **I feel stronger and I feel ready for what I have to face at home.**





Extended Engagement

- 9-week extended engagement style; urban centre
- **RG** = Medicine bundles, Sweatlodge, Spirit Names and Colours; **TO** = Regalia dolls, Spirit Names and Jingle Dress
- **The best thing that could have happened to me is when you came forward and asked me if I'd be interested. It got me off the drugs. It really did. I had something to look forward to, so, no, I was happy. I was real happy.**



Huge - Mother
Heavenly - Daughter
My doll is my inspiration and the window to my spirit
Heavenly is my afterlife and new beginning



Mixed Models

- Combination of both models
- **WPG** = 1.5 day orientation retreat + extended engagement; Medicine bundles, Sweatlodge, Spirit Names
- **MTL** = Urban retreat + day trips; Water ceremony, Bingo, Country Food, Throat singers
- it opened me up. Like I **never, in a million years, thought I would make a drum again. I didn't think I'd get connected back into the sweat lodge** and to, like—to participate in, like, making spiritual items that we can present to our families and our friends, and just to see how the women flourished



VH II Co-Researchers (8 sites)

○ **67 women**

- 54 FN, 7M, 6I, 1O
- 63 F, 4T, 1M
- 24-70 yrs
- 1-34 yrs diagnosed
- 66 engaged in care
- 24 used traditional medicine
- 40 used ceremony

- 52 no partner/spouse
- 48 had children, 21 at home
- 60 always or often have difficulty making ends meet
- 53 adequately housed, 45 Urban Centre; 9 Northern City/Town ; 9 Other Town; 6 Rural/On-Reserve

VISIONING HEALTH II WELLNESS QUESTIONNAIRE

COMPLETED: _____ UNIQUE IDENTIFIER: _____

This is the third time we are asking you to complete this questionnaire once at the beginning of the project. Now we are at the end of the project and are asking you to do it again as a way of measuring any impact that you may or may not have had in your life. When answering the following questions, please think about your experience of participating in Visioning Health. Please remember there are no right or wrong answers.

Following pages contain three sets of statements. Please rate how much you personally agree with these statements. Your first thought or impression is usually the best.

When we begin, we use the term Indigenous to refer to those who identify as First Nations. Some people prefer to use the term Aboriginal, or Native. What term would you like to use?

CONNECTEDNESS

This first set of questions asks about feelings of 'connectedness'. Indigenous worldviews see 'connectedness' as an essential part of holistic health, which includes physical, mental, emotional, and spiritual wellbeing. Connectedness refers to feelings of belonging, or closeness. Some people experience these feelings of connectedness, while others have not.

Please CIRCLE the number that corresponds to your answer. Please use the 'I don't know' options only when necessary.

1. Connectedness – Self

This set of questions asks about your feelings of connectedness to yourself. By 'self' we mean everything that makes you 'you': your thoughts, your emotions, your body, your spirit.

	never	not very often	sometimes
e) I feel connected to myself.	1	2	3
f) I believe in myself.	1	2	3
g) I know how to care for myself.	1	2	3
h) I believe that by helping others I help myself.	1	2	3

1.2 Connectedness – Peers

This set of questions asks about your feelings of connectedness to your peers. Please remember that by Indigenous, we mean HIV-positive Indigenous women or non-status.

VH II Wellness Questionnaire

- VH II team worked together to develop a set of questions based on pre-existing survey tools that have been developed for or adapted to Indigenous worldviews
 - Connectedness** – to Self (4Qs), Peers (4Qs), Family (4Qs), HIV Community (5Qs), Home Community (5Qs), Culture (4Qs), Creator (6Qs), Nature (4Qs) – 36Qs total
 - Self-Determination (Mastery)**, coping with life's challenges) – Self (5Qs), Peers (5Qs), Friends (5Qs), Family (5Qs), HIV Community (5Qs), Home Community (5Qs) – 30Qs total
 - Social Support** – Emotional/Informational (3Qs), Tangible (3Qs), Social Interaction (1Q) – 7Qs total
- These questions (Qs) make up the **scales** and their **sub-scales**

