A Collaborative Exploration of the Future of Engagement

Meaningfully Engaging People with Lived Experiences in Healthcare Policies and Programs

2023

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Throughout the project, regular meetings were held with the Advisory Committee to share progress on the project and to seek advice and expertise at pivotal milestones.

Members of the committee held experience/expertise in at least one of the following areas: engagement, engagement with persons with lived experience, diversity/inclusion/anti-racism in healthcare, project design (design thinking, human-centred design), and/or lived experience in organ donation and transplantation (e.g., patients, families, donors, caregivers).

We encourage you to share this report widely. However, in the spirit of collaboration and participatory design, the collaborators ask that you include them in your socialization efforts — doing so, honours their unique knowledge and voices while making the work more impactful for all.

Land Acknowledgment

"As a result of this project I would like to see better access to care for all and improving the health outcomes for all Indigenous people." C. Woods

We recognize that we all live and work in different places and therefore on different traditional Indigenous territories. We invite you to explore the Native Land website to learn more about the land you live and work on.

We have the responsibility as contemporary stewards of the land to show respect for the contributions of Indigenous peoples dating back countless generations. On a national level, we encourage all people living and visiting Canada to learn about the Indigenous people of the lands on which they live, work, or visit. In the spirit of truth and reconciliation, we respect the self-determination of First Nations, Métis, and Inuit, and their rights and responsibilities in cultures, languages, and the pursuit of wellness.

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The pandemic raised the question, have people lost trust in government? Or is the bigger problem that governments don't trust people?

Either way, the path to rebuilding trust involves greater citizen participation in decision-making.

It's been said that healthcare is all about power. It's also been said that only through authentic opportunities to share power and collaborate with shared purpose, will we witness transformation.

Project Heart is one of those opportunities.

Z.Press, PWLE

"Engaging persons with lived experience is critical to improving public policy, research, and knowledge dissemination efforts.

Meaningful engagement is challenging and takes time, but Project Heart has outlined a pathway for achieving meaningful engagement drawn from current best practices and supported by the many PWLE project participants.

I challenge readers to read the report recommendations, reflect, and plan on how their spaces could allow for engagement – the opportunity is there; all that is left is your commitment to incorporate these principles and recommendations into your work."

M. Escoto, PWLE

"This important project has shown us the need to do things differently. To ensure the voices of persons with lived experience lead the way when setting priorities, making decisions, and developing policy. To fully appreciate the content, I encourage readers of this report to approach it with an open mind, from a place of humility."

K. Coldwell, PWLE

How to Read this Report

Project Heart is a collaborative endeavor. It brings together a multi-disciplinary team of community members with lived experience, researchers, designers, and policy analysts, **to co-envision what meaningful engagement[01] could look like, and in doing so, bring about more caring and equitable futures for all.** This project would not exist if it were not for the generosity, openness, and labour of those who shared their stories, perspectives, and expertise. **It is a privilege to share their unique knowledge in this report.**

Think of this report as an invitation, rather than a prescriptive guide to engagement. This report has been designed to help you think differently about engagement – that is, not as a task to be completed, but as a path to building more meaningful relationships with communities.

Whether you are already experimenting with some of the practices and principles we outline or are getting ready to lead an engagement for the first time, we know that shifting the ways things have been done can be hard. Our desire with this report is to usher in change in a way that feels hopeful and exciting!

01 Engagement refers to activities that have the purpose of gathering input, feedback, or perspectives on policies and programs.

As you sit with the report, we invite you to reflect on the following:

WHAT FEELS COMFORTABLE OR EASY? WHY?
WHAT FEELS UNCOMFORTABLE OR HARD? WHY?

"Although unpleasant responses can teach people when they surface, they are not generative if people get stuck or trapped in them." Vanessa Machado de Oliveira (2021)

Consider that discomfort isn't necessarily something to be avoided, and in fact, it can be a space for radical learning and unlearning. Discomfort often arises from the need or desire for change, and many of us have been taught to see this as failure. We invite you to face change and discomfort with care, and see them as opportunities for transformation[02].

WHAT MIGHT YOU BE ABLE TO START IMPLEMENTING NOW?
HOW DOES THAT FEEL?

"Transform yourself to transform the world."
Grace Lee Boggs (in maree brown, 2017)

Consider that change isn't always top-down. What are the seeds of change that you might start planting among your colleagues now? How might your own relationships or daily interactions become a front line for change?

WHAT ARE YOU HOPING TO LEARN FROM THIS REPORT?

"The times are urgent, let us slow down." Bayo Akomolafe (n.d.)

"A solution is often a problem's way of masking its desire for continuity." Bayo Akomolafe (2018)

We have created this report as a structured learning experience. We start with introducing a new paradigm of engagement, and then share mindsets, approaches, and specific recommendations for more meaningful engagement. If this is your first read, we suggest reading it in a linear manner. If you prefer to dive into specific sections, see below for some guidance on where to begin. Consider, however, that jumping to a list of actions (before taking the time to reflect on the paradigm within which these actions exist) can, at times, make transformation and change even harder to bring about.

[02] We often forget that change and discomfort is experienced in our bodies. If a reflection or thought is uncomfortable, consider exploring Resmaa Menakem's guided practice on navigating discomfort (Mahendren, 2022).

A guide to the report sections

Looking for an overview of findings and to understand the big picture? Go to the "The Overarching Learning" section on page 18.

Looking to challenge how you think about success in engagement? Go to the "Mindset Shifts for Meaningful Engagement" section on page 23.

Looking to dive deeper into approaches to engagement that align with PWLE desires? Go to the "Preferred Approaches for Meaningful Engagement" section on page 28.

Looking for a summary of practices we suggest implementing in engagement? Go to the "Paths Forward Recommendations Summary" section on page 62.

Looking to get into the detailed findings about specific topics around engagement, such as compensation? Go to the "Additional Engagement Insights" section on page 70.

A Note on Language

"So, words really matter. Lived experience may not be my favorite term, but it's not my least favorite term. I don't have a favorite term, because I haven't arrived at one yet. [Lived Experience] honors people's actual human experience in a respectful way." PWLE

Language matters. The words we use to speak about people and their experiences shape our frame of mind around what we see as even being possible to change. Language can help us see people and experiences with empathy and complexity, or in turn reduce people to boxes and categories. As Paulo Freire reminds us, when we name the word, we name the world.

There are a variety of terms in use to reference community members with a specific lived experience of a health-related condition. The project team was most familiar with the term "patient" but as the team shaped the project proposal, we felt that a more inclusive term to use was **Person with Lived Experience (**PWLE**)**. Usage of this term was confirmed by the environmental scan and members of the PWLE community themselves.

"I don't mind the term 'lived experience' because patient partners have a variety of health experiences, and some are caregivers and their families." PWLE

For the purposes of Project Heart, the term Person with Lived Experience is inclusive of a broader scope of descriptors such as patient, family, caregiver, citizen, and community member (CIHR, 2014). The term references someone who has direct personal experience with the specific subject matter. For example, when looking at caregiver support, someone with lived experience could be a person who supports a loved one who struggles with mental health challenges. When looking at post-kidney transplant services, a person with lived experience could be someone who has received a kidney transplant.

"The term [PWLE] is flexible of having or living the lived experience." PWLE

However, when it comes to language or labels of any kind, **our recommendation is to always ask the individuals you are engaging with what term is appropriate.** As you will read in this report, this approach aligns with broader recommendations for engagement: rather than assuming what is best, **collaborate with the communities you are engaging to co-define an approach that aligns with their needs and desires.** By doing this, we have the opportunity to learn what is desired and appropriate according to the population we are working with.

Throughout this report, we speak about the desires and hopes for engagement as told by participants with lived experiences. Yet, **people with lived experience are not monolithic**: different communities, and even individuals within each community, have different needs, experiences, and histories dealing with health systems. The goal here is not to speak on behalf of PWLE everywhere. Rather, we share the stories that people gifted us during interviews and co-design sessions **to open up space for new reflections about engagement.**

The Context

The principle of 'nothing about us without us' is rooted in the belief that people are the experts of their own experiences, and that their insights are essential to creating meaningful change.

Dolores Huerta, labor leader and civil rights activist

It's been demonstrated by evidence over and over again, that involving patients in a variety of activities, leads to better health outcomes.

PWLE

The Story of the Project

We find ourselves in a moment of cultural change — people are becoming increasingly dissatisfied with opaque and top-down processes. In turn, **people are demanding increased transparency into how decision-making happens and expecting to meaningfully participate in shaping the research, policies, and decisions that will impact them[03].**

Within this moment of change, engaging the people who will be impacted by policy — through roundtables, working groups, committees, and councils, for example — is no longer a nice-to-have. Without embedding the expertise of those with lived experience within the design of policies and programs, what is created, at best, falls flat, and, at worst, does more harm than good.

However, when we (as government employees) do engage people, we often focus on what we need and what is achievable (e.g., what we want to learn or what data needs to be collected). Yet, we have little understanding of the needs and desires of those being engaged.

This gap in understanding was the impetus for Project Heart. The goal of the project was to **understand engagement from the perspective of *those being engaged* and how government employees can approach engagements so that engagements are meaningful, inclusive, and impactful *for all involved*.** Through this exploration, people shared what they wanted, expected, and needed from an engagement experience. Together, PWLE and policy analysts envisioned a better future for engagement, as well as ideated and prioritized potential paths to get there.

03 We are seeing a shift towards more participatory and transparent processes happening in many areas, including, but not limited to, design research (see Sanders and Stappers 2008), policy-making in healthcare (see Sheard et al. 2019 and Kimbell, 2015), and corporate decision-making (see Kavakil 2021).

At first, the Project Heart team thought that the work would yield straightforward "do's and don'ts" of engagement or "standards" to implement. However, throughout the 12-month project, a bigger story unfolded. **We learned that engagement is less about following a predetermined checklist; it is more about building relationships that lead to true collaboration**. When we shift from roles to relationships, we can create meaningful and impactful engagement experiences that respect and honour the wisdom and gift of lived experience.

Methodology and Process

The Project Heart team undertook a multi-phased process[04] over a year:

Step 1 **Environmental scan** on established best practices in the engagement space, including review of literature and interviews with engagers.

