PWHR
PARTNERSHIP for
WOMEN'S HEALTH RESEARCH
CANADA

Partnered women's health research for knowledge mobilization

PWHR Knowledge Summary

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PWHR's office is located on the ancestral and unceded territory of the Coast Salish peoples – xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations. Our acknowledgement, gratitude, and respect extend to all the First Nations communities on whose traditional territories PWHR builds relationships.

ACRONYMS

ACRONYMS	DEFINITIONS
ASPIRE	Advances in Screening and Prevention in Reproductive Cancers
CART-GRAC	Contraception and Abortion Research Team-Groupe de recherche sur l’avortement et la contraception
CIHR	Canadian Institutes of Health Research
KM	Knowledge Mobilization
PHAC	Public Health Agency of Canada
PWHR	Partnership for Women’s Health Research Canada
SA/DVTC	Sexual Assault/Domestic VIolence Treatment Centres
UNESCO	United Nations Educational, Scientific and Cultural Organization

INTRODUCTION

> "Knowledge that is created locally, in the world of practice, is cutting edge. The larger questions of life are being addressed in daily practice, not in the academy."
>
> *– Dr. Budd Hall, UNESCO Chair in Community Based Research and Social Responsibility in Higher Education, as quoted by Dr. Janice Du Mont, Senior Scientist, Women's College Research Institute and Professor, Dalla Lana School of Public Health, University of Toronto, November 23, 2022*

This document is a summary of key learnings from the inaugural Partnership for Women's Health Research Canada (PWHR) Seminar Series (2022-2023). The theme of the seminar series was engaged or partnered research to promote knowledge mobilization to benefit the health of women, trans and non-binary people[1]. This summary provides an overview of key principles and tangible practices to support sustainability and meaningful engagement and collaboration with knowledge holders and users.

In our first seminar, Alison Bourgon, Director General of Science Policy at the Canadian Institutes of Health Research (CIHR), shared that "knowledge mobilization signifies an emphasis on researchers engaging in meaningful priority-setting and co-production with communities of knowledge users and holders to ensure that research is responding to pressing needs." The research featured in the seminars and summarized in this document exemplify these practices. From the experiences of women's health researchers engaging with communities, service providers, and policymakers, several themes emerged as principles of successful knowledge mobilization:

- Trust
- Time
- Flexibility and adaptability
- Collaboration
- Sustainability
- Reciprocity

Each of these themes are woven throughout the learnings described in this document. Given that every research project and partnership will encounter its own unique opportunities and challenges, we encourage you to reflect on the ways that these principles can inform your research plans, practices, relationships, and intended outcomes.

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[1] The Partnership for Women's Health Research Canada uses the term women to refer to all people who identify as women. We use trans and non-binary as umbrella terms to refer to people with a wide range of gender identities that are different from the gender they were assigned at birth.

WHY KNOWLEDGE MOBILIZATION

> CIHR sees a future where the gap between discovery and implementation is a thing of the past; where Canadian researchers are at the forefront of knowledge mobilization; and where the uptake, scale, and spread of evidence are engrained in the fabric of Canadian institutions.
>
> *- Government of Canada, 2021*[2]

In 2021, CIHR introduced their new ten-year strategic plan, which includes their commitment to knowledge mobilization (KM).

CIHR describes KM as "an umbrella term that includes a wide range of activities related to both the production and use of research results."[3] Like knowledge translation, KM includes activities like knowledge synthesis, dissemination, and application of knowledge.

ENGAGING WITH COMMUNITIES

> "[The research] has to be designed by the people that live there…they're the experts on the issues that are affecting them. Therefore, building relationships with community members is our foundation rather than a means to an end. It's everything for us. It allows us to have responsive research that's community-led. It allows us to have research that's for communities and benefits communities."
>
> *– Dr. Richard Oster, Scientific Director of the Indigenous Wellness Core, Alberta Health Services, September 22, 2022*

Whether engaging with communities locally or abroad, understanding their priorities, values, and self-identified needs is a critical first step toward building a meaningful and reciprocal relationship. What might this look like in practice?

Identify community champions

This should be done early—before funding applications or even designing the project. Take **time** to understand what community priorities are and whether or how they align with your own research goals.

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[2] Canadian Institutes of Health Research, 'CIHR Strategic Plan 2021-2031', *Canadian Institutes of Health Research,* (23 Feb. 2021), https://cihr-irsc.gc.ca/e/52331.html , accessed 17 Sept. 2023.

[3] Ibid.

