



### Discoveries for Life



Gender inclusivity as a foundation for building healthy communities



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### Introduction

On September 25-27, 2017, the Canadian Institutes of Health Research and the Native Women's Association of Canada Partner for Engagement and Knowledge Exchange (NWAC PEKE), funded through the Pathways for Health Equity for Aboriginal Peoples' Initiative (Pathways), co-hosted the third Pathways Annual Gathering in Whitehorse, Yukon. The Gathering brought together key participants involved in the Pathways Initiative, including an estimated 120 researchers, community partners, Indigenous organizations and local Indigenous representatives.

This year the Gathering welcomed Elder-Youth pairs from all over Canada to share their perspectives on Indigenous health research and New Investigators to provide opportunities for reciprocal capacity building. Local Yukon First Nations Elders were also in attendance to share their experiences and bring a northern perspective to the Gathering.

The theme of this year's Gathering was that of gender inclusivity as a foundation for building healthy communities.

### The objectives of the Gathering are listed below:

- **Promoting equity:** To promote health equity through inclusivity of sex and gender in health research.
- **Preparing for scale up:** To support and prepare for scaleup of community-driven research, centered on Indigenous Ways of Knowing and Being, through moving knowledge into action.
- **Mentoring:** To foster the next generation of Indigenous health researchers through capacity building and mentorship.
- **Strengthening relationships:** To strengthen linkages between Pathways communities and partners through knowledge sharing and learning.

### **Welcome Remarks**

Participants were welcomed with an opening prayer by Kwanlin Dün Elder Billie Giroux. Deputy Chief Michelle Telep of the Ta'an Kwäch'än Council and Judy Gingell of Kwanlin Dün First Nations welcomed everyone to the shared traditional territories of the Ta'an Kwäch'än and Kwanlin Dün Nations. Welcoming remarks were made by Yukon Government's Deputy Minister for Health and Social Services, Stephen Samis. The co-hosts, Francyne Joe, President of the Native Women's Association of Canada and Dr. Carrie Bourassa, Scientific Director for CIHR's Institute for Aboriginal Peoples' Health thanked the host territories and welcomed all participants to the Gathering. Dr. Philip Sherman, Scientific Director of CIHR's Institute of Nutrition, Metabolism and Diabetes, provided a short overview of the Pathways Initiative since its inception in 2012.

### **Elder and Youth Pairs**

On the opening evening, seven Elder-Youth pairs introduced themselves and shared details about their relationship and experience in health research. The involvement of Elders and youth provided important perspectives on the priority topic areas and offered a unique opportunity to support mentoring and capacity building for youth.





### **Cultural Activities**

The Dakhká Khwáan Dancers, a National award winning Inland Tlingit dance group based in Whitehorse, welcomed everyone with their traditional songs and dancing on the evening of the 25th. The Dakhká Khwáan Dancers strive to harness cultural revitalization and community social transformation through the reclaiming of languages, traditional values and the traditional art forms of song, drumming, dance, and storytelling. Throughout their performance, the dancers encouraged audience participation, and brought laughter and smiles to the crowd. Their powerful performance was a great way to start off this meeting.

The first full day of the Gathering, September 26th, participants joined together in a circle to light the sacred fire, which burned throughout the two days. Spiritual leader and Carcross First Nations Elder, Phil Gatensby led the group through the fire lighting with teachings and an opening prayer. Participants were also welcomed to offer tobacco and a personal prayer to the fire. Throughout the Gathering participants came to stand by the fire in meditation or to receive teachings in the fire keeper's tent. Many people passed through the tent to sit and have tea with Elder Phil, who offered a guiet, open and welcoming space to all participants. At the closing ceremony, participants once again gathered around the fire to give thanks to the ancestors and to close the sacred fire. This cultural protocol was an important part in creating a safe and positive environment for guiding discussions of health; the circular nature of the opening and closing prayers demonstrated a holistic view of health, promoting healing and inner reflection at the same

Participants enjoyed a banquet on the evening of the 26th followed by local cultural entertainment. Acclaimed Yukon musician and singer songwriter, Kevin Barr played to the welcoming crowd as they tapped their feet and sang along. This was followed by an uproarious comedy act by well-loved Yukoner, "Gramma Suzie" Sharon Shorty. As one of the Elders so aptly put it earlier that day, "laughter is the best medicine."