Output Hypothesized best practices and areas of exploration for Step 2, interviews with PWLE.

Step 2 **Interviews with PWLE**[05] to explore past and current engagement experiences across diverse PWLE as well as explore what an ideal engagement experience may look like.[06]

Output Insights into the engagement experiences and desires of PWLE. Draft future visions of engagement to move into Step 3, co-design.

Step 3 **Co-Design**[07] sessions with PWLE and policy analysts to co-design learnings about engagement, desired engagement experiences, and paths to getting there.

Output Prioritized future visions and emerging paths to bringing these visions to life.

[04] This project employed open-ended qualitative research methods. This type of research is best suited to exploring the meaning that people ascribe to an experience (like engagement) (Creswell, 2014), allowing us to remain open to hearing participants' own paradigm of what an ideal engagement experience could look like.

[05] Participants self-selected based on one of the following recruitment criteria: experience with engagement activities related to healthcare; experience with organ donation and transplantation; experience being affected by social determinant(s) of health.

[06] A systematic review of different engagement initiatives was not included in the project. Examples of forward-thinking engagement practices can be found in the environmental scan, which can be accessed upon request.

[07] Refer to the Our Suggested Solution - Co-Design section on page 48 to read more about what co-design is and how it was used in this project.

Five Guiding Principles

Grounded in design thinking, design research[08], and participatory design[09], the project was guided by five principles:

Exploratory and Open-ended

Allowing participants to tell us what matters most to them, rather than looking to prove or disprove a hypothesis about what meaningful engagement looks like. For example, from the environmental scan (Step 1), we hypothesized that successful engagement for PWLE meant facing few barriers to being part of an engagement. Despite having this hypothesis, we didn't start the interviews by asking about barriers to participation. Instead, we began by exploring what meaningful engagement meant and felt like to participants themselves. We quickly learned that overcoming access barriers was important, but meaningful engagement required a lot more than easy access.

Empathetic

Deeply understanding an experience from the perspective of another person — their needs, motivations, desires, hopes, and feelings — while appreciating them as a whole human. For example, we chose to conduct in-depth interviews with PWLE over conducting a survey. While a survey may have given us a broad overview of barriers to engagement, we wanted to learn how people deeply felt about engagement. We learned about people's struggles and triumphs while living with complex conditions, and how this shaped their motivations around engagement. We learned how devastating (or in turn healing) engagement could be.

Participatory

Inviting participants to collaborate as co-designers, beyond simply asking them to divulge information on their past experiences. For example, in Step 3, PWLE and policy analysts came together to co-create the goals, design, and outputs of the upcoming co-design sessions.

[08] Design Thinking is an approach to problem solving that is hands-on and user-centred. Design research refers to the methods designers use to deeply understand the experiences of the people they are designing for and with, and ground what they develop in their needs and desires. Both practices assert that what we design should be grounded in a deep empathy for the people who will be using what is ultimately developed. For a brief introduction on both see Gibbons (2016). For an in-depth exploration of the importance of decolonizing these practices see Tunstall (2023).

[09] Participatory design is "a collaborative approach to design that actively involves users and stakeholders in the design process. It aims to create products and services that better meet the needs and expectations of users by levering and applying their knowledge and experiences." (Interaction Design Foundation 2023).

Iterative and Responsive

Adapting and revising project plans, goals, and designs as new learnings emerge. For example, we had originally planned to develop a final report as a project team. We heard early on that meaningful participation was an exchange (rather than being one-sided) and taking an active role in authoring the report was important to people. We shifted the report development process and revised the goals of the report to respond to this learning. Being responsive also meant being open to feedback about what we had missed. For example, we heard from a participant that Land Acknowledgements were important for every meeting, regardless of how formal or informal the meeting was. We took training as a team on conducting Land Acknowledgements meaningfully and shifted how we opened up meetings accordingly. We then checked back in with the person who had shared the feedback to hear more about how the change felt for them.

Reflexive

Being reflexive involves examining and consciously acknowledging the assumptions and preconceptions we bring into our interactions with others and that therefore shape the outcome. For example, before embarking on interviews with PWLE, we asked ourselves what "good" meant for us as a team. What principles did we want to guide our work and efforts — was it about the number of interview questions we covered or was it about the participant feeling comfortable enough to share their story? This revealed our assumptions about engagement and collaboration.
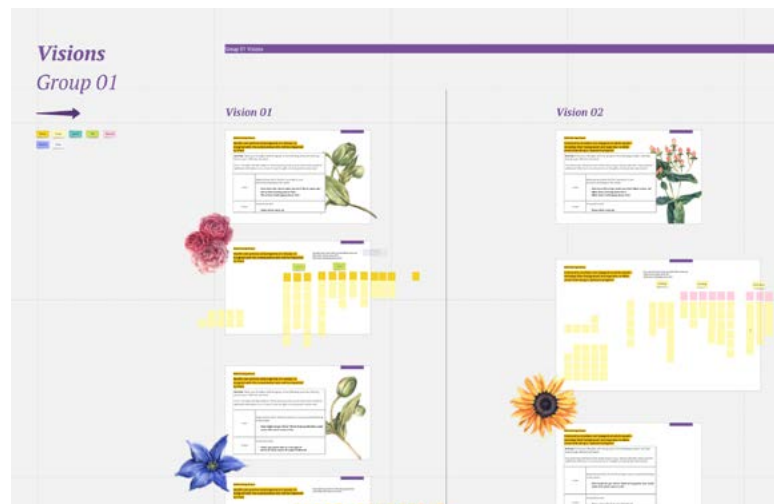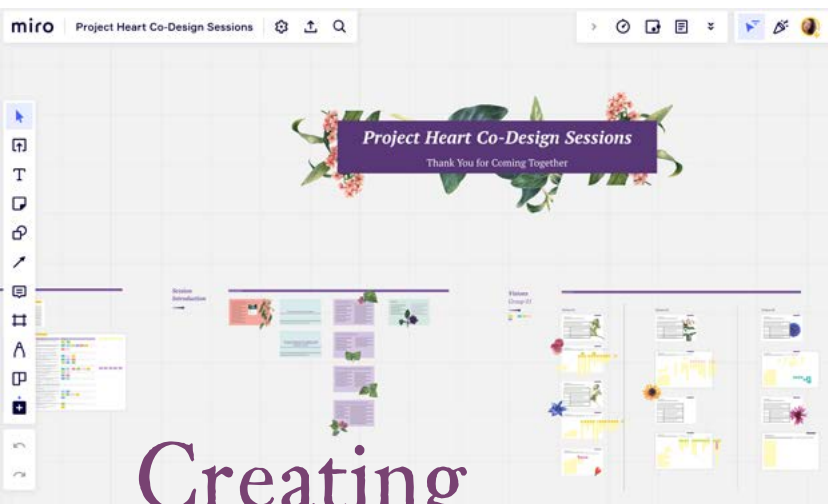
Creating a Collaborative Space

"It was a refreshing change to use collaborative tools like Miro and participate in group work sessions rather than unidirectional meetings. This way of working allowed us to stay truly collaborative and transparent throughout the project." Policy Analyst

This project was funded by the **Solutions Fund**, a program within Health Canada that is committed to employee-led innovation and experimentation. Because of the ethos of the fund and its focus on learning through trying, the project team was able to show up for each other and participants alike from a place of creativity and openness to discovering together. The program also empowers project teams to experiment with a trial-and-error mindset in a supportive, risk-tolerant environment. This provided the team a space to be able to listen and respond to both the learnings and the needs of the collaborators without the burden or constraints of adhering to overly strict or pre-determined deliverables and timelines.

Additionally, working with **collaborative tools** enabled the team to be responsive, iterative, and transparent, both with each other and external collaborators. Throughout the course of the project, the team employed Miro (a digital whiteboard). This living board could be reviewed and edited by all collaborators at any time. This tool enabled the team to hold project work sessions focused on co-building the next steps (rather than simply sharing information or updates to prompt individual work). For example, synthesis (often an individual task) was done collaboratively and in small groups, allowing the team to build shared insights quickly and adapt as needed. Perhaps most importantly, employing collaborative tools helped shift ownership from a "project lead" to a cooperative model of decision-making.

The Overarching Learning

" Engagement is unidirectional. I mean, it's a misnomer. So much of what I've experienced in engagement is not interactive, is not involvement, but it's more extracting.

PWLE

Tokenistic behavior is where you come in, you do your doodly-doo, and then and you're gone, and they've taken something from you. And they're not giving you anything back.
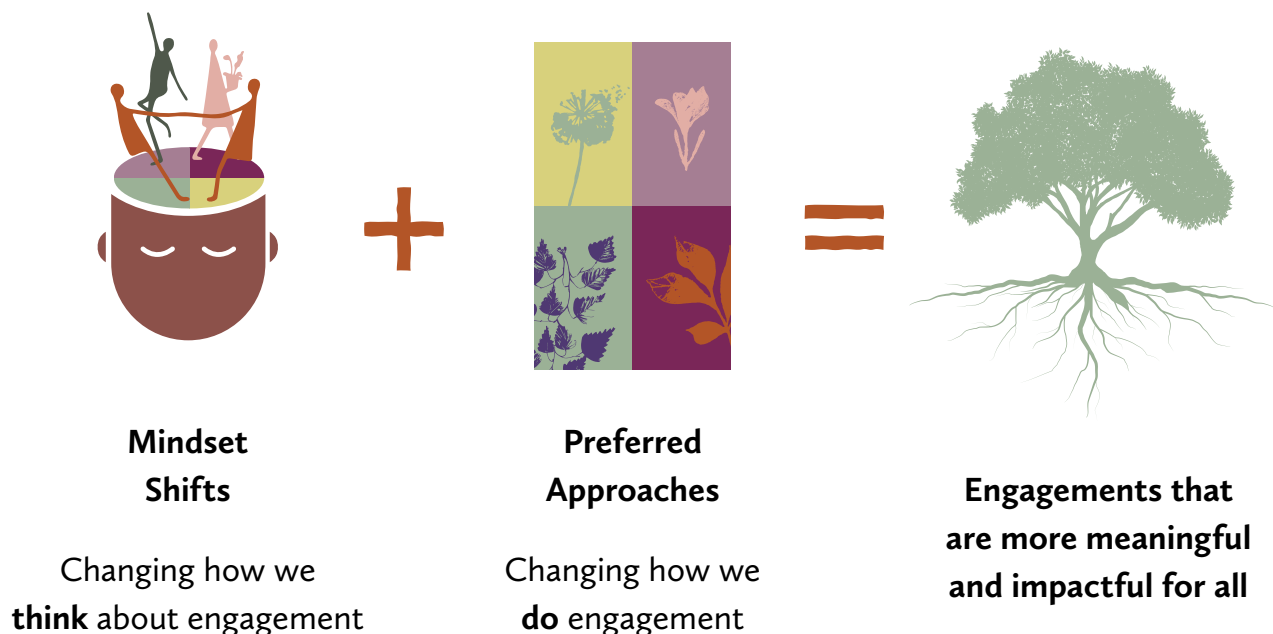
PWLE

