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- • Community engagement in DFM prison health research: Practices and reflections

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Outline

1. Community engagement (20)
 - Definitions, conceptual model, principles
2. Examples from DFM prison health research (20)
3. Activity (10)

What is community?

- US Agency for Toxic Substances and Disease Registry (ATSDR): **“those who are affected by the health issues being addressed”**
 - recognizes that those affected by health issues are often left out of health improvement efforts even though they are supposed to be the beneficiaries of those efforts
 - various stakeholders/“[interest-holders](#),” including academics, public health professionals, and policy makers
- McMaster [sourcebook](#) (guide for community-engaged learning):
 - described as “the intermediary layer between the personal (e.g., family, friends and self) and the structural (e.g., organizations, institutions, policies and structural forces)”
 - We are **“all embedded in multiple overlapping communities”**

What is community engagement? I

- US CDC: **“the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people”**
- McMaster [sourcebook](#): **“the intentional connection between communities and institutions to foster learning and change”**
 - McMaster [definition](#): “...valuing the expert knowledge and passion that members of the community (both local and global) have about their communities and issues affecting them; fostering ongoing collaboration between University and community partners on how to better understand and consider the issues identified as priorities by local and global communities; and perform research, teaching and service with community members and partners for the public good (OCE, CE Education Toolkit, 2018).”

What is community engagement? II

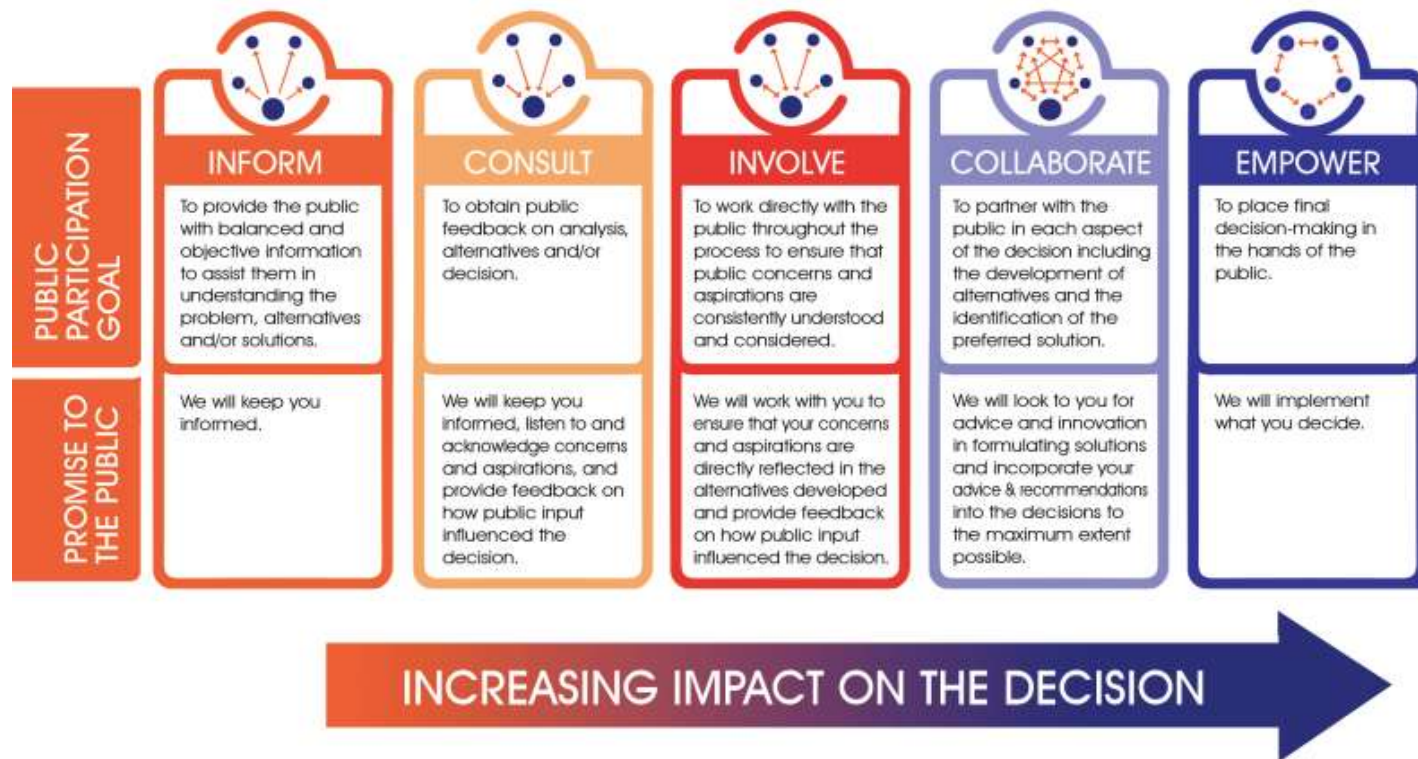
- US ATDSR:

“In practice, community engagement is a blend of science and art. The science comes from sociology, political science, cultural anthropology, organizational development, psychology, social work, and other disciplines, and organizing concepts are drawn from the literature on community participation, community mobilization, constituency building, community psychology, and cultural influences. The art comes from the understanding, skill, and sensitivity used to apply and adapt the science in ways that fit the community of interest and the purposes of specific engagement efforts.”

Why do community engagement?

- to make our work better: more inclusive, more valid, more effective, less harmful
- to support community buy-in
- because it's the right thing to do
- because we are required to

Continuum of community engagement



- ideally, shift to the right over time

Principles of community engagement I (ATSDR)

Before you start	<ol style="list-style-type: none">1. Define goals of engagement and which populations/communities you want to engage.2. Become knowledgeable about the community: culture, SES, networks, political and power structures, history, perceptions of those initiating engagement.
For engagement to occur	<ol style="list-style-type: none">3. Go to the community, establish relationships, build trust, work with leadership, and seek commitment from community organizations and leaders to create processes to mobilize the community.4. Remember and accept that collective self-determination is the responsibility and the right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.

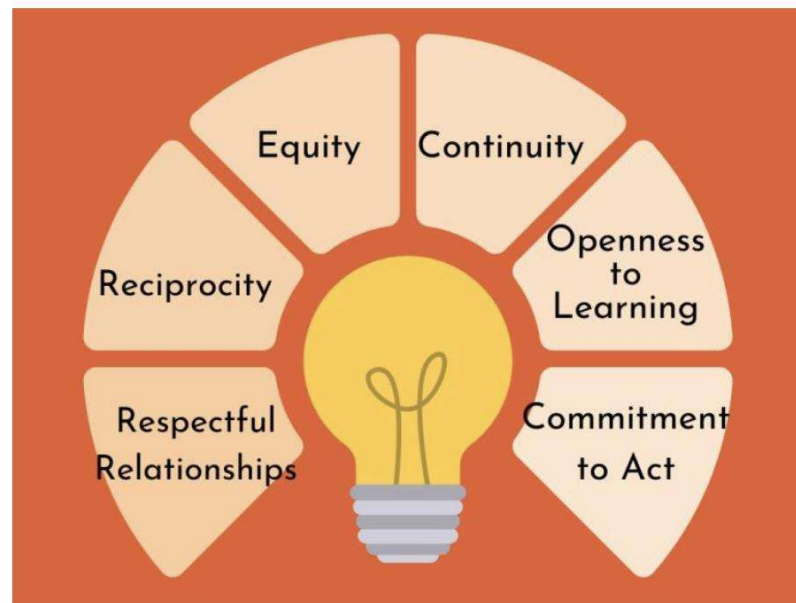
Principles of community engagement I (ATSDR)

For
engagement
to succeed

5. **Partnering** with the community is necessary to create change and improve health.
 6. All aspects of community engagement must recognize and **respect the diversity of the community**. Awareness of the various cultures of a community and other factors affecting diversity must be paramount in planning, designing and implementing approaches to engaging a community.
 7. Community engagement can only be sustained by identifying and **mobilizing community assets** and strengths and by developing the community's capacity and resources to make decisions and take action.
 8. Organizations that wish to engage a community as well as individuals seeking to effect change must be prepared to **release control** of actions or interventions to the community and be flexible enough to meet its changing needs.
 9. Community collaboration **requires long-term commitment** by the engaging organization and its partners.
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Principles of community engagement II

- McMaster [sourcebook](#):