The morning of the second full day, September 27th, NWAC led a Sisters In Spirit Vigil as a way of honouring women and offering up supportive words and prayers to missing and murdered Indigenous women and girls and their families. Paper hearts were handed out and everyone was invited to write a message. As NWAC's Courtney Skye said in describing the heart exercise, by putting our hearts and minds together we become a part of a movement honouring our women and bringing safety and justice to the lives of those we've lost. Each participant was invited to write messages of love, strength and hope to the women and their families and hang them on the wall of the meeting room.









## Gathering Highlights

### Theme and objectives of the event

Dr. Cara Tannenbaum, Scientific Director of CIHR's Institute of Gender and Health introduced the theme of the Gathering on the morning of the 26th, gender inclusivity as a foundation to building healthy communities. Dr. Tannenbaum described the Gathering as both scientific and cultural and encouraged participants to reflect on what success looks like and to give and receive, to listen respectfully and to share. Gender is an important determinant of wellbeing that intersects with other determinants and when addressed in health programs, makes for stronger outcomes for all. She invited the participants to reflect on how gender guides projects and outcomes of research; how gender affects implementation in research and scalability; and how the ultimate objective is to promote health equity.

Dr. Tannenbaum then outlined the difference between scalability and "scaling-up". Assessing scalability is determining if the research will work; it is asking the questions: are the magic ingredients transferrable; will all the communities want to participate; is it a community priority; and how should context be addressed? An important question is also, are people ready? These are all key questions to consider as one negotiates community agreements and assesses scalability. Scale-up is the actual taking of an intervention to other communities. A first step to that is developing a culturally appropriate plan. This needs to be community-driven. Following the planning, the actual scale-up can take place, with the necessary adjustments applied and finally, one can share the lessons learned.

Dr. Carrie Bourassa, Scientific Director of CIHR's Institute of Aboriginal Peoples Health (IAPH) then introduced IAPH priorities and spoke about the value of mentoring and fostering the next generation of Indigenous researchers. She said that research with Indigenous peoples must be built on respect for community and for self-determination. Some concrete examples of this are for communities to hold their own data, for researchers to value the guidance of Elders and to include culture in research protocols; strengthening relationships is one of the most important aspects for CIHR and IAPH. She then spoke about the ongoing priority of CIHR towards Reconciliation; the Pathways Initiative is in part, a path to Reconciliation, where health equity and self-determination are supported and communities are the ones driving the health agenda.

### **Promoting Equity**

Dr. Tannenbaum began her presentation on gender with a policy statement that all research funded by CIHR must express how gender is being taken into account. Dr. Tannenbaum went on to describe the difference between sex and gender. She described sex as a set of biological attributes in humans and animals. It is primarily associated with physical and physiological features including chromosomes, gene expression, hormone levels and function, and reproductive/ sexual anatomy. In comparison, gender refers to the socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people. There are multiple complex aspects of gender at the individual, community and wider societal levels and traditional gender roles vary by region and community. Gender plays an important role in health and wellbeing. Gender identity is the inner sense of self as masculine or feminine, in between, or neither. Gender relations refers to the interpersonal interactions, decision-making and family dynamics. Institutionalized gender is the distribution of power in the wider world, such as a society being classified as either matriarchal or patriarchal. Dr. Tannenbaum spoke about the relationship between gender and the four priority health issues being researched through Pathways Initiative.





### Presentation by Dr. Dawn Martin-Hill

### **Gender through an Indigenous Lens**

A presentation was given by Dr. Dawn Martin-Hill (Mohawk, Wolf Clan), Associate Professor and Paul R. MacPherson Chair in Indigenous Studies at McMaster University. Dr. Martin-Hill's presentation focused on sharing stories of strength and teachings on gender through an Indigenous lens. She spoke about the traditional role that women hold in Indigenous society as stewards of the earth, as clan mothers and as mothers; she spoke of the importance of bringing back these roles as a way of reclaiming women's power and traditions. She shared stories of young men and young women who are taking a stand to protect Mother Earth and Indigenous rights. She also spoke of the importance of sharing what is right about Indigenous people rather than what is wrong and decolonize gender and identity through advancing self-determination. Part of this is the need to uncover the stories and traditional teachings and bringing these back into present day society; for example, traditional people had many teachings about those who were Two-Spirit and their value within the nation. Of paramount importance, is the need to listen and honour our young people, who are increasingly speaking up for how they want to define themselves and their world. For young women especially, they want a positive image of Indigenous women. As one young person put it eloquently, "we need to change our story in order, to change our reality."



# Partners for Engagement and Knowledge Exchange

Within the Pathways Initiative are organizations that are funded to support community engagement and knowledge exchange. These Partners for Engagement and Knowledge Exchange (PEKE) functions are undertaken by the Native Women's Association of Canada, the National Association of Friendship Centres (NAFC) and the Assembly of Manitoba Chiefs First Nations Health and Social Secretariat of Manitoba (FNHSSM). The PEKEs representatives shared reflections on gender and gender-based analysis as detailed below.

