


Project Heart

A Collaborative Exploration of the Future of Engagement

Meaningfully Engaging People with Lived Experiences
in Healthcare Policies and Programs




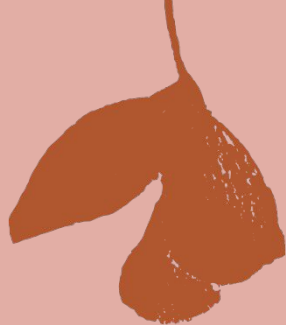


We recognize that we all live and work in different places and therefore on different traditional Indigenous territories.

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.

We invite you to explore the [Native Land](#) website to learn more about the land you live and work on.





“The times are urgent, let us slow down.”

Bayo Akomolafe

Let's take a moment together to pause. Breathe.
Let's tap into our willingness to connect, listen,
and envision something different.

An Invitation to Listening

We invite you to:

- ❖ Think about engagement differently — not as a task to be completed, but as a **path to building more meaningful relationships** with communities.
- ❖ Receive **stories as gifts**.
- ❖ Reflect on the **seeds of change** you might start planting to bring about more caring futures of engagement.

“

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, Collaborator



A Collaborative Endeavour to Co-envision Meaningful Engagement

Team of community members with lived experience, researchers, designers, and policy analysts with diverse experiences in the healthcare system.

Funded by the Solutions Fund: employee-led innovation and experimentation

Project Collaborators *in alphabetical order*

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Project Heart

The Context



We find ourselves in a moment of cultural change — people are becoming increasingly dissatisfied with opaque and top-down processes.

They are demanding increased transparency and expecting to meaningfully shape the decisions that will impact them.⁰¹

01 Sanders and Stappers (2008); Sheard et al. (2019), Kavakil (2021).



The Challenge

- ❖ **Engagements are no longer a nice to have:** roundtables, working groups, committees and councils that include persons with lived experience are becoming more common across governments and other sectors.
- ❖ Yet, when we do engage people, we often focus on what we (as engagers) need and is achievable — **we have little understanding of the needs and desires of those being engaged.**

The Project Goal

Understanding engagement from the perspective of those being engaged (PWLE*) and how we, as government employees, can approach engagements so they are meaningful, inclusive, and impactful for all involved.

***PWLE: Person With Lived Experience:**

- ❖ Someone who has direct personal experience with the specific subject matter.
- ❖ Inclusive of a broader scope of descriptors such as patient, family, caregiver, citizen, and community member.
- ❖ Language matters — rather than assuming what is best, collaborate with the communities you are engaging to co-define a lexicon that aligns with their needs and desires.

“

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] honours people's actual human experience in a respectful way.

PWLE



Our Approach

Grounded in Design Thinking and Design Research

Step 01 Environmental scan

Step 02 Interviews with PWLE

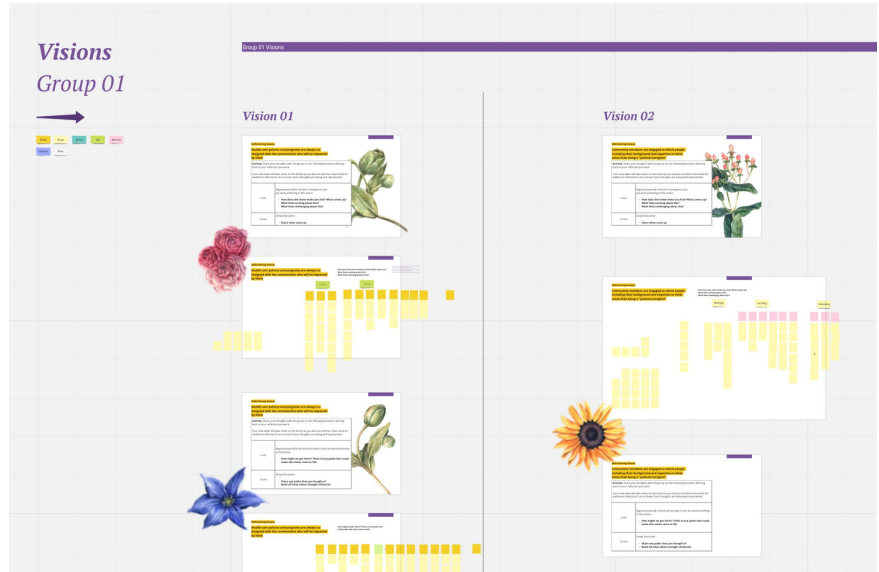
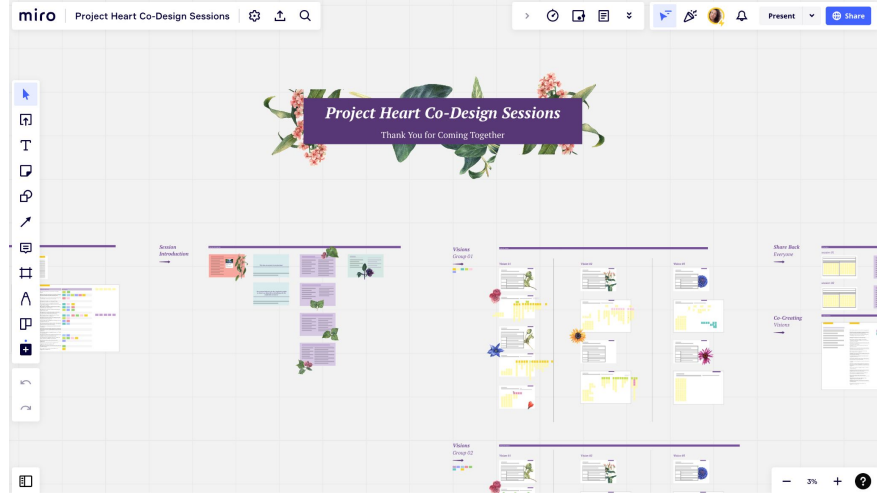
Step 03 Co-design sessions with PWLE
and policy-analysts