Be prepared to unlearn

When engaging with communities, it is imperative to remember that the researcher is not the expert. Approach every step of the research process with humility and draw on community members' strengths to work toward research goals together and build **trust** in your relationship.

Request feedback—regularly

Request feedback and be open to all of it. Under the pressures of tight research timelines this can be daunting. But listening and taking action to respond to community input can help strengthen **trust** in your relationships. This might mean changing interventions, re-engaging ethics boards or funders, or redefining sustainability for your project. Keep community partners informed about how their perspectives and feedback changes the project's status and impact. Have a structure in place to meet with and provide updates to community members is a way that works for them (e.g., a regular community advisory board meeting, attending a community meeting for updates). What works will vary by the community you are engaging with.

Support the community

Ask about their needs. Is there training or resources that could help support them in this work? How would they prefer to meet? To communicate? How can you create space for community members to engage one another? Check in regularly and identify actionable steps to address their needs and make this work **reciprocal**.

Be innovative

Sometimes meaningful engagement is at odds with timelines and structures set out by institutions. An example that highlights **adaptability** in a research partnership shared by Denise Young and Dr. Richard Oster is how the Maskwacîs Maternal, Child & Family Wellbeing research group centres on data sharing and ownership. Their group maintains a living research agreement with Maskwacîs Elders and community members, Maskwacîs Health Services, and the University of Alberta that includes the co-ownership of all research data. To get there, the group prioritized relationships and trust, humility, ceremony, and strengths-based and community led approaches. This took time, effort, reframing western research approaches, and working together over many years to co-develop and ratify their research agreement so that they can make this data governance structure clear in ethics applications and beyond.

Redefine success in research

Think bigger than the publication. Consider co-developing alternative measures of success that centre and prioritize meaningful engagement and **sustainability**. This can involve a longer timeline to build the knowledge, capacity and confidence of your community research partners and champions. But this investment can also result in transformative change.

Community engaged research promotes innovation in Ugandan cervical cancer screening

> "Once [community health workers] acquire the knowledge, they just transform everything."
>
> *- Dr. Carolyn Nakisige, Gynecologist, Uganda Cancer Institute, September 22, 2022*

Cervical cancer (which can be caused by the Human Papilloma Virus [HPV]) "is the most common cancer in Uganda" where it is often diagnosed at advanced stages when survival rates are low.

The **A**dvances in **S**creening and **P**revention in **R**eproductive Cancers (**ASPIRE**) research are conducted by the University of British Columbia internationally with partners and collaborators in low- and middle-income countries. For over a decade, ASPIRE has worked closely with collaborators in Uganda to promote community-based cervical cancer screening through self-collection based HPV testing.

Through **close and sustained engagement** with local communities—including women, men and traditional leaders and community health workers—ASPIRE was able to 1) teach communities about the importance of and methods for self-screening, increasing acceptance and demand at the community-level; 2) promote task shifting to community health workers that relieved overburdened nurses and midwives of screening-related tasks and increased coverage; and 3) increase follow-up rates for women requiring treatment from 16% to 70%.

ASPIRE's findings and impact led to the inclusion of self-screening in Uganda's National Cervical Cancer Prevention and Control Strategic Plan.

ENGAGING WITH HEALTH AND SOCIAL SERVICE PROVIDERS

As with community members and policymakers, engagement with health and social service providers may extend to many stages of the research process—from planning to end-of-grant dissemination and implementation. Whether you hold roles as both a service provider and researcher or you are designing strategies to support care, these are several considerations to guide and strengthen these collaborations.

Leverage others' expertise

Think about the range of knowledge holders and users that are going to benefit from or be involved with the outcomes of your research. This could include a variety of service providers (nurses, midwives, counsellors, physicians) but also hospital leaders, program administrators, members of government, caregivers, or patients. Consider how their expertise and strengths can contribute to your research, and work together to identify areas of alignment and opportunities for **reciprocity**. Importantly, compensate community and patient partners appropriately to recognize their time and expertise.

Be personal

The first point of contact should be from the principal investigator and should be personal. While group communication will be important later, it's important to begin the **relationship** on an individual level.

Keep in touch

Whether it's regular emails, newsletters, or a web portal, ensure that you are keeping everyone engaged in the research up to date about progress and results. For large teams, this can be an especially helpful tool to foster a sense of **collaboration** among team members who cannot attend regular meetings or who are only being brought in at specific stages in the research process.