### **Culturally Relevant Gender-Based Analysis**

Courtney Skye, Director of Strategic Policy, NWAC introduced her Mohawk heritage and culture from a gender perspective and the women who came before her. She raised the issue of inequality across genders and asked. "what is our role to lift up others so they may be leaders in their communities?" Cultural gender-based analysis is both holistic and intersectional. It includes age, location, unique impacts within community/family, and experiences with colonization, which all impact identity. Separation from community and environmental degradation both impact the wellbeing of women and girls, who are inseparable from land and water. Ms. Skye shared some areas NWAC is advancing in development of their gender-based analysis tools, including accessibility and LGBTQ2S inclusivity. She also shared the promise to keep advocating for culturally relevant genderbased analysis for Indigenous populations.



Catherine Graham, A/ Director Research and Special Projects for NAFC, reflected on the keynote presentation and the important work of Dr. Dawn Martin Hill on Indigenous women and the impacts of colonization. She went on to comment on the lack of continuity in the way the federal government approaches gender-based analysis; some departments have frameworks, others do not. Genderbased analysis has been reflected in the NAFC's values and principles for more than half a century. She explained that the important thing in terms of research is that not all research has to be about gender but that it is important to consider whether the work is representative of gender diversity. Ms. Graham also emphasized the importance of listening to our Youth as well as Elders; she also spoke of Indigenous methodology and how it is more important to tell stories and support those stories by allowing space and community ownership.

**Wendy McNab Fontaine**, PEKE coordinator of the FNHSSM introduced herself and her perspective on gender. In her understandings and teachings, and conversations with the PEKE Knowledge Keeper, it is about balance. Gender would not be an issue if we paid attention to traditionally and culturally what was practiced. She spoke of the word "woman" or "ikwe", in Anishinaabe, means body and connection to earth. In everything we do, like research and being inclusive of gender, how are we all connecting to the body and the earth. She shared that the morning presentations about "gender inclusion" felt like we were disconnecting from that and gender was becoming something inanimate, a nonliving "thing". Ms. McNab then led the Gathering in a focusing exercise to reconnect us to the earth and our body. Stressing the necessity of maintain balance with ourselves to support us in the work we all do.



### **Discussions on Promoting Equity**

After the morning's opening remarks and keynote, participants broke out in groups to discuss reflections about gender and gender-based research. Each group had guiding questions to stimulate the discussion, the results of which are described below

### **Gender Neutral Languages**

Participants spoke about different Indigenous languages that are gender neutral, reflecting a worldview that is different from a Western binary view of gender. For example, the community-based survey of Indigenous people in Toronto uses language to be inclusive and strength-based. Finding the appropriate language to describe gender identity and sex- and gender-based analysis (SGBA) is needed, as not all Indigenous communities use the wording "Two-Spirit". The language surrounding SGBA should be culturally appropriate and context specific.

## Gender as a Reality rather than a Concept or Framework

The language of gender as a "reality" rather than as a "concept" was preferred. Gender as a reality intersects with many other factors in determining health. Gender alone is just one layer of analysis. Gender-based analysis for Indigenous communities needs to be thought through and defined more clearly. It takes time to develop trust with an Indigenous community in order to have conversations around gender. Participants felt that the language we use to describe others and ourselves is powerful and thus it needs to be respectfully thought through in developing government policy.

### **Gender Roles**

Women seem to play a larger role in the areas of health and wellness in communities. Challenges can arise from stereotyping women however into gender roles thus making it important for women to be able to speak for themselves. Gender roles influence the whole community and so it is important for health research to look beyond individuals and take these influences into account and adopt a wholistic lens in designing research protocols.

### **Education on Sex and Gender for the Different Ages**

Education on sex and gender and the teaching of respect as a foundation needs to begin with children in school. Education from respected community leaders is also important, especially in consultation with Elders. Elders have an important role to play in discussing sensitive topics and gender intersectionality. However, there is also a need to make space to have discussions with Elders on gender fluidity. Due to the history of colonization and the imposition of Western gender norms through Christian missions, residential schools, and the Indian Act, not all Elders are accepting of different gender identifiers, thus sometimes creating a generational clash between youth and Elders in

terms of their views on sex and gender. It is an opportunity for youth to lead the change; there is a role for youth to take responsibility to educate the older generation on gender identity.