The Bright Light of McMaster's Six Principles of Community Engagement

McMaster checklist for six principles

Principle	Self-assessment questions
Respectful Relationships	<p>Have I taken the time to understand this community by reviewing publicly available materials prior to engaging the community partner? How? Am I listening actively to community partners? How?</p> <p>Have I been open and honest with my community partner about my skills, limitations, and the amount of time and energy I can devote to this project?</p>
Reciprocity	<p>How will I make sure that my engagement contributes something meaningful to this community?</p> <p>How have I considered the community partners' needs and expectations in my project plan?</p> <p>What can I do to ensure that I draw on community partners' time appropriately?</p> <p>What skills do I hope to develop throughout this experience? How can my participation in this project enhance those skills?</p>
Equity	<p>How do my identities (race, gender, sexuality, class) matter in terms of this work? How might community members perceive my participation? What broader power structures affect this issue and how does the community participate in this issue? What are common assumptions and biases about this issue? What perspectives may be missing and why?</p> <p>Is everyone able to participate equally in this process? What are the barriers and how can we use an equity approach to mitigate those barriers and ensure participation?</p>
Continuity	<p>Are there opportunities to build on prior community-engaged learning with this community partner? What are they?</p> <p>Are there opportunities to develop future community-engaged opportunities with this partner? What are they?</p>
Openness to Learning	<p>Are there elements of my lived experience that might make working and learning with this community partner difficult? What are they?</p> <p>What difficulties might I have when learning from and with individuals who are dissimilar to me?</p> <p>How have I demonstrated that I am listening to my community partner? What steps have I taken to ensure there is clear and honest communication with my community partner?</p> <p>How do I approach learning and growing from mistakes and misunderstandings?</p>
Commitment to Act	<p>Do I have sufficient time and energy for this work? What steps will I take to ensure this?</p> <p>What will I do if I need to exit the work early in the process?</p>

DFM prison health research

Who is the community? (ATSDR: “those who are affected by the health issues being addressed”)

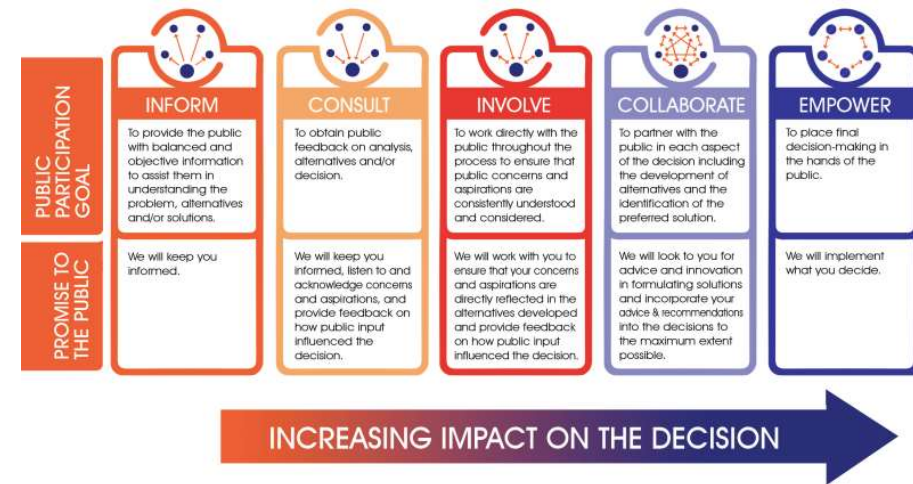
- people who experience incarceration
 - and people at risk of incarceration?
- their families
 - and their communities?
- people working with/for people who experience incarceration
- correctional authorities
- others?

Approaches to engagement

- Examples:

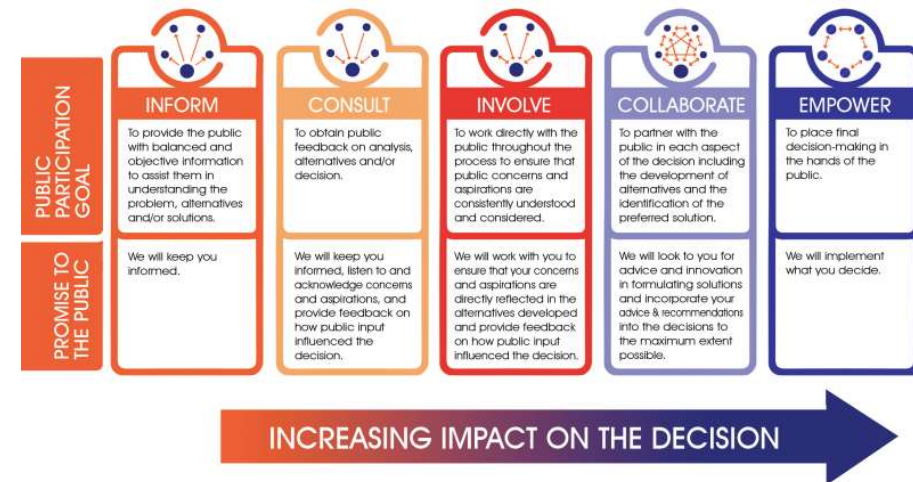
Engagement	Approach	Project example
Project-specific	1. Project Advisory Group	C-CHANGE
	2. Knowledge exchange	Opioid toxicity project
	3. Project team involvement	Indigenous opioid toxicity project
	4. Partnership	CHIRP
Longitudinal	5. Longitudinal engagement	Research Council

1. Project Advisory Group



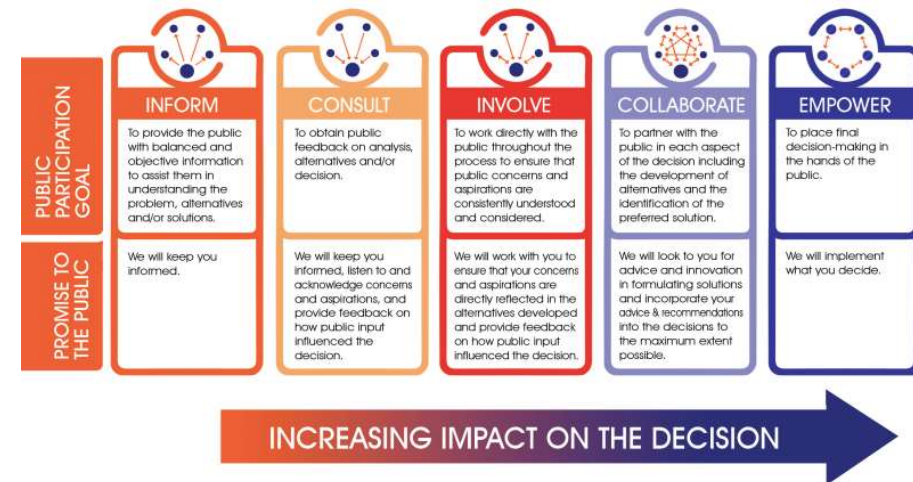
- **Project:** PHAC- funded work to develop health surveillance in federal prisons
- **Goal:** To seek advice, to inform.
- **What was done?** We engaged with people with lived experience of incarceration and people working at organizations involved in service delivery and advocacy.
- **Why this approach?** Early in relationship development, nature of partnerships in project.
- **How did it go?** Accessed information (e.g. how to engage people in federal prison effectively), built relationships.

2. Knowledge Exchange



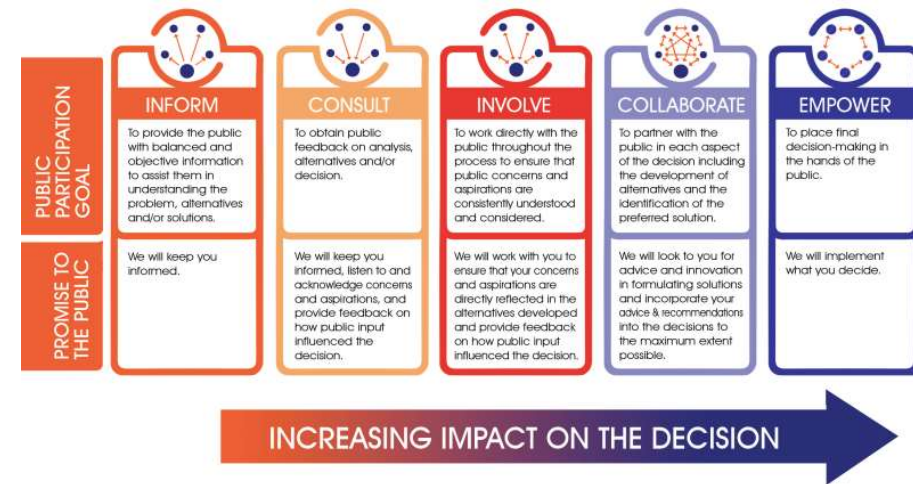
- **Project:** CIHR (CRISM)-funded research project to describe deaths from opioid toxicity in people who experience incarceration
- **Goal:** To support interpretation/framing/dissemination of findings.
- **What was done?** We held 3 end-of-grant sessions with people with lived experience of incarceration and family members, supported by [Amplify Engagement](#). Discussions impacted knowledge products and dissemination.
- **Why this approach?** Recognition of community members' expertise.
- **How did it go?** Accessed information.