Think about the perspectives you're missing

Keeping diverse perspectives in mind can not only help to strengthen **collaboration**, but also improve the **sustainability** of outcomes. It can be easy to build a team of people who are passionate about your research and fall into "preaching to the choir." But, as Dr. Natalie Rosen shared, this might mean you're missing out on collaborators who may not be currently supportive or interested in your goals, but who can bring important perspectives and have the potential to become champions. In her work, those relationships where providers were on their own learning journey about the topic of her research (sexuality) often led to them becoming vocal supporters for sexual health and sexual health research within their own networks.

Bringing together service providers in hospitals and community organizations to better support trans survivors of sexual assault in Ontario hospitals

> "…hear what the frontline clinicians are saying. Because as a study is being designed, it has to work on the frontline."
>
> *– Sheila Macdonald, Director, Ontario Network of Sexual Assault/Domestic Treatment Centres, November 23, 2022*

Dr. Janice Du Mont, a senior scientist with the Women's College Research Institute at Women's College Hospital and Sheila Macdonald, Director, Ontario Network of Sexual Assault/Domestic Violence Treatment Centres (SA/DVTCs), have worked closely with an advisory team of peer leader advisors, trans and gender diverse health experts, and representatives of diverse community and healthcare organizations to advance a program of research to enhance the care provided trans and gender diverse survivors of sexual assault.

Providers within the Ontario Network—which comprises 37 hospital-based SA/DVTCs—initially identified a pressing need on the frontline: clinicians were asking for training and a referral network to better serve trans and gender diverse survivors. To address this need, an in-person trans-affirming sexual assault care curriculum for service providers and a network of trans-positive community and healthcare organizations across Ontario (trans-LINK Network) was collaboratively developed, implemented, and evaluated.

Of the 47 nurses who participated in their pilot in-person training, nearly 70% reported that it was their first training in providing care to trans and gender diverse clients. Upon completing the curricula, participants reported higher levels of perceived expertise in providing this care.

The curriculum, based on its success, was adapted to an e-learning, became a standardized training in Ontario SA/DVTCs, and was shared across the trans-LINK Network through its WebPortal (www.translinknetwork.com/curricula). The e-learning has been accessed by organizations and institutions in many other Canadian provinces, as well as organizations within, for example, the United States, Belgium, Greece, the United Kingdom, and Australia.

ENGAGING WITH POLICYMAKERS

> "This conversation about partnering with policymakers is so essential to our work as women's health researchers. The gap—as we well know—between the incredible research that we do in this country … and its implementation, its uptake—to making a real difference in the lives of … cis and trans women, non-binary folks, folks across the gender diversity spectrum—we need to close that gap. We need to do that work faster, better, [and] more sustainably."
>
> *-Dr. Angela Kaida, Scientific Director, Institute of Gender and Health, CIHR and Distinguished Professor, Faculty of Health Sciences, Simon Fraser University, January 26, 2023*

It might be tempting to believe that engagement with policymakers should begin when your research is nearing the finish line and your outcomes are ready to take hold. But building relationships with policymakers should begin early and with the recognition that the relationship is a two-way street.

Who shares your goals?

When thinking about this relationship, consider policymakers whose visions and strategies could benefit from your research. Understand their values and be prepared to demonstrate how they are in alignment with the knowledge you are developing and would benefit from **collaboration**.

Know how to communicate your research

Practice your "elevator pitch." When first engaging with policymakers, start out with your key points—try to keep them to three or fewer—and be prepared to deliver this information in three to four minutes. Your university may offer media or communications training that can help you prepare and polish the pitch.

Leverage your network

If you don't know the policymaker(s) you want to connect with already, ask for introductions. Look at your own network and think about the connections that might already be in place that can get you one step closer to a new **collaboration**.

Build capacity within your research team

As you establish relationships with policymakers, consider introducing them to other members of your team. Help them to see that you aren't just an individual they can work with, but a team, program, or network they can seek expertise from as a measure of **reciprocity**.

Be ready and available to help

Policymakers may turn to you for support with a rapid review, support with a media response, or other activities related to their work. **Reciprocity**—that is, being responsive to policymaker needs in your area of subject matter expertise—is important for establishing a **collaborative** working relationship and building **trust**. Government timelines are often short (operating on hours, rather than weeks). Be prepared to support policymakers with concise, relevant evidence on a quick turnaround.

Collaborate widely

Working with policymakers is not where your engagement should end. Think about knowledge holders and users across sectors, systems, services, academia, and populations who may be interested in your research outcomes. These **collaborations** can help strengthen your call for new or revised policy and demonstrate to policymakers that the need for a policy change stretches beyond your own research outcomes and goals.