### **Research and Community**

Knowing what is relevant for each community is crucial in community-driven research. Researchers need to work with communities to be inclusive of varying understandings of sex and gender. Current policies on gender and health are based on a structure deeply ingrained in colonialism. Communities may not talk about sex and gender explicitly or in the same words, but Indigenous understandings of gender are intertwined with traditional knowledge, and communities need time to set their "social norms" perspective before determining how they wish to approach the research project. The funding needs to adapt to community needs and the benefits of research need to reach communities. There is a significant difference between "community-placed" research, where there is little follow through to action and "communitybased" or "community-driven" research, where the locus of control lies within the community. Indigenous communities are studied, but often little comes out of it.

### **Empathy and Inclusivity**

The younger generations, families and Elders can lead in advancing empathy and inclusivity of gender diversity. For many youth, every day is a trial of who they are as human beings and many feel excluded or under-valued in their communities. It is important to create welcoming spaces for youth. Youth need their own space to share amongst themselves firstly and then they can be brought together with Elders; fear of Elders amongst youth also needs to be addressed. More representation from LGBTQ2S+ groups is also required in these conversations about gender as those present at the Gathering who did not have that lived experience felt it difficult to speak on others' behalf.

### **Decolonizing Methodology**

It is more important to reclaim the aspects of culture that promote acceptance of gender. Indigenous research, guided by land and by the ancestors, feels holistic, fresh and exciting for many, and is favoured over a western approach, which tends to be driven by academic principles and linear frameworks. The funding structure is problematic, as it does not allow community members to hold grants. The fact that Indigenous community partners can typically only be identified as Knowledge Holders on CIHR funding applications, does not recognize the value of Traditional Knowledge and the role of community and Indigenous peoples as researchers and experts. The language of "knowledge holder" and the funding application structure encourage a colonialized approach that is in juxtaposition to the values and principles of community-based or community-driven, Indigenous research.









## Traditional Knowledge as a Foundation for Two-Spirit Health

Identifying as a Two-Spirit person is a lived reality with many challenges in our society and it is left to healers rather than community to support people. Uncovering Elders' teachings about Two-Spirit health is key to changing this and is key to healing, both Two-Spirit peoples and community. More emphasis is needed on uncovering traditional laws, policies and knowledge, and not having it hinder growth, healing and the rites of passage that relate to gender.

## Other Social Determinants to be considered along with SGBA

A gendered approach in Indigenous communities should consider many other intersecting challenges such as access to food security; access to care; multi-caregiver communities; resource scarcity; income inequality and poverty, and; power and stigma between health practitioners and patients, which can lead to guilt and form a barrier to health equity.

### **Holistic Approach**

Directed calls for specific topics of priority that are driven by and defined by funding agencies can prevent an application from examining multiple interconnected issues and taking on a holistic approach. An example of a single-issue focus versus a holistic, multidimensional approach is to focus on suicide prevention versus promoting mental health. Suicide prevention is a downstream, illness-based approach whereas promoting mental health and wellness is a strength-based and upstream form of prevention. Linking items together for a unified health approach is helpful for community, rather than a segmented approach targeting a singular issue. For example, utilizing the Life Promotion Framework (holistic methodology) considers the spiritual, emotional, physical, and mental aspects of an individual in context to their family, community and nation. The same goes for focusing on sex and gender identifiers as drivers of equality rather than looking at a person as a whole. An Indigenous perspective focuses on the person as a whole.



### **Elder-Youth Reflections on Promoting Equity**

The following section contains some excerpts from the reflections by Elder-Youth pairs on the discussions around gender and promoting gender equity.

"To understand gender inclusivity, we need to know nature, direction, and source."

"In the Cree language, gender is neutral, there is no "he" or "she""

"Gender identity is a matter of personal sovereignty, it is not all of who I am."

"Support role reversal and let youth take responsibility that they have already assumed in spreading the mood of gender inclusivity; let them take the lead."

"Teach and learn meditation practices for brain health – brain based economy – meditation helps keep our brain health."

"My identity is mine to describe and is my sovereignty. Nobody should define who you are."

"English language is noun-based; Anishinaabe is verb-based."

"Gender is a social construct and trying to fit into it, creates boxes. It is Euro-centric."

"Try not to create more boxes, as it can create bias or exclusivity from the start."

"My identity is mine to describe and is my sovereignty. Nobody should define who you are."

# **Strengthening Relationships and Community Engagement**

## Hearing from the Pathways Implementation Research Teams (IRT)

In the afternoon of day one, each of the 14 Pathways IRT Component 2 funded teams, represented by researchers and community members were given the opportunity to briefly describe their project. They gave an overview along with lessons learned from community engagement with the partner communities.