The Context

Our Approach

Guiding Principles:

- ❖ Exploratory and open-ended
- ❖ Empathetic
- ❖ Participatory
- ❖ Iterative and Responsive
- ❖ Reflexive



Principles in Practice

“

This project wasn't about checking a box - it was about a desire to listen, taking things to heart, and being introduced to new ways of working. The way the project was designed helped us connect with participants on a human level, without fear of failure.

Project Heart Collaborator

Project Heart

The Learnings



The Tension

When people speak of **ideal engagements**, they often speak of:

- ❖ Collaboration
- ❖ Partnership
- ❖ Trust
- ❖ Strong relationships

When people speak of **past engagement** experiences, they often speak of:

- ❖ PWLE: Feeling as though they are being invited to check a box, being a token, or feeling that their engagement is inconsequential
- ❖ Policy analysts: Feeling as though they are stuck in a method and process that doesn't serve them; unsure if they are getting it "right"

The Tension

“

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

It's difficult to balance out where you feel there's real added value (to engaging people), to what extent you need to engage so that you make sure that you keep them safe, (and making sure its) not just tokenism.

Policy Analyst



Cultivating meaningful
engagements is like
growing a healthy tree

- ❖ We often focus on the leaves and branches
- ❖ We at times tend to the trunk
- ❖ We most often forget the roots

For a healthy tree, we can't just focus
on the leaves and the branches.
We need healthy roots.



Cultivating meaningful
engagements is like
growing a healthy tree

Leaves the data engagers are hoping to collect

Branches the engagement session itself

Trunk planning of the session (e.g., recruitment, communication with PWLE outside of the session)

Roots mindsets (deeply held beliefs) about engagement; quality of the relationships that are built throughout the entire engagement.

The Main Learnings

**Strong relationships
are the roots of
meaningful engagements**

“

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

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.

Sustainable and **meaningful change requires us to look at the implicit beliefs** (the mindsets, 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.

The Main Learnings

**Strong relationships
are the roots of
meaningful engagements**

More meaningful engagements are:

- **Less about** following a predetermined checklist or about the tools, tech, and methods used
- + **More about** building strong relationships that lead to true collaboration

The Main Learnings



Mindset Shifts

Changing how we **think** about engagement



Preferred Approaches

Changing how we **do** engagement



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



Mindset Shifts

Definition 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.).

Established

Expert Driven

Goal Oriented

Keeping things
under control

Big Data

Emerging

Collaborative

Process Oriented

Embracing learning
and openness

Deep Data

Preferred Approaches *for Meaningful Engagement*



Relate as
Collaborators



Foster
Inclusive
Spaces



Value Whole
People and
their
Perspectives



Demonstrate
Deep
Listening and
Show Impact



Preferred Approaches *for Meaningful Engagement*

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The Learnings

Preferred Approaches
for Meaningful Engagement

Relate as Collaborators

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



“

So much of what I've experienced in engagement is not interactive, is not involvement, but it's more extracting.

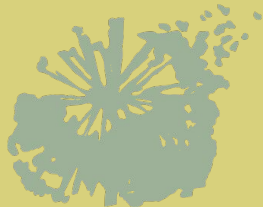
PWLE

The Learnings

Preferred Approaches
for Meaningful Engagement

Relate as Collaborators

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



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 engagement methods, recruitment strategies, possible outputs, impacts, and a communication plan.
- ❖ Invite PWLE to play a role in the engagement sessions itself, such as a facilitator, note taker, or peer mentor.

These are a small selection of recommendations, please see the report for a full list.

Preferred Approaches *for Meaningful Engagement*

Relate as
Collaborators



Foster
Inclusive
Spaces



Value Whole
People and
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Demonstrate
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Preferred Approaches
for Meaningful Engagement

Foster Inclusive Spaces

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



“

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.

PWLE

Preferred Approaches
for Meaningful Engagement

Foster Inclusive Spaces

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



Paths Forward

Recommendations

- ❖ 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.
- ❖ 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.

These are a small selection of recommendations, please see the report for a full list.

Preferred Approaches *for Meaningful Engagement*

Relate as
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Value Whole
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Preferred Approaches
for Meaningful Engagement

Value Whole People and their Perspectives

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



“

I don't need to be subservient to someone's exemplary career and credentials.