Research to public policy: Free contraception in British Columbia

> "The way myself and members of my research team will talk about the aims of the research we are proposing to do will be directly related [to] and using the words of the published strategies of the knowledge user we're speaking to … If we are talking to [policymakers], it's because they are supposed to do something with which we can assist."
>
> *-Dr. Wendy Norman, CIHR/PHAC Applied Public Health Chair, University of British Columbia and Co-Director, Canada's Contraception and Abortion Research Team, January 26, 2023*

Dr. Norman and the Contraception and Abortion Research Team (CART-GRAC) collaborate closely with policymakers and other knowledge holders and users from government, academia, health services (leadership and healthcare providers), and patient and advocacy organizations to identify and act on priorities related to sexual health and unintended pregnancy.

In 2015, the CART-GRAC team launched a provincial Sexual Health Survey in British Columbia. Based on their findings, they used economic modeling to determine that within three years of implementing universal free contraception, the government in British Columbia would see health systems savings of roughly $37 million a year. After many years of providing evidence to the government leaders, supporting the development of policy options (underlining the importance of reciprocity) and regularly engaging with government decision-makers, contraception at no cost to the user was included as an election promise in the platform of the New Democratic Party (which subsequently won the general provincial election). This was followed by ongoing collaborative work by researchers with policymakers, as well as growing civil society advocacy over many years. As of April 1, 2023, contraceptives are now free for residents of B.C. enrolled in the Medical Services Plan—a public policy supported by strong evidence of impact for the health and well-being of women and others who become pregnant, as well as evidence of cost-benefit.

CONCLUSION

> "[Engaged research] was almost a transformative experience for me as an academic. […] We have a tendency to do our research, and to publish it, and to put it into journal articles, and then to move on to the next project. And for me, I was junior in my career when I started this, and I just didn't want my career to look like that. I wanted my career to also be about taking the research and figuring out how to make it more accessible, how to, especially when I do work on sex, how to destigmatize it, to open up lines of communication, and to figure out ways that the general public would also be engaged and want to hear about the work we are doing. And I would say, I would never go back."
>
> *– Dr. Natalie Rosen, Professor in the Departments of Psychology and Neuroscience and Obstetrics and Gynaecology at Dalhousie University, Halifax, November 23, 2022*

Knowledge mobilization is the future of health research. As the 2022-2023 PWHR Women's Health Research Seminar Series demonstrated, engaging with communities, service providers, and policy-makers generates exciting, relevant research questions, empowers researchers and communities, and contributes to systems transformation and outcomes that outlast the funding cycle.

This summary is intended to provide a starting point for thinking about meaningful research engagement and the ways it contributes to KM, specifically for women's, trans and non-binary people's health. Seminars it draws from are available publicly through the Partnership for Women's Health Research Canada website. It is complimented by a tool that further distills these learnings for teams conducting KM, and recommends additional resources to support engaged research practice and reflections on social position, power and privilege in the research process.

ACKNOWLEDGEMENTS

The content of this document draws on the experiences and expertise shared by the speakers and moderators at the 2022-2023 PWHR Women's Health Research Seminar Series. We extend our gratitude to the panelists and their teams for imparting their successes, challenges, and lessons learned with the PWHR community and beyond.

Panelists and Moderators: Women's Health Research Knowledge Mobilization to Improve Policy, Practice, and Outcomes. PWHR Women's Health Research Seminar Series (2022-2023)

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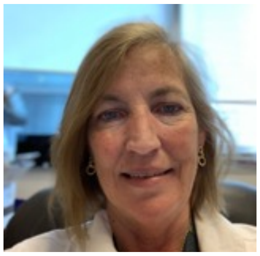
Lorraine Lipscombe, MD, MSc, FRCPC

Senior Scientist, Women's College Research Institute, Professor, Department of Medicine and Director, Novo Nordisk Network for Health Populations, University of Toronto



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Director, Ontario Network of Sexual Assault/Domestic Violence Treatment Centres

Carolyn Nakisige, MD

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Wendy V. Norman, MD, CCFP, FCFP, DTM&H, MHsc

Professor, Department of Family Practice, Faculty of Medicine, University British Columbia and Co-Director, Canada's Contraception and Abortion Research Team

Richard Oster, PhD

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Laurie Smith, RN, MPH

Program Manager, Global Control of HPV Related Diseases and Cancer Research Program, Women's Health Research Institute

The Honourable Jenna Sudds

At the time of seminar, M.P. for Kanata--Carleton, Parliamentary Secretary to the Minister for Women and Gender Equality and Youth; currently Minister of Children, Families, and Social Development.

Denise Young, BS

Research Assistant, Maskwacîs Maternal Child & Family Wellbeing Research Group

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