



UNIVERSITY
OF MANITOBA

ninecircles
COMMUNITY HEALTH CENTRE

HIV STIGMA & DISCRIMINATION IN MANITOBA

Stop Stigma Forum Summary Report

University of Manitoba & Nine Circles Community Health
Center

Date of report: June 26, 2017



Acknowledgement

Nine Circles Community Health Centre and the University of Manitoba would like to thank all those from across Manitoba who participated this Stop Stigma Forum, held at the West End Commons in Winnipeg, Manitoba on Wednesday, April 12th 2017.

Stop Stigma Forum 2017 Partner:

We would like to thank our valued partner, the Manitoba HIV program for their input, support and participation during the entire Stop Stigma Forum.



Stop Stigma Forum 2017 planning and implementation team:

Gayle Restall, Mike Payne, Stephanie Van Haute, Hanxiao Zhao, Ken Bristow, Laverne Gervais, Rick Lees, Albert McLeod, Helal Mohiuddin, Laurie Ringaert, Alexandria Simms and members of the HIV Stigma and Discrimination Research team

Stop Stigma Forum 2017 Financial Partner:

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Introduction

Stigma and discrimination are some of the biggest challenges for people living with HIV and can create barriers to HIV prevention, treatment, care and support. HIV-related stigma needs to be understood in the social and cultural context in which it occurs to effectively target and design appropriate interventions to improve the health, well-being and community participation of people living with HIV. However, there is very little known about the experiences of stigma and discrimination among people living with HIV in Manitoba.

The forum is the first phase of a project, “HIV Stigma and Discrimination in Manitoba” that uses a community based research approach. This approach values the views of people living with HIV in all stages of the research and as active research team members. The project also aims to adhere to the principle that the results of research will have the best chance of being used if the people who make decisions about programs, services and policies are involved from the beginning. The overall aim of the project is to build capacity to better understand and positively address the experiences of HIV-related stigma in Manitoba.

Stop Stigma Forum Goals

The goals for the forum were:

1. Develop a strong research partnership between communities affected by HIV, service providers, policy makers and researchers
2. Exchange diverse forms of knowledge about the experiences of stigma and discrimination
3. Develop future research and action to address the challenges of stigma and discrimination experienced by people living with HIV in Manitoba
4. Prioritize important issues to develop specific research questions and to implement the People Living with HIV Stigma Index.

Participants in the Forum

Forty-one (41) people attended the forum including people living with HIV (21), service providers (18), researchers (16), and policy makers (5), with some identifying in more than one category. The group included women (61%) and men (39%), a wide range of ages (27 to 61 years) with an average age of 47, and people from different cultural backgrounds (31% identified as Indigenous ethnicity). Participants identified their sexual orientation as heterosexual (59%), gay (17%), bisexual (17%), two-spirit (5%) and other (2%).

The Day

The Stop Stigma Forum was held at the West End Commons in Winnipeg, Manitoba and ran from 10:00am to 3:00pm. Mike Payne, the Executive Director of Nine Circle Community Health Centre, opened the day with a welcome message followed by reviewing the agenda. Albert McLeod, the Co-director of the Two-Spirited people of Manitoba Inc., welcomed the participants. Mike Payne covered the aims of the forum. Stephanie Van Haute facilitated introductions. Rick Lees, Executive Director of Main Street Project, provided the definition of stigma and outlined the importance of stopping stigma toward people living with HIV. Gayle Restall set the context of the day by introducing People Living with HIV Stigma Index Manitoba pilot study. The day was divided into two parts. The first

part included World Café¹ conversations. The second part involved identifying priority issues and actions through a process called dotmocracy².

World Café Conversations

A World Café format was used for the first part of group discussion. A World Café is a method of focusing on specific questions in an environment that encourages everyone's equal participation. A café area was set up which included six tables with chairs for seven to eight people. The tables were covered with brown paper and a tumbler that contained a variety of colorful writing instruments, and note-cards. Participants were encouraged to write down any comments or ideas on brown table paper. In total 159 comments and 'doodles' at the tables included the use of small sketches, connecting arrows, and the use of different colours, font style and size for emphasis of ideas.