### **Summary of Lessons learned**

Most of the research teams spoke of the importance of **community-led** projects and listening and respecting the voices of the community. Each community dictates what success looks like for them and must guide the process. For example, in one project, there are learning circles, where partners get to share what they are learning with and from each other; in another project, there is a focus on building food skills by starting with what people want to eat and slowly moving towards talking about healthy choices.

Another lesson learned is the importance of volunteering first in the community if you want to do research. That way, communities will get to know you and recognize you. There is nothing to replace the **face-to-face meeting** through a gathering prior to developing a grant proposal. Each community is different with different venues and preferences of communication. Invite lots of groups to share what is going on at their community-level and work together to address some of the challenges that are happening on the ground. Community gatherings are a best practice as well as a key tool for integrated knowledge transfer.

**Training** is also something central to the research relationship. It is this that leads to action – as was brought up by one of the teams, if there is no action, then what is the point? We need action for reconciliation to happen. One example suggested for building research capacity is to promote First Nations principles of OCAP® training for all research partners.

Another key lesson is the importance of **strength-based approaches**. For example, instead of talking explicitly about suicide, talk about how we can create mentally healthy communities. Some ways to promote this are through knowledge and skills development.

**Cultural approaches to health and healing** are also key components. For example, learning the Indigenous names of plants and other non-human beings is connected to our wellbeing, our communities, and our ancestors. This strengthens our overall health and this radiates outwards. Another element is to remember that the number one rule of cultural activities is to have fun. Laughter is the best medicine.

Partnership is about trust, confidentiality, and encouragement. Establishing relationships and sustaining relationships between community-university, community-community, and amongst youth mentors, must involve action as a key ingredient. Building relationships is key, even though researchers may have prior research relations with different groups. Trust is built by taking the necessary time for building new relationships and allowing respectful relationships to grow. Another important point related to partnership is to get proper agreements in place that recognize jurisdictional boundaries.

At the core of it, **community engagement** is about being together and feeling safe. Achieving community engagement can be done with support from Indigenous Centres and through circles of communication. A significant challenge of community engagement is dealing with confidentiality; confidentiality can be especially hard in small communities, therefore it is important to talk about confidentiality with community from the get-go.

Involving **youth** through promoting a greater understanding of their own history is another central lesson from the IRT Pathways funded teams. School curriculum can support and carry new messages of identity and history. In working with youth, it is important to also work with the whole community. Youth need to be supported by a wider network in community and the wider community is not a community without the youth.

When considering the role of **research and reconciliation**, it is important to not forget the truth. Many want to move straight to the reconciliation part. We must honour the past in order to learn from it and move forward. This includes respect and reciprocity and recognizing that everything is connected. There is lots of decolonization work that must be done, especially in research. Reconciliation in research must happen at individual, community, and systemic levels.



### **PEKES Reflections on Community Engagement**

**Sarah Harney**, PEKE Coordinator, NWAC, sees first and foremost, the building of relationships through taking time to meet each community even before the research process begins. She believes that it will help in better understanding each other in the research partnership. Flexibility is needed in building a solid plan. Community engagement is about accessibility for everyone, including diverse community members and we need to remove barriers and reach out to people. We must also respect communities as experts, and constantly ask ourselves how research is benefiting communities.

Catherine Graham, A/ Director of Research and Special Projects, NAFC reminded participants that Provincial/ Territorial associations are autonomous and therefore support research at the community level. Community-driven research is about visiting and spending time asking community what they want and working with community to make that goal a reality. It is about recognizing that communities are the experts and have the capacity and our role, as researchers is to support. Research starts with good relationships and that leads to good research. Equity of compensation is also key for ensuring true community-driven research. For example, one research project ensured that the peer researchers were paid the same as their university research counterparts.

**Wendy McNab,** PEKE Coordinator, FNHSSM, spoke to the importance of taking time to build relationships for community engagement. She reiterated that relationships can take a long time to develop and that this can be challenging in a tight research schedule and funding structure. When entering a community, it is important to ask first and be invited. Having and promoting respect in the relationship is a must.

### **Elder-Youth Reflections on Community Engagement**

The following quotes are from Elder-Youth Pairs about their reflections on the discussions around community engagement.

"Support, grow, and reversal of roles where youth take the lead or take responsibility."

"Tell stories that redirect our narrative on topics such as gender inclusivity."

"Community engagement is first sharing who you are and not defining others."