Strong Relationships are at the Core of Meaningful Engagement

"Patients can tell if it's not true engagement, we're not sort of naive students here. Most of us have lived experiences, and we've been around the block." PWLE

This project sought to explore what meaningful engagement looks and feels like for people with lived experience with a health-related issue. What quickly became clear was that meaningful engagement was about more than the engagement event itself (e.g., the tools, technology, and methods used). Rather, it was about **building strong, collaborative, and humanizing relationships** throughout the entire process. Surprisingly (or perhaps not so surprisingly), engagers also hoped to feel more humanized in the process of engagement.

In other words, **bringing about more meaningful engagement requires us to do more than simply follow a list of guidelines — it requires us to look at the implicit beliefs that shape how we think about engagement** in the first place. In this report, we outline a) four mindset shifts, and b) four preferred approaches that are pivotal to bringing about more meaningful engagements for all.

**Mindset
Shifts**

Changing how we
think about engagement

**Preferred
Approaches**

Changing how we
do engagement

**Engagements that
are more meaningful
and impactful for all**

When asked what meaningful engagement meant to them, PWLE spoke of collaboration, partnership, trust, and strong relationships. Yet, many engagements they took part in felt the complete opposite, that is, tokenistic and inconsequential. In these cases, PWLE were left asking themselves if they were invited to an engagement simply to "check a box." Likewise, engagers also often felt stuck in a method and process that didn't serve them — they felt that they couldn't show up as their full selves during engagements and were left feeling unsure if they were getting engagement "right."

"About 65-75% of the work is building relationships and 25% of the work is actually doing the work that you are setting out to do." PWLE

A metaphor[10] can help us make sense of this tension. Imagine that cultivating meaningful engagements is like growing a tree — each part of the tree represents a central component of engagement activities.

Leaves (the visible, most often the guiding light of engagement): The types of data engagers are hoping to collect, and/or what reports need to be created.

Branches (the visible, what often is focused on): What is done during an engagement session such as logistics, methods, platforms, and activities used in the session.

The trunk (the partly visible, focused on from an internal stakeholder perspective): How engagement sessions are planned and prepared for, including recruitment, and communication with PWLE outside of the session itself.

Roots (the invisible, what is often forgotten): How we think about engagement (our deeply held beliefs or mindsets) and the quality of the relationships that are built throughout the entire engagement.

10 This metaphor is inspired by the olive tree metaphor created by author Vanessa Machado de Oliveira (2021). Originally the metaphor uses the visible and invisible parts of a tree to symbolize modernity, and how interventions on each layer have different purposes and impacts.

When trying to grow a healthy tree, we might be drawn to focusing on what's visible, caring for the leaves and branches. Instead, we need to consider the whole tree, including the parts that are not always visible — parts of the trunk, the roots, and even the soil are fundamental for the tree to thrive. Of course, caring for the leaves and branches themselves matters, but for a sustainably healthy tree we need healthy roots.

"We need to feel safe, we need to feel secure, we need to feel we're respected. So, if that's one thing that I would try and make it a policy for every single committee to do that." PWLE

Similarly, meaningful engagements happen when we tend to the entire tree (rather than just focusing on the outputs or logistics of engagement). Through this project, we heard that **strong relationships are the invisible roots of trust, collaboration, and mutually beneficial engagements.** In other words, we were constantly reminded to focus on the roots. Both engagers and PWLE alike feel that Health Canada has the unique opportunity to become a leader in bringing about more meaningful engagements.

"This project really connected me with the human side of our work. It made me aware that we can do things differently."
Policy Analyst

Mindset Shifts for Meaningful Engagement

Mindsets[11] *or mental models*	Habits of thought — deeply held beliefs and assumptions and taken-for-granted ways of operating that influence how we think, what we do, and how we talk (Kania et al.).

Shifting how we engage with PWLE requires more than a list of new processes or guidelines. **Although guidelines are pivotal to creating change, on their own, they can at times reinscribe the very problems we are hoping to solve.** We were reminded of this repeatedly throughout the project. For example, during one of the co-design sessions, the aim was to ideate guidelines around what "good" communication looks like during the entire engagement process. Many of the co-designers kept on reminding us that "good" communication wouldn't come from simply telling engagers to ensure that they do a set of actions (e.g., send an email to explain the goals of the session). Although this was important, on their own, these prescribed actions could easily start to feel like a box-checking exercise and leave PWLE feeling tokenized once again.

In other words, co-designers were asking engagers to do more than only reflect on the actions that make up good engagement (the leaves and branches) — they reminded us that **sustainable and meaningful change requires us to look at the implicit beliefs** (the mindset shifts, the roots) **that shape how we think about what engagement is, what we define as success in engagement, how we see ourselves as engagers, and how we see participants.**

In this vein, we introduce Four Mindsets that we can tap into to help bring about more meaningful engagements[12].

[11] To learn more about mindsets (mental models) that help facilitate meaningful change, we recommend exploring adrienne maree brown's book Holding Change (2021).

[12] We want to recognize that our current systems are built on established mindsets. This means that tapping into emerging mindsets is fundamentally challenging. When we do so however, we have the opportunity to meet needs and desires that have often been left aside.

	Established Mindsets[13]	Emerging Mindsets[14]
	the common way, what has been often done	the less travelled path, what has often been forgotten
Mindset 1	**Expert-driven**	**Collaborative**
	Traditional experts (people with higher academic education and in senior positions) are the best poised to make decisions. Experts know more than non-experts.	Decision-making is most effective when it happens between diverse experts and the people who will be impacted by the decision. People with lived experience have valuable "expertise" that cannot be accessed solely through academic training.

"During an interview, when asked about the meaning of lived experience, the participant opened his heart and explained the hardships of seeing his children affected by a particular disease. He described lived experience as something that can't be read in a book or heard in a story. Lived experience is in the soul, your bones, and your skin. It's unique to a person and is both emotional and physical."

Policy Analyst

[13] We do not mean to say that current Established Mindsets are wrong or bad - these models have greatly served us (and continue to serve us). However, opening space for models that have been on the margins, allows us to meet needs that have often been underserved and challenge how we usually think about what success looks like in engagement.

[14] This framework of emerging and established mindsets was inspired by the research conducted by Meninato and Lima (2019)

	Established Mindsets	Emerging Mindsets
Mindset 2	**Goal-oriented** Success is based on our ability to accomplish project goals and emerge with rigorous data. Move at the speed of the predefined timeline.	**Process-oriented** Success is based on the quality of the experience of going through a project. Move at the speed of trust.

"I believe a shift is necessary for the way we think about engagement – instead of reducing participants to data points, engagers must view participants as multi-dimensional individuals with different sensitivities, complex struggles, and personal triumphs. Most importantly, engagers must focus on humanizing participants and communities throughout the engagement process."

Policy Analyst

	Established Mindsets	Emerging Mindsets
Mindset 3	**Keeping things under control**	**Embracing learning and openness**
	Keeping things under control, knowing the right path from the jump, and avoiding failure when possible, makes for a successful project. Making mistakes is a setback and risks undermining our credibility.	Being open to what emerges and being able to hold multiple viewpoints makes for a successful project. "Failure" is learning; it allows people to be perceived as complex humans and invites others to provide feedback and learn alongside them.

"And I think that you'll see that patient partners are actually people who are willing to work with you and improve the process. And we don't expect perfection, because if we did, we wouldn't be doing this at all."

PWLE

	Established Mindsets	Emerging Mindsets
Mindset 4	**Big data**[15]	**Deep data**
	Quantitative data is the best way to understand a social experience as it is easily comparable and representative of an entire population. Outliers in quantitative data are to be excluded to avoid skewing data sets. Qualitative data is largely anecdotal, biased, costly, and time-consuming.	Qualitative and quantitative data serve different purposes, and each offers valuable (but different) insight. Effective research knows how to leverage the differentiated strengths of each method. Qualitative research is best suited to capturing complex and multilayered social experiences and understanding how people make sense of these experiences. Qualitative research is pivotal to innovation as it opens space for the emergence of unexpected/divergent views that may have previously been overlooked.

"I'm so grateful to have had the opportunity to sit down for an hour (and sometimes even more) to hear a person's experience of being engaged. The dialogue was plentiful; more than I could ever learn from reading survey results. The act of interviewing also allowed me to learn as I went, adjusting my questions to suit the lived experience of the person sitting in front of me. This led to the data we collected being richer."

Policy Analyst

[15] For further reflections on evidence in policy making, see Kimbell (2015)

Preferred Approaches for Meaningful Engagement

"

Until we begin to actually involve people in a meaningful way, we won't see dramatic differences in our healthcare system. It's not just a structural crisis, it's a human crisis.

PWLE

Establishing genuine relationships is fundamental to foster a transparent, comfortable environment.

Policy Analyst

In addition to the mindset shifts described above, we identified four preferred approaches that are core to bringing about engagements that are more meaningful, inclusive, and impactful for all involved. Within each, we explore how mindsets for more meaningful engagement can be brought to life through action. We put forward specific recommendations for future engagements that align with PWLE desires. While separated into four distinct sections for this report, these approaches are deeply interconnected and ideally applied in that manner.