We had three different questions on the café tables. The three questions were divided among the six tables. Over the course of an hour, people were encouraged to move to a new table with new people and a new question every 20 minutes. A table facilitator remained at the same table to welcome new people and summarize the previous discussion. The questions were:

1. When you think about HIV-related stigma and discrimination in Manitoba, what is the first thing comes to mind?
2. What are the effects of the experiences of stigma and discrimination on individuals and communities?
3. What actions related to reducing stigma and discrimination would make the most difference to people living with HIV in Manitoba? What strategies do you know about that have worked for individuals and communities?

After the three rounds of World Café conversations, the last group at each table summarized all the ideas for their table topic. Three World Café questions were posted separately on large sheets of paper on the wall. Participants from each table were encouraged to present the ideas from their table question on the wall paper. There were 15 notes affixed to question 1, 20 notes affixed to question 2, and 11 notes affixed to question 3. After the forum the research team gathered all of the ideas and themed them into category topics. The categories of responses, with examples of ideas posted from the table notes are summarized below.

Question 1: "When you think about HIV-related stigma and discrimination in Manitoba, what is the first thing that comes to mind?"

Three category topics were identified by participants:

1. **The lack of education and knowledge on HIV**, especially on ways of transmission and effect on life span. (e.g. "*HIV is a 'gay' disease*"; "*being looked as a gay while being heterosexual*"; "*HIV does not equal to death*"; "*let's talk about HIV as a chronic disease*").
2. **The criminalization for non-disclosure to sexual partners** (e.g. "*Criminalization! Severe punishment for not-disclosure. Why?*")
3. **Effect of HIV-stigma and discrimination on families** (e.g. "*protect my family (child) ... so they don't face the discrimination and sigma. I do not want them treated differently because of my status*").

¹ Brown, J., & Isaacs, D. (2005). *The World Cafe: Shaping our futures through conversations that matter*. San Francisco, CA: Berrett-Koehler Publishers.

² Diceman, J. (2010). *Dotmocracy handbook*. Retrieved from http://files.uniteddiversity.com/Decision_Making_and_Democracy/dotmocracy_handbook.pdf

Question 2: “What are the effects of the experiences of stigma and discrimination on individuals and communities?” Two types of effects emerged from the answers:

1. **Immediate effects:** including isolation, destruction of social/community networks, delaying access to healthcare
2. **Long-term effects:** including low self-esteem, addiction problems and feelings of disempowerment (e.g. “*you lost voice/decision making ability, others consider you disqualified to speak*”)

Question 3: “What actions related to reducing stigma and discrimination would make the most difference to people living with HIV in Manitoba? What strategies do you know about that have worked for individuals and communities?” Participants suggested the following actions:

1. **Educate providers and outside agencies** (e.g. “*show people anyone could be affected and it is not a death sentence; HIV has no face/sex, a good life can be hard...; rewrite HIV 101*”)
2. **Normalize testing** (e.g. “*change the message, don’t just test the ‘risk’ groups, EVERYONE needs to be tested*”)
3. **Change the law**
4. **Increase peer support and other support programs** (e.g. “*peer providers as part of care and education*”; “*...support for people dealing with (Child and Family Services); more support for positive parents (e.g. childcare for meetings and appointments*”)

Identifying Priority Issues and Actions

To identify the most important research topics and actions we used “dotmocracy.” Dotmocracy is a process in which many ideas gathered from a large group are organized into a usable priority list. This was accomplished in the forum by brainstorming ideas in table groups, posting ideas for the rest of the participants, and providing all participants with an opportunity to vote on ideas. Nineteen research questions and 23 actions were posted on the wall. Each participant was given 6 dots and asked to put their dots on the research questions and actions that were most important.

Participants gave priority to three research topics they felt might help reduce stigma and discrimination in Manitoba.

