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Family Medicine



David Braley  
Primary Care  
Research  
Collaborative

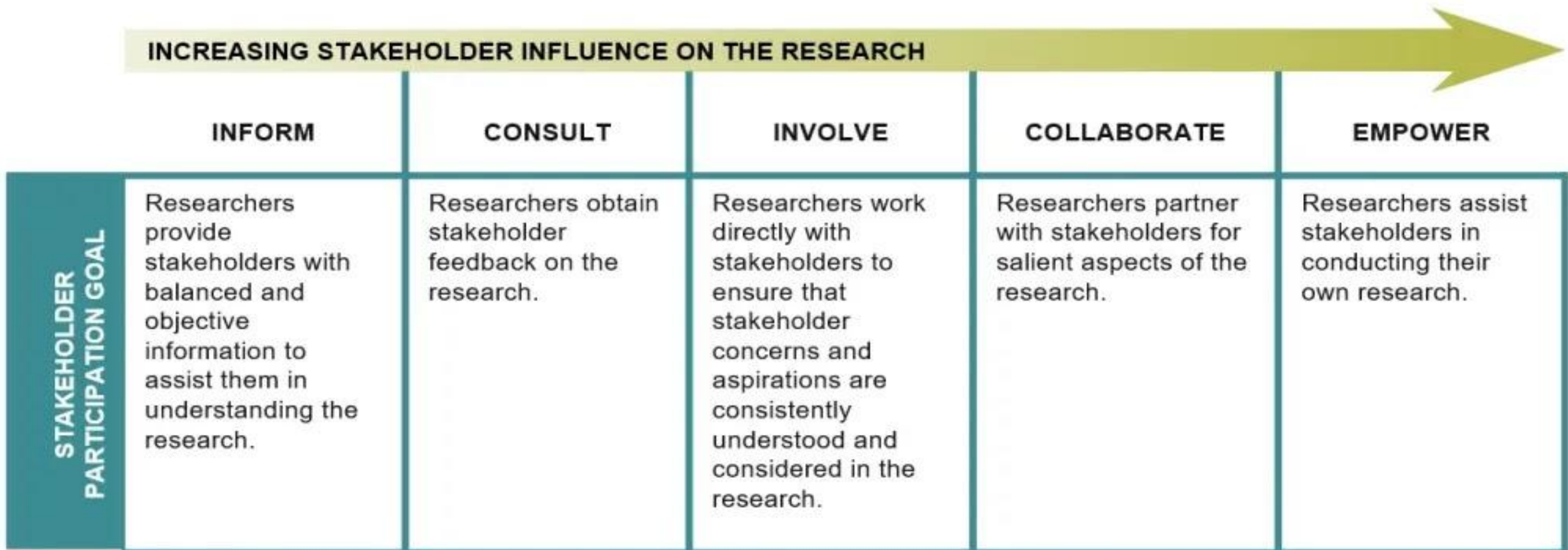
# Developing a Prison Health Research Council of People with Lived Experience of Incarceration

Presented by

Members of the Prison Health Research Council:  
Brian Beck Pascoe and Tiina Eldridge

# INITIAL VISION

To move prison health research in the Department of Family Medicine (DFM) at McMaster University along the iAP2 Stakeholder Engagement Options Framework, from primarily research activities that primarily inform and consult (current state) towards a spectrum of research activities that also involve stakeholders, collaborate with stakeholders, and support stakeholder-led research (future desired state).



# Project Development: Initiation

- Faculty researchers and research staff in an academic Department of Family Medicine – including a Community Investigator with lived experience of incarceration – we developed an initial conceptualization of what a Prison Health Research Council might do and might look like.
- We applied and successfully accessed seed funding from our affiliated Family Medicine Associates.

# Objectives of the Initial Grant Application

1. To establish a Research Engagement Council of people with lived experience (PWLE) of incarceration in Ontario to shape research on the health of people who experience incarceration across the province;
2. To evaluate the feasibility and value of the Research Engagement Council to PWLE and the Department of Family Medicine

## Project Goal

To establish a Research Council of people who have/had experienced incarceration, including from populations that are over-represented in prison, creating a space where Council members could drive the direction of the Council and prison health research overall.