PWLE

(I want to) exist in the space (of engagement) wearing multiple hats, as patient and policy-analyst

PWLE

Value Whole People and their Perspectives

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



Paths Forward

Recommendations

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

These are a small selection of recommendations, please see the report for a full list.

Preferred Approaches *for Meaningful Engagement*

Relate as
Collaborators



Foster
Inclusive
Spaces



Value Whole
People and
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Demonstrate
Deep
Listening and
Show Impact



Preferred Approaches
for Meaningful Engagement

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

Preferred Approaches
for Meaningful Engagement

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.

Paths Forward

Recommendations

- ❖ Be clear and transparent from the start with participants on the potential impact of the engagement, and keep participants up to date as things progress.
- ❖ 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.

These are a small selection of recommendations, please see the report for a full list.

The Learnings



When engagement
is done meaningfully,
it benefits all involved

- ❖ Improve health outcomes by centering the experiences of PWLE (including those from historically marginalized or underserved groups) in policies and programs
- ❖ Build trust with communities and humanizes people in the process
- ❖ Increase the chances of what we rollout being relevant, useful, and useable to the people it is meant to impact (rather than misplaced investment)
- ❖ Make recruitment easier for future engagements
- ❖ Allow for internal capacity building
— lessening the reliance on external resources

Project Heart

Putting Co-Design at the Centre of Engagement



Why Co-Design?

Co-design: 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)

- ❖ Participants 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
- ❖ In co-design, everybody is allowed to bring ideas and take action

Our Approach to Co-design

A series of sessions including PWLE and policy analysts

focused on co-designing solutions for more meaningful engagement and testing co-design as a methodology for engagement.

The co-design sessions included:

- ❖ co-designing the co-design sessions
- ❖ co-envisioning desired futures of engagement
- ❖ prioritizing these futures
- ❖ ideating paths towards this ideal future state
- ❖ gaining feedback on the experience of co-designing

The Learning

Collaborative approaches like co-design feel impactful to both PWLE and policy-analysts and work to build trust and strong relationships

“

[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

My input was valued and my voice was encouraged throughout the discussions.

PWLE

Project Heart

What happens next



Health Canada has the opportunity to lead the way towards more meaningful engagements.

“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).”



Next Steps for the Project Heart team

- ❖ Sharing findings more broadly about meaningful engagement
- ❖ Sharing learnings about ways of working to build capacity to innovate across the organization
- ❖ Inspiring diverse stakeholders to test and prototype the approach themselves
- ❖ Work with the Solutions Fund on designing a subsequent proposal for piloting and implementing a collaborative approach to engagement

Next Steps for you

- ❖ **Reflect** on what felt challenging, inspiring, familiar, or surprising and explore what this may signal for you.
- ❖ **Implement paths forward** in your next engagement — consider starting with a few and gaining feedback.
- ❖ **Experiment with mindsets.** Trial an “emerging mindset” in your next engagement to learn and see how it shifts your, your team’s, and PWLE experiences.
- ❖ **Share your learnings to spur conversation** with your colleagues, managers, senior leaders, and other decision-makers. Begin a conversation around your current engagement practices and the “health” of their roots.

Spearheading change



“

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.

PWLE

For me, participating in Project Heart has emphasized the importance of humanizing health care 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.

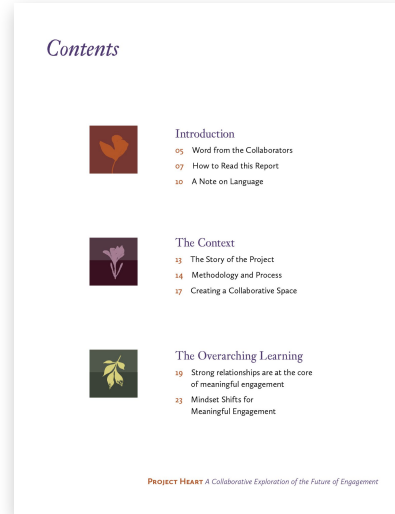
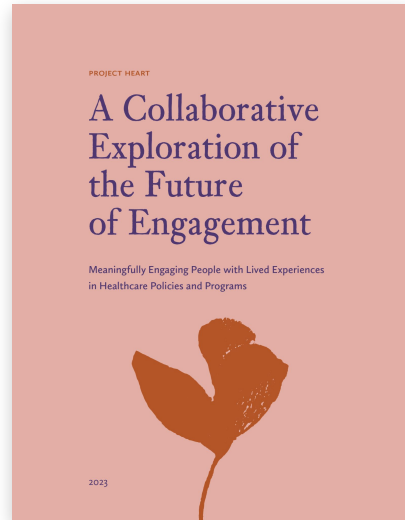
Policy Analyst

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

Policy Analyst

Reach out to Read the Full Report

A preview



Reach out to Read the Full Report

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.

Reach out to Read the Full Report

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The Solutions Fund

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- ❖ Deep dive into methods, process, and learnings
- ❖ Additional engagement insights that share findings around compensation, recruitment, motivations to participate and more
- ❖ In-depth outline of co-design sessions and learnings from the sessions