1. **Impact of social and cultural factors on stigma** (e.g. “research on cultural factors that may affect HIV research; separate female and male during HIV research”; “effects of religion, the church on HIV stigma”; “different experiences of stigma on reserve, off reserve, rural and city”)
2. **Family dynamics and HIV stigma** (e.g. “involve families in the project”; “how stigma (is) affecting children of HIV positive persons”)
3. **Impact of education on reducing stigma** (e.g. “...HIV awareness would help reduce HIV related stigma”; “As a provider, on what do you base your decision to test... or not. Provider biased on who you test”)

Participants prioritized the following action items that they proposed would be helpful to reduce stigma and discrimination in Manitoba.

1. **Change in legislation and policy** - There needs to be a change to the legal system to avoid criminalization and to protect the rights of HIV positive population.
2. **Educate** - We need to educate healthcare providers, including physicians, nurses, healthcare aides, social workers, as well as families and younger generation.
3. **Support** - We need to provide peer support, social support and family support, sharing circles
4. **Advocate** - We need to use media, social networks to raise the awareness of HIV

Implementing the Stigma Index

The last part of group discussion was asking participants to brainstorm how we ensure diversity and safety when implementing the HIV Stigma Index in Manitoba. Again, participants were encouraged to write down any thoughts or comments, and post these on the wall papers to share with all participants.

When discussing implementation of the HIV Stigma Index in Manitoba, participants offered suggestions in the following themed categories.

Diversity:

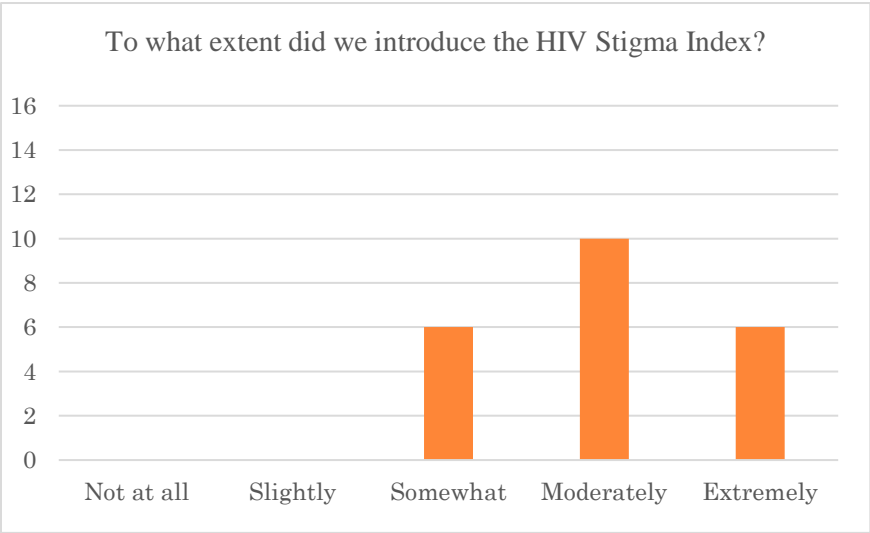
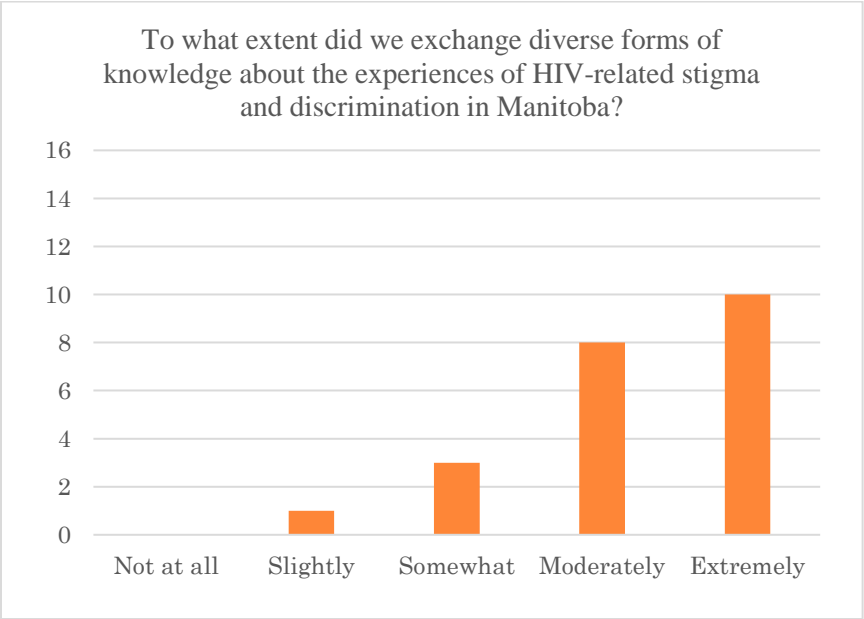
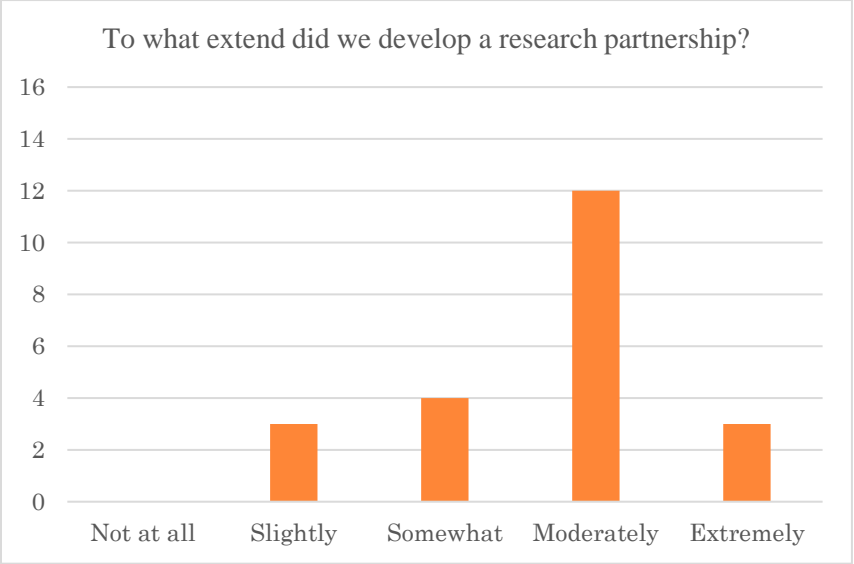
1. **Where to recruit:** social media group networking; clinics; food banks, churches, resources center, community center; street connection van etc.
2. **Interviews:** flexible locations and time; interview at Thunderbird House and Aboriginal Health and Wellness Centre; diverse team-administering the survey, depending on participant's comfort level (e.g. male, female, cultural background).
3. **Barriers and supports for participants:** childcare for parents; language programs for non-English speaking immigrants.
4. **Other things to consider:** newcomers; how to capture a broad age group; reaching people who do not have access to social media, news etc.

Safety:

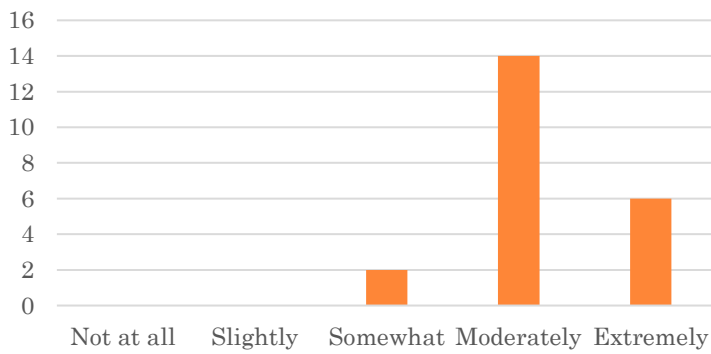
1. **Training and support for interviewers:** education for the team administering the survey; peer interviewers need training in how to conduct the survey.
2. **Ensuring confidentiality**
3. **Location of interviews:** safe environment non-identified to HIV; if doing "home visit" interviews have cellphone, safety plan and contact
4. **Interviews:** self-administered survey; having options do it in diverse setting; give person a choice of who is the interviewer.