Connectedness - Changes over Time (n=59)

	N at T2	T1-T2	T1-T3
Overall Connectedness	15 women	p=0.18	p=0.03
– Self	51 women	p=0.01	p=0.02
- Peers	47 women	p<0.001	p<0.001
- Family	48 women	p=0.16	p=0.08
– HIV Community	39 women	p=0.02	p=0.06
- Home Community	42 women	p=0.02	p<0.001
- Culture	55 women	p<0.001	p<0.001
- Creator	36 women	p=0.004	p=0.03
- Nature / Land	48 women	p=0.02	p=0.02

- N is the sample size at time 2; sample size at time 3 not shown
- 'statistically significant': $p \leq 0.05$



Connectedness

To Self

- I feel more at peace with myself, and other than that hopeful for the future for myself, and where I really want to go.

To Peers

- I thought I was the only one in the community who had HIV... I always thought I was alone.

To Culture

- It's changed me, looking at my culture different. Definitely. I haven't...like I've been raised in the churches so you know, it's really opened my mind to, you know, my culture.

Self-Determination- Changes over Time (n=59)

	N at T2	T1-T2	T1-T3
Overall Self-Determination	34 women	p=0.04	p=0.17
- Self	48 women	p=0.23	p=0.09
- Peers	46 women	p=0.002	p=0.02
- Friends	45 women	p=0.09	p=0.61
- Family	50 women	p=0.12	p=0.91
– HIV Community	46 women	p=0.03	p=0.26
- Home Community	45 women	p=0.02	p=0.03

- N is the sample size at time 2; sample size at time 3 not shown
 - 'statistically significant': $p \leq 0.05$



Self-Determination- Changes over Time

It made me feel alive. I can do
anything else. That's how it made me
feel to do this kind of work

Social Support – Changes over Time (n=59)

	N at T2	T1-T2	T1-T3
Overall Social Support	45 women	p=0.05	p=0.04
Emotional/ Informational	51 women	p=0.05	p=0.009
Tangible	48 women	p=0.02	p=0.07

- N is the sample size at time 2; sample size at time 3 not shown
 - 'statistically significant': $p \leq 0.05$



Social Support – Changes over Time

... when you first find out, you're diagnosed, you're by yourself, you're locked up, you're all alone. And **by attending a group like this, it's able to open up everybody's eyes and hearts. And knowing that you're not the only one out there undergoing that, there is a way to get through this.** And you've got... you know, somebody... somebody's hand to hold on to, instead of trying to hold on to your own.



Evaluation

Overwhelmingly positive

- This group is the best thing that's happened to me
- I wish it would never end
- I wish there were more programs like this.
- I feel like every essence of my being from within has been touched. And I don't want to cry [tearful and emotional] in saying that. I just feel like I'm taking a lot with me, and I feel like I even grew taller. I know I probably didn't, but I feel taller. **I feel stronger and I feel ready for what I have to face at home.**

Health for HIV+ Indigenous Women (N=67)





Outcomes

Support

- National network of Positive Indigenous Women
- Cadre of Knowledge Carriers who can work in this area
- In most cases women are connected locally to services

Building Capacity

- Stepping-stone for many women to other work / jobs / goals



Challenges

Logistics

- meeting space, timing, length of time
- compensation for CRCs / peer mentors

• On-Going Engagement

- Limited mechanisms for on-going support/engagement of co-researchers/participants in each region

*The only time we get to see each other
is places like this*

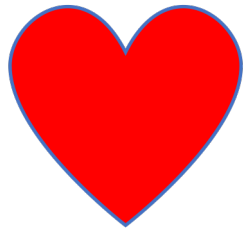


Learnings to Date

- When we create opportunities for women to come together in meaningful ways, in safe spaces, in ceremony, and in strengths, transformation occurs
- VH is working, i.e., having the effect that we hoped it would
 - Women feel stronger coming out of VH, more connected to themselves, to their peers, to culture, to Creator
 - Feel less alone / have more support
 - Leads to greater sense of self-mastery/self-determination