"It's a responsibility that what I am doing is not oppressive. It is not my responsibility to speak on behalf of people's experiences I know nothing about."

"What is our source – from where do we come is unique. It is about balance and the roles and responsibilities we carry. Within balance are reminders of key responsibilities: peace of good relationships and inner peace; to think before we say or do things, and to do it with respect."

"Love is a feeling of warmth, connection, grounding for ourselves, and relationship to people and environments."

"Women are keepers for our community."

"Conference after conference without action – we can no longer do this. Conferences need to lead to action."

"Important to walk together, work together, and hold each other up."



"Important to walk together, work together, and hold each other up.

# Preparing for Component Three of the Pathways Initiative

### **Discussions on Rippling-Out**

Discussions on the final day of the Gathering, focused on the topic of "scaling-up" or "rippling-out" of the 14 projects. While scale-up is often the focus on health interventions and research, according to many participants, scale-up was not an Indigenous concept. The term "rippling-out" was suggested and favoured instead. The term, "rippling-out" more adequately captured the wholistic and circular expansion of a project versus more of a linear perspective in the domain of what is traditionally considered "scale-up". For example, many participants talked of vertical scale-up, either within the same community to different target populations or throughout the lifespan. Instead of taking the intervention/project/program to other communities, the focus of "scale-up" or "rippling-out" could be on harnessing and building onto sustainability aspects within the community.

The final day welcomed much discussion on the topic of scale-up and rippling out. Once again participants broke into groups for discussions. Below is a summary of themes that arose from these discussions.

### Themes about Scale-Up or Rippling-Out

### **Knowledge Mobilization**

Scale-up should really be about **knowledge sharing**; it should be about sharing what was learned in one community with others. It doesn't have to be about reinventing the wheel but context and community relevancy needs to be at the forefront. There is a need for money to guide this approach however – the focus is often left up to researchers to share on behalf of communities, whereby communities should be the ones to share their outcomes and lessons with other communities. Just as the community needs to be driving the process of knowledge gathering, it also needs to be in control of the knowledge sharing and mobilization efforts as well.

### **Scale-Up and Sustainability**

Scaling-up is not an Indigenous term. While there are many ways to "scale up" a project, often the onus is on scaling up and out to other communities, amassing in scale and number of participants instead of asking what are the ingredients for ensuring that an intervention, project or program is going to be sustainable within that community. Aspects of sustainability need to be addressed early on in a project's lifecycle and incorporated into the planning stages. Scaling-up may not always be the best approach or goal of the community; this needs to be honoured. A number of the discussion groups and participants in the plenary group raised the point that we should be thinking about **vertical scale-up** (or "scale-down" which means scaling to more systems-level or upstream prevention). Scale-up can also be done according to a lifecycle approach (i.e. taking an

intervention targeted to youth to adults of younger children). It was also noted by a community participant that another way of thinking about this topic could be scaling back on interventions and scaling up on health promotion to prevent the issues from arising.

### **Sovereignty and Power Dynamics**

As with the discussions around gender and selfdetermination, sovereignty for communities in research is also very important. Communities need to be driving the processes and in control of the product and communications, especially when it comes to rippling-out. The ability to define oneself and control the images and storyline is vital for communities and for Indigenous peoples as a sovereign people. Care needs to be taken to address the often-nuanced power dynamics between researchers and communities and between institutional process requirements and the realities on the ground. For example, ethics board reviews are often centered in an academic or government institutions and capacity and expertise to engage equally with the legal frameworks and review processes may differ between community and these institutions. There needs to be more community reviews as part of the research process and these should hold equal standing as their Institutional counterparts.

Also, part of this discussion is power dynamics between types of research and how we define "success". In scale-up and assessing scalability there is a focus on quantitative measures. Part of shifting power and acknowledging sovereignty is valuing qualitative, Indigenous methodologies and approaches to stand equally as measures of "success".

Compensation is another aspect of power. What this looks like for example, is equal pay for community researchers as university researchers as well as fair compensation for those participants who are contributing themselves and their stories for the research. One participant noted that the research can't be done without Indigenous peoples' input, but \$500 for two weeks does not reflect such a partnership.

### **Process is Important**

Implementation science lends insight into the relationship between process and outcome. Process is just as important as the product. There are a lot of positive lessons that can be learned by the process. Just because a project does not result in a change in numbers this does not mean that the project was pointless. Process-focused research can be highly relevant to the lessons of scale-up and knowledge sharing.