Relate as Collaborators

PWLE are collaborators in the entire engagement process and co-envision the engagement itself.

Foster Inclusive Spaces

Engagements address and recognize power dynamics and privilege to help create more inclusive and caring spaces.

Value Whole People and their Perspectives

PWLE are seen and valued as an expert in their own right and are engaged as whole people.

Demonstrate Deep Listening and Show Impact

Contributions from PWLE are heard and included in engagement outputs and the potential impact of these outputs is clear from the start.

Relate as Collaborators

PWLE are collaborators in the entire engagement process and co-envision the engagement itself.

"

People are not really engaged, not really respected, not usually utilized to their full potential. It's a big turn off, and it hurts people. And it actually creates trauma.

PWLE

(Engaging PWLE earlier on) you would learn a lot, and then your team just gets better and better all the time. They're going to take those learnings and they're going to apply them the next time.

PWLE

Overview

PWLE often feel they are engaged far too late in the process. They are invited to an engagement session but have little say in how the engagement is designed or what comes of it. As one PWLE shared, *"(It's as if) you're going to build a bridge (...) and then halfway through (you) engage the engineer!?"* Moreover, once the event is over, PWLE often hear very little back from the engagers. And when they do, communication can be hard to understand. When this happens, engagements feel tokenistic and inconsequential.

Instead, PWLE hope to be brought in as collaborators, rather than research subjects. This means **being given the opportunity to co-envision the engagement itself**. It also means being kept in the loop on the project's progress before and after an engagement: *"If you would normally communicate to the rest of the team, why wouldn't you communicate to the other (PWLE) team members?"*

PWLE understand that co-envisioning everything isn't always possible and that project delays happen. There isn't an expectation for engagers to always get it "right". However, opening up the space for PWLE to play a role as collaborators earlier on (even in a small way) radically changes the experience and can have a positive effect on the overall engagement. And providing regular updates (even to let participants know that little has changed) can go a long way.

Mindsets in Action

From		To
Engaging subjects to extract data	→	Partnering with collaborators to co-creating learning
Predefined process	→	Iterative and responsive process

Paths Forward

Recommendations

- Invite PWLE (more than one) to participate in the planning phase of the engagement. During this phase, collaborate with PWLE on defining the goal and scope of the engagement, methods, recruitment strategies, facilitation style/focus, and potential outputs and impacts.

- Prior to beginning an engagement, co-define roles and responsibilities (through a partnership agreement for example), while remaining flexible to people's emerging desires and limitations.

- Create (or co-create) a communications plan early on in the process that has regular updates for participants designed in the plan and offer opportunities for others to validate this plan. Don't wait for major milestones to communicate with PWLE; communicate at regular intervals instead. Be transparent in communications about project delays.

- Throughout the engagement, provide PWLE with opportunities to comment on and shape the process as it unfolds. For example, during the research preparation phase, PWLE can contribute to interview guides (adding questions, flagging unfamiliar language). Another example is to open up space for feedback on the agenda of an engagement session before it happens.

- Clearly designate a point of contact for all communications and questions to create clarity and a sense of continuity. Offer multiple ways to communicate and ask participants their preferred communication method.

- Invite PWLE to play a role in the engagement sessions itself, such as a facilitator, note taker, or peer mentor.

⚘ Invite PWLE to shape and co-author outputs of engagements, and co-present findings of engagements. Cite, when desired, PWLE as authors and contributors.

⚘ Use plain language (define acronyms, avoid academic jargon, and internal lingo) in all communications. Employ translation services as needed to ensure that communications are accessible to different language speakers.

⚘ Prioritize long-term engagements over one-offs; long-term engagements help build relationships and allow time and space for iterations and adjustments as the engagement unfolds.

Foster Inclusive Spaces

Engagements address and recognize power dynamics and privilege to help create more inclusive and caring spaces.

"

When working with doctors and researchers, you know when they understand privilege. You just sense it. You can hear it in the tone of voice, and they validate what you say. For those that don't understand privilege, I won't continue to work with them.

PWLE

I'm not going to speak into a void. I said I'm going to be speaking about things that are really personal. I could be really emotional. I need to feel safe. I need to feel people care. Think about how uncomfortable I may feel, not knowing (if) anybody out there is listening to me.

PWLE

Overview

Even when PWLE are included in engagements, engagements do not always feel inclusive. This often begins with recruitment. Recruitment efforts may happen through larger healthcare centres in urban areas which may exclude non-urban PWLE and historically marginalized or underserved communities. Furthermore, when engagers do reach out directly to communities, they don't always take the time to build a relationship with them and truly understand local barriers to engagement. This does not go unnoticed. As one participant shared, *"I've gone to another (engagement) where I felt I wasn't welcomed. I was the only black person on these committees and summits (…) and I would look around the table, oh my God, where are the rest of the people? (…) I have requested for all the committees that I'm on. If we don't have diversity, whether it's seniors, race, gender, then it's not something I can be involved with."*

Mindsets in Action

From		To
Focusing on who is in the room	→	Considering who isn't in the room and whose voices are not heard
Avoiding difficult topics	→	Opening space for healing conversations

During engagements, PWLE often feel that the engagers don't recognize the power and privilege they hold and that may be present in the room. This results in PWLE **feeling that their voices are perceived as "less valid" or that they cannot speak openly** about their experience. For example, PWLE often find themselves as the sole representative of a lived experience in the room or of a specific community, making the engagement feel tokenistic and lowering their confidence in speaking out. As one participant explained, *"Some people get really intimidated being with researchers, or being with policy-makers or people in those types of positions because it is a power imbalance."*

Furthermore, when engagers fail to build meaningful relationships with PWLE, **sharing difficult stories can feel one-sided, voyeuristic, and triggering.** This is further exacerbated when facilitators may (unknowingly) represent institutions that have caused PWLE harm in the past. Difficult conversations are necessary, but without a caring space, can become harmful[16].

PWLE described **meaningful engagements as addressing power and privilege throughout the entire process** — from recruitment to facilitation to outputs. For example, effective facilitators are seen as understanding privilege, having humility, and addressing power differentials between stakeholders.

16 We want to recognize that a larger conversation is taking place around terms used to describe spaces that support transformative conversations. The limitations of terms such as "safe" and "trauma-informed" have recently been highlighted. Scholars and thinkers have put forward alternative terms such as "accountable"; "brave"; "healing"; and "trauma-responsive" spaces (see respectively Arao and Clemens, 2013; Stewart, 2017; Ginwright, 2018, and Fathallah, 2020). In this report, we have opted for the words "caring" and "healing." These terms helped us, on one hand, move away from the tendency to avoid conversations that may be challenging and, on the other hand, frame participants as resilient and complex (rather than solely through the lenses of trauma and deficit).

Paths Forward

Recommendations

To support more inclusive recruitment:

⚘ Employ multiple recruitment methods (such as through healthcare practitioners, word of mouth, social media, and patient organizations) to reach PWLE.

⚘ Include more personal recruitment outreach when possible (e.g., emails reaching out directly to people).

⚘ Build relationships with community leaders and organizations to reach excluded voices and understand local barriers to involvement. Start building relationships with potential participants early on.

⚘ Understand and consider the needs and histories of local communities before reaching out to them. This includes acknowledging past harms or exclusions.

⚘ Consider recruiting diverse PWLE roles, such as patients, caregivers, and loved ones.

Before the session, support PWLE in feeling confident in their contribution:

⚘ Ensure that PWLE have clarity on their role and the structure of the session, to ensure that they feel confident in participating. Consider sharing an accessible summary (one-pager) of the session structure and questions beforehand.

⚘ Connect one-on-one with each participant before the engagement to build a relationship, and help them feel that they know at least

one person in the session. This helps increase comfort and avoid PWLE feeling as though they are sharing their stories in a void or with strangers.

⚜ Develop (ideally collaboratively with PWLE) invitations on how to show up during the session that centre listening, openness, and respect (e.g., there is no right or wrong). Socialize with PWLE to gain feedback and elevate.

⚜ Provide training for PWLE (e.g., on engagement processes, storytelling) to help them feel confident in participating and "finding their voice."

⚜ Provide training to engagers to help them understand and recognize their power, privilege, assumptions, and unconscious bias.

⚜ Check in with participants on needs/desires to support well-being, including physical (e.g., food), cultural (e.g., presence of healers, translation), practical (e.g., support with technology), and emotional (e.g., caregiver presence).

⚜ Provide resources to support participation, such as childcare, transportation, and translation services, along with compensation.

During the session, co-create a space that addresses power differentials between roles:

⚜ Prioritize methods that centre relationship building, trust, and inclusion (e.g., talking circle, working groups, co-design sessions). De-prioritize one-off, quick, or purely asynchronous engagements that can limit the possibility for trust-building.

⚜ Consider the ratio of participants to facilitators. Avoid having more facilitators or internal actors than PWLE. Ensure that there is more than one PWLE present (ideally equal ratio to other participants).

⚜ Include PWLE mentors who have been part of engagements in the past to support PWLE who may be new to engagement.

⚛ Provide breaks (to rest and recuperate) and a variety of refreshments (suitable to the needs of those being engaged), keeping in mind the physical impacts of certain conditions.

⚛ Offer and make clear to participants that they have multiple ways to share their input both during and after the session.

⚛ Offer flexible engagements, from light engagement (one or a few sessions, or shorter sessions) to full engagement (all sessions, or longer sessions). Check in with participants around the best times to hold the sessions, depending on time zones, working schedules, and other commitments.

Create a caring space that is conducive to healing conversations:

⚛ Provide training to engagers on trauma-informed and responsive facilitation methods as well as how to hold space for the sharing of challenging experiences.

⚛ Check in with participants after a session on their experience and provide any support they may need.

⚛ Provide resources/supports for both facilitators and participants (e.g., counseling services, peer support). Offer these supports automatically to all participants to avoid putting the burden of "asking" for support on participants and possibly creating more harm.

Value Whole People and their Perspectives

PWLE are seen and valued as an expert
in their own right and are engaged as whole people.

"

If you want people to come and sit together, and
speak together, and have a discussion, and feel like
they're having an equitable place at the table, why
are you labelling [them with titles]?