VH II REGINA





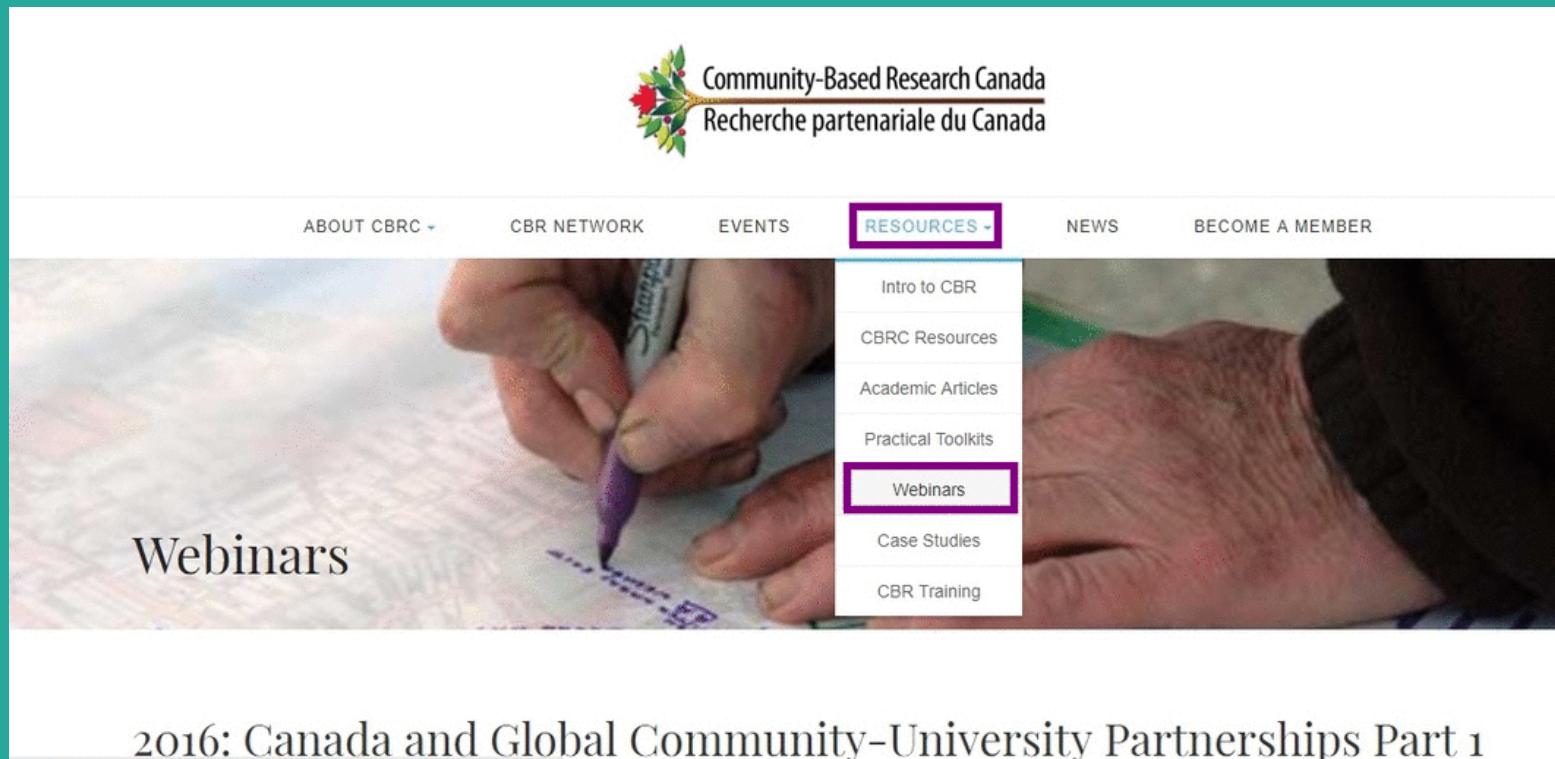
“Do I look taller?
I feel taller.”



Thank You / Miigwetch / Marsi



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