# Why a Prison Health Research Council?

- **Lived experience is a pillar to the truth;** Lived experience represents expertise, and people with lived experience of incarceration bring critical perspectives on health, health care, and incarceration experiences.
- People who experience incarceration are often included in research as *participants*, but are often not included in leading, collaborating, and planning research.(IAP2 Framework)  
Including people whom the research is about can make the work more appropriate, valid, and ethical.
- The experience, credibility, and expertise of people with lived experience may not be recognized. **Disenfranchised population.**
- Research tends to be mainly around Federal prisons, as information is more available. Provincial jails in ontario need research to be done to show how the healthcare of those incarcerated is horrendous and harmful and counterproductive to the idea of “jail is for rehabilitation”.
- Research is geared towards “crime”, recidivism, not how incarceration affects someone's health, also how healthcare is distributed within correctional institutions, barriers

# Project Development: Engagement & Recruitment

- We worked with a community engagement consultant, Amplify Engagement, to develop a recruitment and engagement strategy, with an explicit focus on diversity of sociodemographic characteristics and perspectives.
- We shared info through personal and professional networks and social media, and we held two virtual information sessions.
- **44 people applied!**
- We selected 14 people, including people who are Black, Indigenous, Queer, Trans, and 2 Spirit, recognizing these populations are disproportionately represented in Canadian correctional facilities and/or face specific structural barriers to health.

## Meet the Council

- ★ Kanor
- ★ Latasha
- ★ George
- ★ Sonia
- ★ Marcie
- ★ Nat
- ★ Mike
- ★ Fallon
- ★ Tiina
- ★ James
- ★ Honey
- ★ Brian

## Meet the Project Team

- Dr. Claire Bodkin: Co-primary Investigator
- Dr. Fiona Kouyoumdjian: Co-primary Investigator
- Lindsay Jennings: Community Investigator
- Jessica Gaber: Research Coordinator

# Work to Date: Administering the Council

- We have been holding virtual, 2-hour monthly meetings since January 2024.
- Meetings routinely include Council members and the project team of faculty researchers and research staff, and may also include project guests.
- We pay honoraria for Council members, consistent with best practices for patient and public engagement.

# KEY THEMES ACROSS MEETINGS

- **Collaboration and Community Building:** Regular efforts were made to strengthen relationships among Council members, ensuring effective collaboration and a supportive environment.
- **Research and Advocacy:** The Council consistently focused on integrating lived experiences into research, identifying gaps in prison healthcare, and advocating for policy changes.
- **Feasibility and Funding:** Discussions often included assessing the feasibility of proposed projects and securing funding to sustain the Council's work.

**Guest Speaker Engagement:** Guest speakers provided insights into various prison-related issues, which informed the Council's ongoing discussions and planning.

# Work To Date: Learning about and contributing to existing research

- While some Council members had substantial experience with research, others were new to research, and we spent time discussing basic information about research; such as the stages of research and how to access research funding. (Research 101 workshop)
- We have discussed prison health research projects at various stages of development and implementation, led by researchers in the McMaster Department of Family Medicine and other Canadian researchers, on Council members engaged in discussions with researchers and provided input based on their expertise.

## Work to Date: Identifying areas for future research and work

- Through a structured exercise, we began to explore priority areas for research and for our Council, which we framed as “Small Wins and Big Dreams,” recognizing both challenges and the potential for our Council to make major contributions.
- We collaborated on the development of many applications for funding to CIHR that were led by the researchers and were responsive to Council discussions.

## Successful Grants

- CIHR Planning and Dissemination Grant: “The Research involving People who are incarcerated (RESPECT) Guidelines Project”:
- McMaster University Academic Family Medicine Associates (FMA) Grant, “Mortality in people who experience incarceration in Canada”
- CIHR Planning and Dissemination Grant, “Launching a Research Council of people who experience incarceration to advance collaborative research on prison health”
- Heat Related Deaths CIHR- Waiting on Decision
- CIHR Catalyst Grant: Waiting on Decision

# Impact to Date: Contributions to Prison Health Research

- Council has contributed work or perspectives to projects on topics such as:
  - mortality from opioid toxicity
  - shifts in drug enforcement and impacts on people who use drugs
  - life sentences and “lifers”
  - climate justice in prisons
  - health care standards (HSO) in Canadian federal prisons
  - reporting guidelines for prison health research
  - Consultation on legal claim for individuals in federal custody with mental health concerns, in collaboration with Prisoner Legal Services.

# Value for Council Members

- Providing people with criminal records part time paid roles
- Introducing new skills, building on existing skills, building resume experience
- Giving people whom the research is about space and opportunity to lead research, give their perspectives on existing research, and collaborate with other researchers across the country.

# What's Next?

- Setting up a webinar to present on work to date
- Seeking funding for ongoing Council sustainability (ideas/contributions welcome!)
- Working collaboratively to develop new research that the Council and researchers can co-lead
  - we spent 2 full council meetings going through the process of identifying a topic of interest, developing a research question and identifying methods)
  - we will continue working towards grant preparation

# Conclusions

- The Council works towards ameliorating the systemic exclusion of people with lived experience of incarceration from research through reflecting the needs, priorities, and issues of people who experience incarceration.
- This work holds relevance to researchers in other jurisdictions who want to bring voice, power, and opportunities to the people whom their research is about.



# PRISON

HEALTH RESEARCH COUNCIL

Find us on our new website!  
<https://prisonhealth.ca/>

# Our Reflections of the Prison Health Research Council

**Thank you!**

**Questions?**