PWLE

There are many tools available to arrive at fair
compensation, but those tools are useless unless
there is a strategic priority by an organization to
value and invest in patient involvement.

PWLE

OVERVIEW

During engagements, PWLE often sense that their lived experience is not as credible as other people "at the table" who are deemed "experts." A heavy reliance on titles or credentials to prove expertise signals to PWLE that their lived experience is not as valid. This is further exacerbated when PWLE are the only people not being compensated for their time. As one participant stated, *"Lived experience is a superior thing that can't be learned in a book."* PWLE also resent when they are asked to share their experience but are not given proper credit for contributing to the output. *"I don't need to be subservient to someone's exemplary career and credentials."*

PWLE want to be **valued as experts in their own right.** When the focus is on **engaging as humans (rather than as titles)**, participants can connect on equal footing and demonstrate respect for unique points of view. In doing so, everyone (including policy analysts) can show up as their fuller selves[17], including their cultural backgrounds, worldviews, and transferable skills from other areas. *"(I want to) exist in the space (of engagement) wearing multiple hats, as patient and policy analyst."*

While compensation is not a motivator in and of itself for many PWLE to participate in an engagement, it does signal that their time and knowledge are valued by the organization. When fair compensation has been planned for in the design of an engagement and throughout larger budgeting cycles, PWLE see this as a commitment on behalf of the organization to take their perspectives seriously.

17 It is important to consider that simply asking people to show up as their "whole selves" isn't enough. We heard that participants often evaluate which parts of themselves they feel they can "safely" reveal based on how privilege and power is showing up in a given space.

Mindsets in Action

From		To
PWLE experience as anecdotal	→	PWLE as experts of lived experience
Relating as roles/titles (e.g., patient, policy analyst)	→	Connecting as whole people with complex and varied experiences

Paths Forward
Recommendations

🌾 Rethink focusing on titles — they reinforce power dynamics between established "experts" and other participants. Find creative ways to introduce participants that don't solely rely on sharing credentials or job titles and help people connect as humans beyond their roles[18].

🌾 Consider language that reinforces the value and expertise of PWLE (e.g., experts with lived experience). Ask participants what language they prefer whenever possible.

🌾 Clearly explain the value and role of PWLE in the engagement to further validate their expertise for other stakeholders present.

🌾 Plan Branch or Directorate resource expenditures in advance to ensure funds are available to support meaningful engagements (e.g., compensation, childcare, transportation, accessibility needs).

🌾 Compensate fairly and separate compensation from other engagement-related expenses (e.g., travel, childcare). Compensation for participants should be flexible and shouldn't create more challenges for participants (for example, limiting them from accessing financial aid)[19].

[18] For example, in the co-design sessions, instead of asking participants to introduce themselves with their titles, we asked them to share three words that describe them (in any way they wanted) and about their relationship to their community or the land around them.

[19] Refer to "Insights B Learnings on compensating PWLE for engagements" on page 74 for more insight into compensation during engagements.

Demonstrate Deep Listening and Show Impact

Contributions from PWLE are heard and included in engagement outputs and the potential impact of these outputs are clear from the start.

"

I've done hundreds of surveys but actually stopped doing them because often I don't get feedback on those surveys. [They will] send you your honoraria, but [I] rarely ever hear what kind of impact my input may have had.

PWLE

Don't make me think that I can actually contribute to where the policy is going, if it's already there.

PWLE

Overview

During engagements, PWLE expressed that they often feel as though they have **been invited to "be in the room" physically, and yet they don't feel heard in the process and don't see their contributions in the outputs.** As one participant stated, *"Sometimes you provide all kinds of comments, and then you see the final version and don't know how you contributed."*

This is deeply frustrating, especially because "making a difference" is what motivates PWLE to participate in engagements in the first place. *"Health Canada engages a whole bunch of people from the public and does something with that engagement, but never gives it back to the people that they engage."* This feeling of voicelessness can lead to further disengagement and erodes trust in the institution(s) leading it.

Mindsets in Action

From		To
Ambiguous data collection	→	Outputs that reflect PWLE contributions
Sharing information on a "need-to-know" basis	→	Building trust through transparency

Instead, PWLE would like their lived experiences to be heard, validated, and translated into actions to make the healthcare system better for their community. This requires engagements to occur at a stage of policy or program development when **people actually have the opportunity to influence the outcome**, rather than at a later stage when the engagement is largely a "check the box" activity. It also requires a willingness for the engagers to truly listen and respond to what they hear. PWLE know when they've been heard (*"I know when people are hearing it, is that they are repeating it and we are having real conversations"*) and they appreciate methods that demonstrate listening on behalf of the engager (*"When you see the writing, I mean, it could be on a computer, projection screen, wall chart, you see that your words have been taken and put somewhere, then people don't feel that they're not listened to"*).

The potential impact of the engagement should be transparent from the start. This can be a deciding factor for PWLE to participate. It is understood that not all input will be actioned or included in deliverables. As one participant shared, *"People are respectful, (they) don't expect that 100% of your input is going to be acted on. But when it is zero percent then you have a problem."*

Paths Forward

Recommendations

- Be clear and transparent from the start with participants on the potential impacts (and limitations/risks, including budget constraints) of the engagement, and keep participants up to date as things progress. This could be done through plain language communications or meetings before the start of the engagement.

- During the engagement, listen with openness and to learn, rather than to share your opinion. Ask thoughtful questions, take notes, and affirm what you've heard.

- Throughout the session, reflect back to participants what was heard. Consider using collaborative tools (e.g., digital whiteboards like Miro) to capture contributions in real time and in a transparent way.

- Close engagement sessions with clear next steps, timelines, and possible future moments of input.

- Create summaries of what was shared after the session for people to see their words reflected and provide an opportunity for participants to add nuance/context/changes as needed.

- Review and evaluate outputs based on their effectiveness to make the change that PWLE wanted to see. Consider using tools like evaluation frameworks and/or promote accountability by connecting engagement funding to demonstrating impact.

- Provide training for engagers to learn to listen deeply and how to take what they are hearing and translate it into policy.

- Provide training for engagers to explain and share in plain language what they heard from participants.

⚘ Share experiences with decision-makers of how engagements with PWLE have led to meaningful insights and make clear the importance of collaborating with PWLE to create change within the organization.

⚘ Make deliverables available to all participants.

⚘ Create opportunities for participants to provide feedback on the experience and outcomes. Use this information to shape future sessions and future engagements.

A Test Trial to Bring these Visions to Life

"

[They] did a wonderful job of genuinely listening/open to feedback and setting the stage for a true co-design session where PWLE and other stakeholders actually determined the scope and priorities.

PWLE

I felt proud to have been part of this project and inspired to continue in engagement with PWLE.

Engagement Specialist

Our Suggested Solution — Co-Design

Throughout the interviews, the project team heard over and over again from PWLE that they wanted to be more than a source of data; they wanted to collaborate on creating ideas, strategies, and solutions to the topic they were being engaged on. Moving beyond simply sharing their story, attending a roundtable, or filling out a survey, they wanted to use their lived experience to collaboratively and actively help solve the problem at hand.

This desired approach pointed directly to a co-design methodology. The term "co-design" has roots in participatory research. Essentially, it is a **process where by participants become part of the design team as "experts of their experience" and play a role in knowledge/concept development and idea generation** (Sanders and Stapper, 2008). Throughout the co-design process, participants (or co-designers) are treated as equals, rather than subjects.

The Project Heart team had the opportunity to test a co-design methodology in the third phase of the project. The goal of this stage of the project was to use what we learned about engagement in previous project activities (interviews and environmental scan) **to co-design desired futures of engagement, prioritize them, and ideate paths toward this preferred future state.**

By using this approach, we were also able **to test what engagement might look like when it prioritizes collaborative and meaningful**

relationships. To do so, we designed a series of co-design sessions as a pilot. In the spirit of iterativeness, we wanted to test this early on to learn and adapt each session as we went.

The result? We learned through participant feedback that **bringing people in as collaborators builds trust and makes engagement more impactful**. We hope to continue test trialing and prototyping this approach more broadly. Below, we outline in detail the approach with the hope that others can learn from what worked and what could be further developed.

Co-Design Methodology

Planning Co-Design (Co-Designing the Co-Design)

Wanting maximum collaboration from a co-design approach, the project team decided to include community co-designers at the earliest possible stage: the planning of the co-design session. Three co-designers, who represented a variety of lived experiences, were recruited from the Advisory Committee and prior project phases. Two two-hour virtual planning sessions were held using Zoom. Miro was used as a tool to work collaboratively before, during, and after the planning sessions.

The first planning session focused on getting to know each other and collectively determining the goals of the co-design sessions. Ideas for inclusivity and meaningful participation were shared. After the session, the contributions were distilled into a draft plan. These ideas included how to build relationships between participants, how to support participants, and the importance of communicating the potential impact of the work. Aligning with what we learned from other phases of the project, the co-designers emphasized that our co-design sessions should focus more on relationships and dialogue and less on completing a set amount of work.

The second planning session focused on reviewing the draft plan and tweaking it based on dialogue from the group. Draft versions of "visions" for better engagement were presented for revision and validation. Roles and recruitment strategies were also discussed, and co-designers were invited to take on a role during the co-design sessions (e.g., participant, facilitator, or participant mentor). The participant-mentor[20] was something new for the project team; the co-designers described this role as a person with lived experience that could play a dual role: participating but also supporting other PWLE participants if and when they are having a difficult time during session activities.

Once a plan was finalized, a dry run was held with members of the Advisory Committee. This provided an opportunity to rehearse facilitation, practice note-taking, and test the overall flow of the session. At the end of the dry run session, valuable feedback was shared. "Test" participants appreciated the overall pace and atmosphere of the session and offered tangible suggestions related to managing the virtual space (e.g., suggestions on how to use chat functions, offering breaks).

Overall, co-designing the co-design was a valuable addition to the project. It gave us better insight into the needs of participants and concrete ideas on how to make the time together meaningful. It helped us to break away from commonly held assumptions of how meetings or workshops are run, and opened up a space for shared decision-making and new approaches to the work. The co-designers emphasized bringing "humanness into meetings" and highlighted the importance of transparency before, during, and after the co-design.