Forum Evaluation

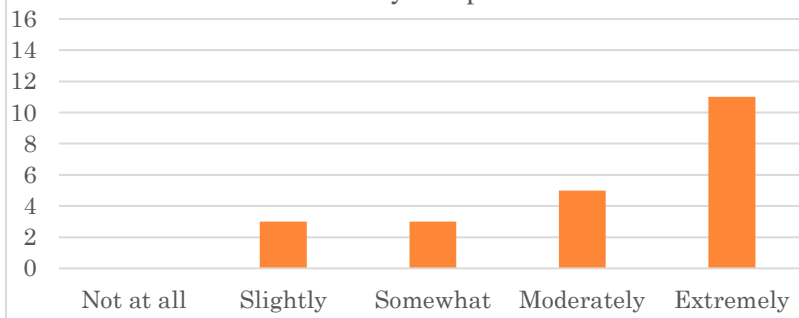
At the end of the forum, participants were encouraged to complete a post-event questionnaire. Twenty-two (22) (54%) participants completed the survey. The survey asked participants to rank the extent to which the forum achieved its objectives as well as to respond to open-ended questions about their experiences. Overall, the feedback received from participants in the post-event survey indicated the forum met its objectives and was a positive event. Responses are summarized below.



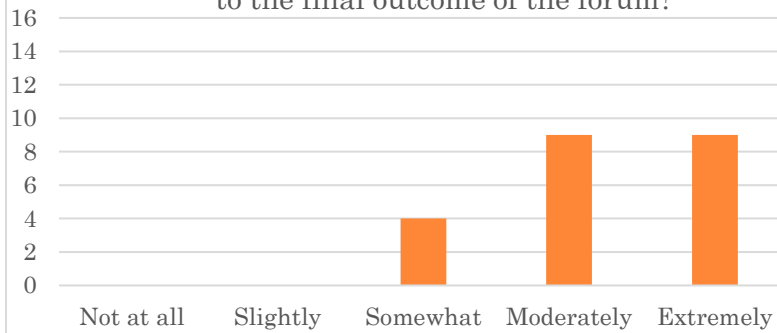
To what extent did we identify actions to address HIV-related stigma and discrimination in Manitoba?



To what extent did you feel you had the opportunity to share your opinions?



To what extent did you feel that you contributed to the final outcome of the forum?



Positive comments from participants included: *it was very informative; friendly, safe and fun; Need for another forum, there is more to talk about if I was prepared; I enjoyed it was very much and would like to see more of sessions for everyone to learn from. Love it.*

Good things that were identified about the Forum included: *the amount of people from different ethnic/religious backgrounds; what is stigma with Rick...; hearing from people with lived experiences; discussion, participation of people with HIV in the discussion; I appreciate sitting and learning with researchers, (PHAs), service providers, etc.; it opened the conversation; great connecting with others who want to work towards change, opportunity to hear others ideas for change; got to meet people, other peers and professionals such as researchers; got to tell (about) my life living with HIV.*

The most relevant take-away messages for the participants include: *good learning on how to facilitate a daylong event with diverse people; getting knowledge on research (with the) HIV Stigma Index; how to less stigmatize myself; get more involved in HIV policies; more open to talk about HIV (especially in groups); more informed and more likely to speak; increased awareness of some less commonly known issues will assist me when training staff; increased understanding of how “complex” this issue is.*

Recommendations for suggestions for improvements included: *more time, especially for the slide presentation; more structured discussion; heat was making me sleep; different ways of sharing information for afternoon; more information, i.e. papers.*

Conclusions

The Stop Stigma Forum engaged community stakeholders as a first phase in the implementation of the HIV Stigma and Discrimination in Manitoba community-based research project. Participants engaged in meaningful discussions that will guide and support the project through the next phase of the research.