### Decolonization

Listen and learn first. That is a first step to decolonizing methodology. Letting Indigenous communities control the stories about themselves and the ways that they want to engage with research. We have made much progress in the areas of community-based research and the many powerful projects and positivity in the room at the Gathering

is a testament to that. However, we still have work to do. Processes need to be examined through a decolonizing lens; the theme of "ticking box" arose in many of the discussions. What people were saying is that we need to be careful that we are not just creating more boxes in our attempt to be inclusive to multiple gender identities and to community-driven processes. A good research project should not be measured as one that ticks off the most boxes, or is scaled to the most communities, but as one that leads to sustainable outcomes for Indigenous peoples.

Decolonizing methodology is one aspect, but systems need to be decolonized as well. There is a co-learning aspect that needs to be considered – we talk often of co-learning as a part of community-based research, however we often think of it between researchers and communities; co-learning must also happen at the systemic level, between funders and communities. The Pathways initiative is an opportunity to advance this.

### **Responsibility of Knowledge**

"Knowledge is power." This we have heard many times. But knowledge for the sake of knowledge can perpetuate unequal power dynamics and ongoing health inequities. There is a responsibility in knowledge gathering. This responsibility must respect the knowledge and the knowledge holders. It must also respect the relationships and the communities who decide to take part in the research. There is a responsibility to knowledge in community-based research that it leads to action, first in communities whose knowledge is driving the outcomes and then the lessons can be shared with others, or scaled as appropriate to the communities involved. The other aspect of this is that Indigenous knowledge must be respected equally to other aspects of knowledge. "Experts" are not just from a scientific background or people who have a PhD, but Traditional Knowledge holders are also experts and should be valued as such.



### **Suggestions for Component 3 and Rippling Out**

CIHR Institutes welcomed input from participants on shaping Component 3 of the Pathways Initiative, as described below.

**Focus on knowledge mobilization/sharing over scale-up.** It should be about sharing successes and this news will travel to other communities who may then step forward to participate.

**Relationship-Building is Key.** Relationships need to be built on a foundation of trust and trust takes time to build. If a project is moved to a new community, relationship building needs to start afresh.

**Communities Need to be Driving the Process.** Indigenous peoples are a sovereign people and can speak for themselves; control, knowledge and power over processes, stories and data are key aspects to community-driven research.

**Knowledge and Responsibility.** There is a responsibility to knowledge and what the purpose of knowledge is in the research; does it lead to action; does it lead to new discovery or does it lead to exploitation? These are critical questions that need to be defined prior to community research. We must respect knowledge and knowledge holders.

**Language is important.** Reclaiming language is a pathway to health and also a powerful tool for reclaiming identity, control and culture. We need to look carefully at the language of research, as these can perpetuate power dynamics and unintentionally promote disenfranchisement.

**Shifting Perspectives.** Decolonizing methodologies and systems is about a shift in perspective. This includes focusing on sustainability aspects over scalability and rather than capacity building there should be a focus on co-learning.

We are starting to see a shift in perspectives and this Gathering was a good example of a venue where this colearning can happen. There is still much work to be done however. Change will happen, but first we must listen, then reflect, and respect the communities who are leading this chorus for change.

## Elder-Youth Reflections on Rippling Out and Reflections

Following the discussions around rippling out and scaling up, Elder-Youth Pairs took to the stage a final time to give their final remarks. The following is some of what they had to say.

"Need more Two-Spirit and LGBTQ people here to speak for themselves"

"Very important to have the perspective of our powerful Elders."

"The Gathering has been a positive space to be able to speak out truth."

"The burning fire was very powerful."

"We were taken care of (at the Gathering) in a good way, close to nature, by the river. Emotional."

"Working across multiple ways of looking at the world is very valuable."

"When working with people, come from a place of love and respect first."

"Scaling down is important – true prevention is upstream."

"Each First Nation has complex solutions to complex problems."

"Blessed to be invited and blessed to have strong leaders who advocate for you."

"Would like to be invited again to future events."

"Happy the youth came to the Gathering."

"Very important to have the perspective of our powerful Elders."

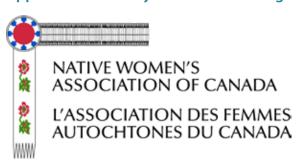
### Closing Remarks

Dr. Carrie Bourassa closed the Gathering by acknowledging the importance of having Elders in the room as they are the knowledge keepers. She acknowledged the youth and community partners by saying that this work can't be done without them. Dr. Bourassa acknowledged that language and words are important and we need to follow the advice of the communities, for example, starting with finding other words rather than scaling up. Communities must be selfdetermining and communities need to guide the research. Dr. Bourassa also thanked the Scientific Directors and staff of the various CIHR institutes for coming to the Gathering and listening to the communities. Dr. Bourassa expressed her sincere gratitude to everyone for coming and making the Gathering such a success. She thanked the planning committee and Marilyn Van Bibber and Jody Butler Walker for their efforts at facilitating the Gathering.