It was also critical to have the opportunity to have a dry run with participants who were both internal and external to Health Canada. It gave us a safe space to "test" a new way of working with a mix of people with various professional and personal backgrounds. It was reassuring and confidence-building that this approach was appreciated and even a welcome change.

[20] In certain research traditions, including a mentor can be seen as distorting data. In participatory methods such as co-design, where the focus is on creating a space in which everyone takes part in decision-making, mentors can work to increase comfort and encourage participants to take a more active role in sessions.

Co-Design Sessions: An Overview

Like the planning sessions, the co-design sessions were held virtually (Zoom), and a collaborative space (Miro) was designed for each session. Co-designers included interested past interviewees, Advisory Committee members, and policy analysts. Before the session, all co-designers completed a prioritization and reflection exercise on the "visions for better engagement," helping them feel prepared for the prompts that would be discussed in the session itself.

The sessions began with Land Acknowledgements and a moment of pause to reflect. Co-designers then broke out into small groups, with one facilitator per group. One facilitator was a PWLE with facilitation experience and the other facilitator was the project consultant. In addition to a facilitator, each small group consisted of two policy analysts from Health Canada/Public Health Agency of Canada, two PWLE representatives, a PWLE participant-mentor, and a note-taker. After introducing themselves, the small groups discussed the "vision for better engagement" that they prioritized, exploring the challenges and opportunities for each. From there, they ideated solutions and actions that could contribute to bringing these visions to life. The sessions ended with the smaller groups coming back together to share their overarching reflections and learnings.

Co-Design Sessions: A Detailed Breakdown

Below is a summary of practices employed during the co-design sessions based on the team's learnings and feedback from the co-design planners. **As mentioned elsewhere, these actions should be co-defined with PWLE collaborators and that the tone and manner of these steps are equally important.**

Before the engagement

- Co-designed the co-design sessions with PWLE.

- Created and recruited PWLE roles, such as a facilitator and mentors for each small group. Recruited a diverse mix of participants (six PWLE and four policy analysts).

- Consulted financial policy resources to determine compensation amounts and processes.

- Held pre-session meetings with individual participants to share project information, learn about participant needs, discuss pre-work, share information on compensation, and build comfort.

- Sent a welcome package (video and text) to participants outlining the goals of the sessions, possible impacts, and invitations on ways of working together. This also included compensation paperwork.

- Sent pre-work to participants five days ahead of the session and invited them to spend time reflecting on prompts prior to the session. This also included a list of participants using their names and three self-generated words to describe themselves.

- Sent reminders to participants with the online meeting link and phone number of the project team (in case of technology issues).

During the engagement

- Started each session with a land acknowledgement and a moment of pause, led and created by the PWLE facilitator. The introduction also included an invitation for participants to show up as their "whole selves" and not limit their participation to a particular "role."

- Avoided focusing on titles/roles as part of introductions; invited people to share about their relationships to their community or land.

- Shared the potential impact of the project/co-design at the beginning of each session.

- Held three sessions with the same participants, rather than three sessions with different participants to allow time and space for relationship building and dialogue.

- Reduced the number of visions we previously thought we would work on during the sessions to ensure we had time to fully discuss and include moments to pause and reflect.

- Used a collaborative tool (Miro) to collect and validate participants' input in real time.

- Opened up space to receive feedback on the sessions, including what worked and what could have been improved.

In-between Sessions

- Sent emails to the participants after each session to say thank you.

- Offered opportunities for participants to provide feedback.

- Held meetings/touchpoints in between sessions with PWLE co-facilitator to make adjustments for upcoming sessions based on participant feedback.

- Kept collaborative spaces (Miro) open for contributions in-between sessions.

After the sessions

- Processed compensation.

- Maintained ongoing communication related to project updates and opportunities to contribute to and share feedback on draft reports.

Learnings from Trialing Co-Design

Since the third session of our co-design was focused on getting feedback on the co-design experience, we were able to gather valuable learnings from participants to apply to future sessions. Co-designers were asked to use the prompts "I like, I wonder, I wish"[21] on a variety of topics, including atmosphere, communication, relationship building, and being invited to brainstorm. Based on the feedback, we learned about the things that worked well, what we should do more of/ continue, and what we would change for future session.

WHAT WE WOULD DO MORE OF

"I love the co-designing format and overall approach to the work." Co-design participant

"I appreciated the additional meeting to properly onboard and knew I could request more support if needed." Co-design participant

"My input was valued, and my voice was encouraged throughout the discussions." Co-design participant

[21] The "I Like, I Wish, I Wonder" is a commonly used tool in design to elicit feedback. It encourages participants to reflect on areas that resonated (I like), areas that could have been done differently (I wish), and starting points for unanswered questions and emerging ideas (I wonder).

Generally, most participants appreciated the co-design approach and had positive things to say about the overall atmosphere and time management of the sessions. Participants expressed that they felt heard and valued and that they felt comfortable sharing their ideas. Participants also appreciated the pacing of the session, noting that they did not feel rushed and that there was enough time allotted to discuss the topics.

Participants also had positive reflections on the opportunity to work with others. They appreciated that the group formations were based on a prioritization exercise. Participants noted how they appreciated working with people who had different personal and professional experiences (e.g., the mix of policy analysts and PWLE). Participants also noted that they were able to show up as their "whole selves," and were not expected to only contribute from the viewpoint of a certain role or title. In fact, most participants shared that they liked that there were no labels or titles used throughout the sessions.

Participants also provided feedback on communication throughout the process. Things like having one contact person, having a phone number to call, and onboarding meetings were appreciated. One participant shared, *"Despite having a few different people involved it was good to get emails from only one person and have that person serve as the main contact. Often this piece can be confusing."*

Most participants were pleased with how compensation was handled. They felt that it was transparent and embedded in the project, and therefore they didn't have to advocate or ask for it. Some participants did have questions about the timing and processing of payments, noting that they were aware of the amount but not aware of when the payment would be processed. Participants were also curious about the financial policy that determines the amount of compensation.

WHAT WE WOULD CHANGE FOR NEXT TIME

"I found the time to prepare and reflect was a little too short. Ideally the time between when materials are shared and the next meeting would be a solid week. It was difficult to carve out time to review and do my homework for the next session with only 2-3 full days, especially given those are workdays." Co-design participant

"I wish we had a separate session to get to know each other before the start." Co-design participant

"Another session would be helpful, but not another Friday. Three weeks consecutively — people need to rest." Co-design participant

Although the project team felt that we had allocated a good amount of time and opportunities for relationship building, what was apparent in the feedback from participants was that they wanted more —more time, more sessions, more opportunities to connect organically with fellow participants, even beyond the dialogue prompted by the facilitator.

Participants also suggested that we give more time for pre-work and spread the sessions out further apart. Despite some participants stating that they felt the time in the sessions was sufficient, other participants would have liked more time in the sessions for brainstorming and dialogue.

Due to the nature of this exploratory, employee-led project, it was hard for the project team to clearly map out if and when changes would occur in the organization, but it was clear that co-design participants wanted to see this work amount to something impactful. Some participants also shared a desire to support the next phases of the project. One person shared that they are *"keen to see the outputs and how this approach will translate into results"*. A policy analyst participant shared their desire for Health Canada to adopt an approach that would *"effectively engage persons with lived experiences to assist policy makers in creating human/community focused health policies."*

Conclusion

> "

As a community member engaged in the project, I hope that the outcomes of Project Heart will demonstrate the importance of engaging community members as whole people beyond their patient or caregiver identity, and how this approach can result in more comprehensive solutions to healthcare challenges and better outcomes.

A. Nicola, PWLE

For me, participating in Project Heart has emphasized the importance of humanizing healthcare and policy. I hope an impact of this project will be to continue challenging the status quo by raising PWLE voices to the forefront and instilling honesty, respect, and trust into the work that we do.

L. Dunkley, Policy Analyst

Key Takeaways

"I wish this activity could grow into a broader movement within the organization to fuel change."

PWLE

Project Heart set out to define what meaningful engagement looked like for PWLE. In doing so, we learned that meaningful engagement was about a lot more than the engagement session itself — it was about **embodying new ways of showing up for each other grounded in collaboration, humility, and trust.**

Specifically, the project:

Redefined engagement from the perspective of PWLE, learning that engagement is less about following a predetermined checklist, and more about building strong relationships that lead to true collaboration.

Tested a different engagement approach grounded in co-design and relationship building.

Explored new ways of working and outlined mindset shifts that can help teams collaborate differently to create meaningful change.

Through the process of redefining engagement, we learned that **when engagement is done meaningfully it benefits all involved.** First and foremost, it builds trust in communities and humanizes people as active and valued contributors. The impact of this cannot be overstated — doing so has the potential to interrupt cycles of inequalities in the healthcare system. It also helps ensure that PWLE experiences, including those from historically marginalized or underserved groups, are reflected in healthcare policies and programs, resulting in better health outcomes for all people living in Canada.

Secondly, it increases the chances of what Health Canada rolls out being relevant, useful, and usable to the people it is meant to impact. In doing so, it helps circumvent misplaced investments.

Lastly, a collaborative approach allows for internal capacity building. When PWLE are engaged as collaborators, engagers have the opportunity to learn through practice how to meaningfully lead engagements. In doing so, engagers can build long-term relationships with communities while lessening Health Canada's reliance on external resources.

Looking Forward

This report is a starting point, rather than an end. It is an invitation to relate to engagement differently — that is, not as a task to be completed, but as a path to building more meaningful relationships with communities and each other. It is a rallying call to all engagers and Health Canada staff to re-envision policy development through the lens of "Nothing About Us Without Us." In the words of one participant: *"Lots of organizations connected to Health Canada are (taking) a forward-thinking and active approach in policy development. It's overdue and disappointing (that Health Canada hasn't)."* We see this as a unique opportunity for Health Canada to not only action the findings from Project Heart, but to also become a leader in this space.

Looking forward, the Project Heart team will continue to speak out about the importance of this approach to engagement. Specifically, the team will focus its efforts to:

Advance and recommend **learnings about meaningful engagement** more broadly across Health Canada at various levels (including employees, management, and senior executives).

