



Family Medicine



# **Centering Lived Experience of Incarceration in Research: Developing and Implementing a Prison Health Research Council**

Presented by

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*& member of the McMaster University project team:*

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# 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 *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)

INCREASING STAKEHOLDER INFLUENCE ON THE RESEARCH					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
STAKEHOLDER PARTICIPATION GOAL	Researchers provide stakeholders with balanced and objective information to assist them in understanding the research.	Researchers obtain stakeholder feedback on the research.	Researchers work directly with stakeholders to ensure that stakeholder concerns and aspirations are consistently understood and considered in the research.	Researchers partner with stakeholders for salient aspects of the research.	Researchers assist stakeholders in conducting their own research.

# Project Development: Initiation

- Started with Claire Bodkin (DFM faculty researcher) and Lindsay Jennings (a DFM Community Investigator - a *new* staff role for McMaster, designed with feedback from DFM - with lived experience of incarceration)
- Developed an initial conceptualization of what a Prison Health Research Council might *do* and might *look like*
- Development and initial implementation of the Council was funded by seed funding from our affiliated Family Medicine Associates

## 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 expertise

- Like in the iAP2 framework: People who experience incarceration are often included in research as *participants*, but are not often included in *leading, collaborating, and planning* research.
- The experience, credibility, and expertise of people with lived experience of incarceration may not be recognized (a disenfranchised population)
- Lived experience represents expertise, and people with lived experience of incarceration bring critical perspectives on health, health care, and incarceration experiences.
- Including people whom the research is about can make the work more appropriate, valid, and ethical.

# Why a Prison Health Research Council?

## More prison health research needs to be done

- 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”.
- A lot of research is geared towards “crime”, recidivism, not how incarceration affects someone's health, also how healthcare is distributed within correctional institutions and barriers to health and care

# 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
- There are now **10 standing members of the Council**

## Meet the Council

- ★ Kanor
- ★ Latasha
- ★ George
- ★ Sonia
- ★ Nat
- ★ 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 Jan 2024
  - **21 regular meetings** so far, plus extras for project work
- Meetings include Council members, McMaster DFM project team (faculty researchers and research staff), and often guests
  - **Guests: 15 so far**, from 9 projects/organizations doing work around health in prisons
- Council members get hourly honoraria, consistent with best practices for patient and public engagement
  - **\$50/hr**, paid for 2 hours meeting + 1 hour prep

# Key Themes Across Meetings

- **Collaboration and Community Building:** Regular work is done to strengthen relationships among Council members and project team members (e.g., through a WhatsApp Council member chat, check-ins at the beginnings of each meeting, and email connections) to support collaboration
- **Research and Advocacy:** The Council is planning and contributing to research; consistently focusing on integrating lived experiences into research, identifying gaps in prison healthcare, and advocating for policy changes.
- **Feasibility and Funding:** The necessary discussion of planning project feasibility, and securing funding to sustain the Council's work and support relevant projects.
- **Guest Speaker Engagement:** Guest speakers provide insights into various prison-related issues, which inform the Council's ongoing discussions and planning, and the Council informs them from the lens of lived experience

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

- While some Council members had substantial experience with research, others were new to it
  - We spent time discussing the basics, including in a “**Research 101**” workshop (e.g., the stages of research and how to access research funding)
- We have discussed prison health research projects at various stages of development and implementation, led by researchers at DFM and across Canada
  - Council members engage in discussions with researchers and provide input based on their expertise

# Impact to Date: Contributions to Prison Health Research

- Contributed work/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
  - harm reduction in jails
  - mortality in prison
  - reporting guidelines for prison health research
  - managing mental health issues in federal prisons
  - solitary confinement policy
  - potential for an Indigenous men’s Healing Centre

# Impact to Date: Grant Collaborations

- Collaborated on grant applications led by the research team & responsive to Council discussions:
  - CIHR Planning and Dissemination Grant: The RESPECT Guidelines Project: **successful!**
  - McMaster FMA Grant: Mortality in people who experience incarceration: **successful!**
  - CIHR Planning and Dissemination Grant: “Launching a Research Council of people who experience incarceration to advance collaborative research on prison health”: **successful!** *(funding extended the Council itself)*
  - CIHR Project Grant on climate risks in Canadian prisons: **Waiting on decision**
  - CIHR Partnering for Impact Catalyst grant to extend the council again: **Waiting on decision**

# Work on a Research Project of Our Own

- Early on, we did a “**Small Wins and Big Dreams**” structured brainstorming exercise
  - We found shared interest in starting a research project together, identifying gaps in healthcare, impacting policy, doing advocacy, promoting the Council, and getting it funded
- We have now started prep on a research project of our own, on **post-incarceration syndrome**
  - We spent 2 full council meetings going through the process of identifying a topic of interest, developing a research question and identifying methods
  - We submitted a grant specific to this work
  - We are starting to prepare a review about this relatively new topic

# Impact to Date: 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?

- Continuing to promote the Council
  - At activities like this!
  - Through our website which we built <https://prisonhealth.ca/>
  - Through a webinar launching the Council more broadly on Wed Feb 4
- Continuing to seek funding for ongoing Council sustainability (ideas/contributions welcome!)
- Continuing to work on our research project, and bringing in researchers nationwide to consult on research about the health of people who are incarcerated



# 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.



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HEALTH RESEARCH COUNCIL

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