### **Appendix**

### Appendix 1: Pathways Annual Gathering Agenda





Pathways Annual Gathering 2017 September 25-27, 2017 Kwanlin Dün Cultural Centre Whitehorse, Yukon

### **AGENDA**

### 2017 Theme: Gender inclusivity as a foundation for building healthy communities

### **MEETING OBJECTIVES:**

- 1. **PROMOTING EQUITY**: To promote health equity through inclusivity of sex and gender in health research.
- **2. PREPARING FOR SCALE UP:** To support and prepare for scale up of community-driven research centered on Indigenous Ways of Knowing and Being through moving knowledge into action.
- **3. MENTORING:** To foster the next generation of Indigenous health researchers through capacity building and mentorship.
- **4. STRENGTHENING RELATIONSHIPS:** To strengthen linkages between Pathways communities and partners through knowledge sharing and learning.

### **September 25, 2017**

3:00 p.m.	Registration opens	
6:00 p.m.	Ceremonial Greetings & Opening	
6:10 p.m.	Opening & Welcome from Canadian Institutes of Health Research – Institute of Aboriginal Peoples' Health (CIHR-IAPH)	Carrie Bourassa Scientific Director CIHR-IAPH
6:15 p.m.	Welcome from Native Women's Association of Canada (NWAC)	Francyne Joe President NWAC
6:20 p.m.	Welcome from Host Territory	
6:30 p.m.	Reception	
7:00 p.m.	Look back on Pathways so far	Philip Sherman Scientific Director CIHR - Institute of Nutrition, Metabolism and Diabetes (INMD)
7:10 p.m.	Elder-Youth Pairs Sharing	
8:00 p.m.	Dakhka Khwaan Dancers	
8:50 p.m.	Housekeeping messages	
9:00 p.m.	Closing	

### September 26, 2017

8:00 a.m	Breakfast	
8:30 a.m.	Opening prayer	
8:40 a.m.	Welcome & opening remarks	
8:45 a.m.	Theme & Objectives of the event	Carrie Bourassa (CIHR-IAPH) and Cara Tannenbaum Scientific Director CIHR-Institute of Gender and Health (IGH)
	PROMOTING EQUITY Session Objectives: To frame Indigenous health research within the lens of Gender-Based Analysis+ and to present various perspectives To highlight gender-based community-driven Indigenous health research perspectives	
9:10 a.m.	Session 1: Gender through an Indigenous Lens	Dawn Martin-Hill Assistant Professor McMaster University
10:50 a.m.	BREAK	
11:05 a.m.	Session 2: Gender and Indigenous research session breakout groups	
12:20 p.m.	LUNCH	
1:15 p.m.	Hearing from the Pathway's Implementation Research Teams Session Objectives: To provide the teams an opportunity to share their work and progress To allow participants an opportunity to learn what others are working on	
2:25 p.m.	AFTERNOON BREAK	
	STRENGTHENING RELATIONSHIPS  Session Objectives: To highlight best practices in community/ researcher relationship building  To highlight best practices for community engagement in Pathways	
2:40 p.m.	Session 1: Reflecting on the Community/Researcher Collaboration	Plenary Session
3:40 p.m.	Session 2: Hearing from the Pathways Partners for Engagement and Knowledge Exchange – Community Engagement	
5:00 p.m.	Wrap-up	
	BREAK	
5:30 p.m.	Networking Session Session Objectives: To provide participants an opportunity to network and share learnings in community intervention research To provide participants with a venue to discuss opportunities for future collaborations	
6:30 p.m.	Banquet	

### **September 27, 2017**

8:00 a.m.	Breakfast	
8:30 a.m.	Welcome & opening remarks / Recap of Day 1	
8:50 a.m.	MENTORING / CAPACITY BUILDING	
	Elders' Perspectives	
9:30 a.m.	Cultural Activities	
11:30 a.m.	LUNCH	
12:30 p.m.	PROMOTING A RIPPLE EFFECT	
	<b>Session Objectives:</b> To identify challenges and opportunities for scaling up of community driven research interventions	
2:10 p.m.	CIHR-IAPH Closing Remarks	Carrie Bourassa (CIHR-IAPH)
2:20 p.m.	Wrap-up	
2:25 p.m.	Closing prayer	
2:30 p.m.	Departure	