Share **learnings about ways of working** to build increased capacity to innovate across Health Canada, and inspire diverse stakeholders to test and prototype the approach themselves. This includes **hosting a co-design workshop** for interested Health Canada staff.

Work with the Solutions Fund on designing a subsequent proposal for **piloting and implementing a collaborative approach to engagement.**

However, large-scale change across Health Canada cannot be left solely to the Project Heart team; it requires resolve from leaders across the system, at all levels, to move beyond the status quo and commit their will and effort towards this vision (NHS 2018). In this vein, we outline **ways in which *you* can start to bring about change in your work** that would be a purposeful step along the journey to meaningful engagement.

Opportunity 1:
Self-Reflection.

Now that you have read the report, take the time to reflect on the approaches and mindsets that are calling you. Reflect on what felt challenging, inspiring, familiar, or surprising as you read this report and explore what this may signal for you. Consider what you feel is stopping you and why.

Opportunity 2:
Implement paths forward.

Start implementing new paths forward in your next engagement — consider starting with a few and gaining feedback. With each engagement, try implementing other paths forward to learn and grow towards more collaborative relationships.

Opportunity 3:
Experiment with mindsets.

Start experimenting with "emerging mindsets." Explore (alone or with your colleagues) how "established mindsets" may show up in your ways of working and what they allow and limit. Trial an "emerging mindset" in your next engagement to learn and see how it shifts your, your team's, and PWLE experiences.

Opportunity 4:
Share your learnings to spur conversation.

Share your learnings and/or this report with your colleagues, including managers, senior leaders, and other decision-makers to spur conversation. Begin a conversation around your current engagement practices and the "health" of the roots of your engagements.

We look forward to hearing from you and continuing the movement to bring about more meaningful engagements together!

Paths Forward

*Recommendations
Summary*

Paths Forward Summary
Recommendations

Below is a comprehensive summary of the recommendations presented in the Preferred Approaches. For ease of reference, we have organized these by phases that take place in typical engagements.

Throughout the entire engagement
Prioritize collaboration and relationship building.

- Provide PWLE with opportunities to comment on and shape the process as it unfolds. For example, during the research preparation phase, PWLE can contribute to interview guides (adding questions, flagging unfamiliar language). Another example would be to open up space for feedback on the agenda of an engagement session before it happens.

- Use plain language (define acronyms, avoid academic jargon, and internal lingo) in all communications. Employ translation services as needed to ensure that communications are accessible to different language speakers.

- Prioritize long-term engagements over one-offs; long-term engagements help build relationships and allow time and space for iterations and adjustments as the engagement unfolds.

BEFORE THE ENGAGEMENT
Setting up a meaningful engagement

Defining the scope and methods of the engagement

- Invite PWLE (more than one) to participate in the planning phase of the engagement. During this phase, collaborate with PWLE on defining the goal and scope of the engagement, methods, recruitment strategies, facilitation style/focus, and potential outputs and impacts.

- Prior to beginning an engagement, co-define roles and responsibilities (through a partnership agreement for example), while remaining flexible to people's emerging desires and limitations.

- Create (or co-create) a communications plan early on in the process that has regular updates for participants designed in the plan and offer opportunities for others to validate this plan. Don't wait for major milestones to communicate with PWLE; communicate at regular intervals instead. Be transparent in communications about project delays.

- Prioritize methods that centre relationship building, trust, and inclusion (e.g., talking circle, working groups, co-design sessions). De-prioritize one-off, quick, or purely asynchronous engagements that can limit the possibility for trust-building.

- Offer flexible engagements, from light engagement (one or a few sessions, or shorter sessions) to full engagement (all sessions, or longer sessions). Check in with participants around the best times to hold the sessions, depending on time zones, working schedules, and other commitments.

- Plan Branch or Directorate resource expenditures in advance to ensure funds are available to support meaningful engagements (e.g., compensation, childcare, transportation, accessibility needs).

Recruiting and compensating participants

⚜ Employ multiple recruitment methods (such as through healthcare practitioners, word of mouth, social media, and patient organizations) to reach PWLE.

⚜ Include more personal recruitment outreach when possible (e.g., emails reaching out directly to people).

⚜ Build relationships with community leaders and organizations to reach excluded voices and undertand local barriers to involvement. Start building relationships early on.

⚜ Understand and consider the needs and histories of local communities before reaching out to them. This includes acknowledging past harms or exclusions.

⚜ Consider recruiting diverse PWLE roles, such as patients, caregivers, and loved ones.

⚜ Compensate fairly and separate compensation from other engagement-related expenses (e.g., travel, childcare). Compensation for participants should be flexible and shouldn't create more challenges for participants (for example, limiting them from accessing financial aid).

Connecting with participants before the engagement session

⚜ Connect one-on-one with each participant before the engagement to build a relationship and help them feel that they know at least one person in the session. This helps increase comfort and avoid PWLE feeling as though they are sharing their stories in a void or with strangers.

⚜ Clearly designate a point of contact for all communications and questions to create clarity and a sense of continuity. Offer multiple ways to communicate and ask participants their preferred communication method.

⚜ Be clear and transparent from the start with participants on the potential impacts (and limitations/risks including budget constraints) of the engagement, and keep participants up to date as things progress. This could be done through plain language communications or meetings before the start of the engagement.

⚜ Consider language that reinforces the value and expertise of PWLE (e.g., experts with lived experience). Ask participants what language they prefer whenever possible.

Planning the delivery of the engagement session

⚜ Develop (ideally collaboratively with PWLE) invitations on how to show up during the session that centre listening, openness, and respect (e.g., there is no right or wrong). Socialize with PWLE to gain feedback and elevate.

⚜ Invite PWLE to play a role in the engagement sessions itself, such as a facilitator, note taker, or peer mentor.

⚜ Ensure that PWLE have clarity on their role and the structure of the session, to ensure that they feel confident in participating. Consider sharing an accessible summary (one-pager) of the session structure and questions beforehand.

⚜ Consider the ratio of participants to facilitators, avoid having more facilitators or internal actors than PWLE. Ensure that there is more than one PWLE present (ideally equal ratio to other participants).

- Include PWLE mentors who have been part of engagements in the past to support PWLE who may be new to engagement.

- Provide training to PWLE (e.g., on engagement processes, storytelling) to help them feel confident in participating and "finding their voice."

- Check in with participants on needs/desires to support well-being, including physical (e.g., food), cultural (e.g., presence of healers, translation), practical (e.g., supports the use of technology), and emotional (e.g., caregiver presence).

- Provide resources to support participation, such as childcare, transportation, and translation services, along with compensation.

Providing training to engagers

- To help them understand and recognize their power, privilege, assumptions, and unconscious bias.

- To learn to listen deeply and how to take what they are hearing and translate it into policy.

- To explain and share in plain language what they heard from participants.

- On trauma-informed and responsive facilitation methods as well as how to hold space for the sharing of challenging experiences.

DURING THE ENGAGEMENT
Facilitating a caring and inclusive space

- Rethink focusing on titles — they reinforce power dynamics between established "experts" and other participants. Find creative ways to introduce participants that don't solely rely on sharing credentials or job titles, and help people connect as humans beyond their roles.

- Clearly explain the value and role of PWLE in the engagement to further validate their expertise for other stakeholders present.

- Offer and make clear to participants that they have multiple ways to share their input both during and after the session.

- During the engagement, listen with openness and to learn, rather than to share your opinion. Ask thoughtful questions, take notes, and affirm what you've heard.

- Throughout the session, reflect to participants what was heard. Consider using collaborative tools (e.g., digital whiteboards like Miro) to capture contributions in real time and in a transparent way.

- Provide breaks (to rest and recuperate) and refreshments (suitable to the needs of those being engaged), keeping in mind the physical impacts of certain conditions.

- Provide resources/supports for both facilitators and participants (e.g., counseling services, peer support). Offer these supports automatically to all participants to avoid putting the burden of "asking" for support on participants and possibly creating more harm.

- Close engagement sessions with clear next steps, timelines, and possible future moments of input.

After the session
Activating learnings meaningfully

- ⚘ Check in with participants after a session on their experience and provide any support they may need.

- ⚘ Create summaries of what was shared after the session for people to see their words reflected and provide an opportunity for participants to add nuance/context/changes as needed.

- ⚘ Create opportunities for participants to provide feedback on the experience and its outcomes. Use this information to shape future sessions and future engagements.

- ⚘ Make deliverables available to all participants.

- ⚘ Invite PWLE to shape and co-author outputs of engagements, and co-present findings of engagements. Cite, when desired, PWLE as authors and contributors.

- ⚘ Share experiences with decision-makers of how engagement with PWLE led to meaningful insights and make clear the importance of collaborating with PWLE to create change within the organization.

- ⚘ Review and evaluate outputs based on their effectiveness to make the change that PWLE wanted to see. Consider using tools like evaluation frameworks and/or promote accountability by connecting engagement funding to demonstrating impact.

Additional Engagement Insights

INSIGHTS A

Learnings on PWLE Motivations to Engage

"What motivates me generally is giving back to the community. So, people with lived experience sometimes get so frustrated with their experiences. They want to help other people that are going through similar things, in hopes they have an easier time than they did." PWLE

"When I got better, and a new drug came on the market, a new clinical trial, and I was benefiting from all this science, I wanted to give back because I knew that some people can't express themselves in the worst times of their lives." PWLE

There are a wide range of motivations for PWLE to participate in engagements about policy and program decisions. Overall, PWLE are motivated to make an impact on their community and beyond, and have a deep desire to improve the healthcare system.

Making a positive impact on the healthcare system
By participating in engagements on issues relevant to them, many PWLE feel that they can induce change in Canada's healthcare system. Through sharing their perspective, PWLE hope to raise awareness of the issues facing PWLE and advocate for policy changes that will improve the quality of care and access to health services. Conversely, if the potential impact is not clear or doesn't seem strong enough, PWLE may not be inclined to participate.