3. Project team involvement



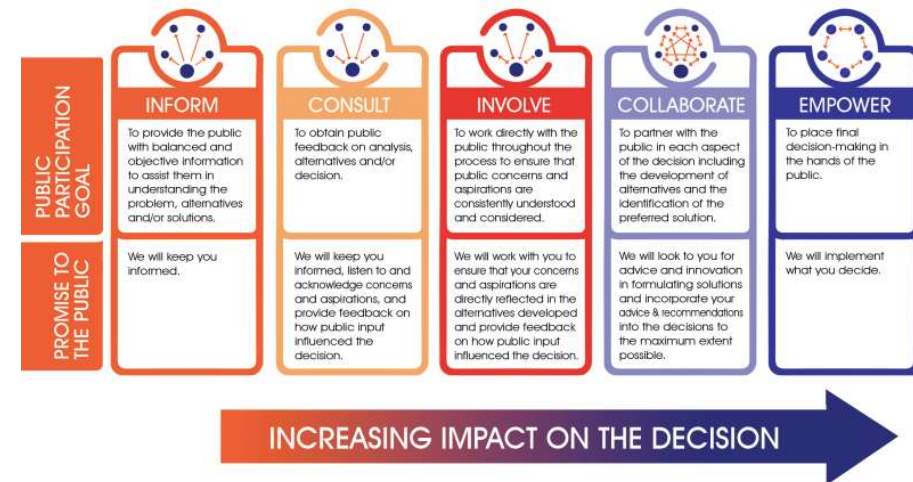
- **Project:** Component of opioid toxicity project focused on Indigenous people
- **Goal:** To seek advice, to inform.
- **What was done?** Project team included an Indigenous researcher, Indigenous people with lived experience of incarceration and substance use, family members, and a representative of a National Indigenous Organization.
- **Why this approach?** Recognition of community expertise, [TCPS2](#) requirements
- **How did it go?** Supported framing of findings, built relationships

4. Partnership



- **Project:** CIHR-funded project to estimate the number of children who experience parental incarceration (CHIRP) and explore their health.
- **Goal:** To ensure research answers questions, to understand research context.
- **What was done?** We partnered with a national organization focused on children who experience parental incarceration, and we are conducting end-of-grant knowledge exchange sessions to discuss findings.
- **Why this approach?** Project requested by national organization, value of community knowledge.
- **How did it go?** Limited resources.

5. Research Council



- **Project:** Development of a 12 member Council of people with lived experience of incarceration for engagement in prison health research.
- **Goal:** To partner/collaborate, to share information.
- **What was done?** We worked with Amplify Engagement to develop the Council, ongoing developmental and collaborative work.
- **Why this approach?** Interest in doing research better.
- **How did it go?** Need time to build relationships and support co-led work, challenges with funding.

Lessons learned

- value of longitudinal relationships AND diverse voices/ perspectives
- need funding/ resources to support community engagement
- tailor community engagement to align with goals
- best time to plant a tree...

Activity

- Consider a research project that you are currently involved with:
 - Who is the community?
 - How are you engaging with the community now?
 - What would improved community engagement look like?
- Take 2 minutes to consider and 4 minutes to discuss with a partner (or as an online group).

Take home messages

- Plan for community engagement
 - get help and access internal and external resources
- Work to shift right on the continuum
- Best time to plant a tree...

Resources

- ATDSR. Principles of Community Engagement- Second Edition.
<https://www.atsdr.cdc.gov/communityengagement/>
- IAP2. <https://www.iap2canada.ca/foundations>
- McMaster sourcebook.
<https://ecampusontario.pressbooks.pub/communityengagedlearningatmcmaster/front-matter/welcome-to-community-engaged-learning-at-mcmaster/>