Advocating for themselves and others

Many PWLE see participating in engagements as a way to advocate for themselves or others with similar health challenges. For example, adverse and frustrating experiences with the healthcare system has led many PWLE to participate in engagements simply because they did not want others to have the same negative experience with healthcare.

A desire for a strong healthcare system for the country

Some PWLE feel that engagements are a way of supporting and improving the well-being of citizens in this country. They describe this as patriotic as PWLE want to shape policies that benefit their communities and country as a whole.

Knowledge of or emotional connection to the topic

Many PWLE are motivated to engage in issues that felt close to their hearts and that they were familiar with. Engaging about a topic that is valuable to an individual can motivate them to advocate more passionately.

Giving back to the community

Many PWLE feel that by giving their time and input during an engagement that they are giving back to both the broader community and to individuals who may have similar healthcare experiences or conditions.

Inclusion of a diverse range of perspectives

Many PWLE expressed a desire for engagements to include individuals that can represent diverse perspectives, including those that have been traditionally underserved or excluded. If these perspectives are missing from the engagement, some PWLE may decline to participate.

Engagement methods that allow for collaboration and co-design

PWLE are more inclined to participate and contribute throughout the engagement process when the process emphasizes the value of their input through collaborative co-design.

Inspiring innovation

By participating, PWLE hope to inspire innovative solutions that address healthcare challenges from a novel perspective. Many PWLE felt that there is a lack of innovation in healthcare, especially from governments and their departments. Thus, some PWLE believe their advocacy can inspire the innovation they feel is necessary to address their concerns.

Credibility and expertise

PWLE believe they bring a level of authenticity that policy-makers may not have. They can give accounts of their experiences with the healthcare system, both negative and positive. This can help to highlight what works and what does not for policy-makers. PWLE are motivated by the idea of sharing "teachable moments" for policy-makers.

Learnings on Compensating PWLE for Engagements

"You need to compensate the patient (PWLE), whether they want it or not. I think compensating them puts them on an equal level as the rest of the team. Every other team member is paid for their time and effort." PWLE

"Tax implications of compensation are frustrating for those on income assistance." PWLE

PWLE shared that being compensated for their time and expertise is an important part of engagers valuing lived experience. However, compensation needs to be fair and flexible, and avoid creating financial or administrative challenges for PWLE.

Compensation signals to PWLE that they are valued

During engagements, most participants (e.g., clinicians or policy analysts) are compensated by the organization that they represent. PWLE, however, depend on engagers to compensate them for their time and expertise. Doing so signals that their presence is valued, like any other participant.

Depending on an individual's circumstance, monetary compensation may create income challenges

Because compensation is considered taxable income, accepting monetary compensation could impact the amount of taxes an individual pays or

the amount of benefits or tax credits they may receive (e.g., disability benefits). Having alternative ways to compensate, such as gift cards or charitable donations, and providing these different compensation options to the participant, could help to mitigate these challenges.

Compensation for participation is separate from covering the costs of attending the engagement

Costs such as travel, childcare, meals, and accommodations are important enablers of participation, but they should be budgeted separately from compensating individuals for their time and expertise. Money to cover these costs should be provided upfront so PWLE are not waiting to be reimbursed afterward.

It is important to be transparent about compensation amounts and processes before the start of the engagement

This includes rates for compensation, paperwork requirements, payment methods, and timing of payments. PWLE appreciate having the opportunity to ask questions and receive information before agreeing to participate.

Paperwork can be burdensome and sharing personal information is unnerving

Documents that require electronic signatures or the ability to print and scan documents can be difficult for some people. Requiring participants to provide personal details such as addresses, Social Insurance Numbers, and banking information can feel like an overreach on behalf of the organization and may actually exclude people from participating. There is a desire for organizations to be flexible in their compensation policy, such as issuing cheques or gift cards and creating systems that don't require the collection of personal information. Furthermore, engagers need to understand the populations they are engaging and any associated protocols. For example, asking Indigenous Elders for Social Insurance Numbers or banking information can be inappropriate.

INSIGHTS C

Learnings on Recruiting for Engagements

"If you want to engage people, you need to know your city, you need to know your town, you need to know 'who do I talk to', how we can engage this particular community."
PWLE

Meaningful engagement cannot happen if recruitment is not successful. Recruitment should include multiple methods and focus on relationship building.

Employ multiple recruitment methods
This includes posters/flyers, email distribution, website or social media postings, and "word-of-mouth." Leverage established healthcare providers, health networks, patient networks, and different patient groups or organizations to support these multiple methods.

Include personalized outreach when possible
Reaching out directly to potential participants with a personalized invitation with targeted information may lead to better response rates.

Offer a variety of response options
Allow response options to range from low-tech (e.g., phone number) to electronic (email, QR codes).

Recruit a variety of PWLE roles
Some examples are patients, caregivers, family, and loved ones.

Involve community leaders and organizations to reach excluded voices and understand local barriers to involvement
Community leaders and organizations are very well placed to give recommendations on recruitment; it is often best to partner with these leaders or organizations to support recruitment efforts. Start building these relationships early on.

Understand and consider the needs and histories of local communities before reaching out to them
This includes acknowledging past harms or exclusions.

Be aware that language can impact participation
Respectful, inclusive language in recruitment materials demonstrates that the organization respects the perspective and expertise of those they are looking to recruit.

Include all relevant information in recruitment materials
For participants to make an informed decision, include details such as engagement methods, recruitment criteria, time commitment, location, compensation, and contact information.

Allow time for a conversation or information session before the engagement
Give potential participants the opportunity to ask questions and learn more about the engagement. This also helps to build trusting relationships early on in the engagement.

Learnings on PWLE Expectations for Health Canada to Engage

"I would suggest that the wonderful people at Health Canada think about working a little bit more with their key pan-Canadian stakeholders on engagement, and then reaching groups they tend not to reach in general." PWLE

"I do find the general person living in Canada probably doesn't truly understand the magnitude of what Health Canada does and what they might engage on right now." PWLE

Overall, PWLE believe that Health Canada has a responsibility to engage as part of decision-making processes. However, PWLE feel that there is a lack of clarity around jurisdictional authority and how/when policies are made, thus limiting opportunities for PWLE and others to be part of engagement activities.

Health Canada should actively engage before decision-making

Most PWLE felt that it was appropriate for Health Canada, as a federal department, to be conducting engagements. Despite the grievances some PWLE expressed with previous engagement experiences, many PWLE still believe that to improve the healthcare system Health Canada should engage before decision-making. One PWLE stated, *"I think it's appropriate for any organization, whether federal or provincial associations, or departments, to be engaging. If people don't [engage] with those they serve, they're being foolish."*

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Health Canada can play a leadership role by committing to meaningful engagement

Some PWLE believe that having Health Canada conduct engagements is beneficial *"because the more engagement that is led by different groups and agencies, the more commonplace it will become."* There was also a desire for Health Canada to partner with provinces and other health organizations to make engagement more relevant, seamless, and coordinated.

Decision-making within the healthcare system can be difficult for people to navigate

Throughout the engagement process, many participants shared that they were uncertain about the role Health Canada plays in the administration of the Canadian healthcare system. With multiple levels of government involved, as well as various healthcare providers and stakeholders, it can be difficult to understand how different pieces fit together and how decisions are being made. One PWLE noted, *"Health Canada needs to be clearer about what they do and what they can impact."*

Learnings on the Experience of Being Engaged Virtually Versus In-person

"[Virtual engagement] offered us an opportunity for greater engagement, greater consultation capability, where we can bring people together on a national level, in a much easier fashion, without having to consider travel and other kinds of accessibility issues." PWLE

"I mean, the last few years with COVID and everything being done over Zoom didn't help. It's tough to get engaged when you're looking at a couple of squares on the screen." PWLE

There are benefits and drawbacks to both in-person and virtual engagements. Overall, rather than having a strong preference for one method over another, PWLE expressed that participation should be accessible and promote an environment of equitable participation. Engagers should be aware of considerations for both methods and accommodate accordingly. Hybrid models (mix of online sessions and in person sessions) are seen as effective as they leverage the best of both modalities.

Considerations for a virtual format

Virtual engagement can be very cost-effective compared to in-person engagement as there is no need to rent a venue or pay for travel costs. Virtual engagements can support geographically broad participation and allows people to participate from the comfort of their own home or other preferred environment. However, virtual engagements assume that everyone has access to Wi-Fi and laptops/devices and that they can navigate online platforms such as Zoom or Microsoft Teams. Some PWLE also cautioned that building relationships and encouraging participation may be more challenging online. *"We've tried break-out rooms online, but it is just not the same [as being in person]."*

Considerations for an in-person format

Some PWLE shared that there is an innate human element to in-person engagements, which makes building connections easier than online. Technological barriers are not present in an in-person engagement and in-person engagement can be a great way of establishing connections and meeting other people. However, participation may be limited to those in a certain geographical area or those who can travel. The cost of in-person engagements can be higher and therefore limit the length of the engagement.

Definitions of Key Terms

Person with lived experience

Someone who has direct personal experience with the specific subject matter. The term is inclusive of a broader scope of descriptors such as patient, family, caregiver, citizen, and community member.

Engagement (community)

The meaningful involvement of individuals and communities for a variety of purposes, including defining issues and needs, considering solutions, establishing priorities and implementing a program, project or service change (LHIN, 2011).

Inclusive/inclusion

The practice of using proactive measures to create an environment where people feel welcomed, respected and valued, and to foster a sense of belonging and engagement (Government of Canada, n.d.).

Miro

A digital whiteboard that can be reviewed and edited by all collaborators at any time (see images on page 17).

Mindsets (mental models)

Habits of thought; deeply held beliefs and assumptions and taken for granted ways of operating that influence how we think, what we do, and how we talk (Kania et al.).

Marginalized group

A group of people that is excluded from full and meaningful participation in society, typically through discrimination or other means of oppression (Government of Canada, n.d.).

Trauma-informed facilitation

An approach to facilitation that prioritizes creating a safe and supportive environment for individuals who have experienced trauma (BC Campus, 2022).

Co-Design

The term has roots in participatory research; essentially, it is a process where participants become part of the design team as "experts of their experience" and play a role in knowledge/concept development and idea generation (Sanders and Stapper, 2008).

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