

Café Scientifique: Sharing Best Strategies for Inclusion of Mental Health Patients and Families in Research

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INTRODUCTION

- World Health Organization (WHO) reports that 1 in 8 people worldwide live with a mental illness, which has only increased during the COVID-19 pandemic.³
- To mitigate systemic inequities related to accessing mental health services, interdisciplinary collaborations with people with lived and living mental health experiences are needed.^{1,2}
- Strategies for meaningful inclusion of patients and families with lived and living mental health problems (e.g., Strategies for Patient-Orientated Research [SPOR]) are needed to promote equitable mental health services and support.^{1,2}

Purpose

- To promote meaningful dialogue with members of the public on best practices for SPOR.

METHODS

Promotion

- Times Colonist: Newspaper and online event page.
- University of Victoria (UVic) TV screens (Digicaster).
- Connected with local health organizations in Vancouver Island: Mental Health Recovery Partners in the South Island, Vancouver Island Mental Health Society, Island Health.

CAFÉ SCIENTIFIQUE:
SHARING BEST STRATEGIES FOR INCLUSION OF MENTAL HEALTH PATIENTS AND FAMILIES IN RESEARCH

FRIDAY, MARCH 1, 2024
4:00 PM - 6:30 PM

IN PERSON: MICHELE PUJOL ROOM, UNIVERSITY OF VICTORIA
ONLINE: LIVESTREAMED VIA ZOOM

THIS EVENT IS FREE TO ATTEND
THOUGH REGISTRATION IS REQUIRED.

INFORMATION & REGISTRATION
<http://tinyurl.com/CafeSciMentalHealth>

The Institute on Aging and Lifelong Health is committed to supporting equity, inclusion and diversity. Participants with diverse perspectives are welcomed and valued as strong, beneficial resources.

Hosted by the Health Services & Systems Research Cluster at the Institute on Aging and Lifelong Health, University of Victoria

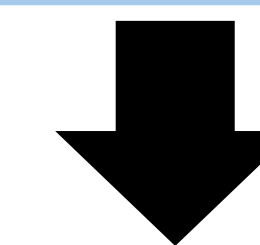
Funded in part by the Canadian Institutes for Health Research

RESULTS

Panelist Presentation Key Takeaways

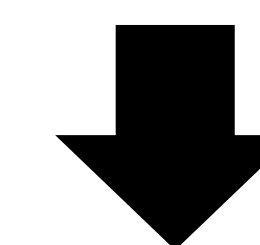
Davina Banner-Lukaris & Anita David - *Adopting Equitable Research Processes and Partnerships*

- Building partnerships require time and effort, valuing individual perspectives, while recognize personal experiences may not capture diversity of an entire community.
- Partnerships should involve reciprocity, providing support to communities. Individuals have the right to be included in the process, expect meaningful engagement. If expectations are not met, they have the right to choose to disengage from partnership.



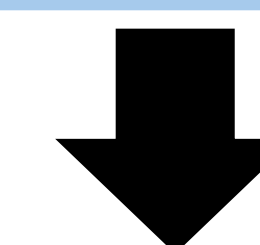
Clayon Hamilton & Anja Lanz - *Meaningful Partnership with Patients and Families in Research*

- Ensure meaningful involvements of People With Lived and Living Experiences (PWLLE) from the start, valuing diversity in participants and recognizing varying expertise levels on research.
- Collaborate in a learning journey, embracing unique perspectives, needs, and wants to enrich the research process.



Iva Cheung - *Improving Human Rights for People with Lived Experience Through Policy Research*

- Health Justice: Non-profit organization in BC, engages in research, policy development, and improvement related to coercive mental health and substance use in healthcare.
- Employs a governance model, guided by a human rights-based approach and principles outlined in the BC Mental Health Act.
- Ensures everyone's voices are heard and valued in the inclusive approach, encouraging collaboration for more enriched work with diverse participation.



Clara Rubincam & Zoe Newson - *Involving People with Lived and Living Experience in General (Including Patients, Families and Caregivers)*

- Peer Support Program at Island Health (IH) 7 days a week. Promoting Improvements in Psychiatry Emergency Services (PIPES).
- Recognize and compensate expertise throughout the engagement process, acknowledging burdens and mitigating costs. Set reasonable expectations and encourage continuous involvement.
- Foster transparency by sharing information and closing communication loops.

DISCUSSION

- Engaging discussions about how patients, families, and community to get involved in partner researchers (e.g. Reach BC, Health Research BC) and access mental health resources (e.g. Foundry, Health Justice, Peer Support at IH).

Strengths

- Active participation, engaging questions, and lively exchange of ideas between the audience and panelists during Q & A session. Several 1-on-1 conversations with panelists after Q & A session.

Limitations

- 8 in-person and 10 online audience. Lower than expected attendance. Event to be held on Wednesday or Thursday rather than Friday evening.
- Connecting with local health and community organizations earlier on to send recruitment poster. Releasing Eventbrite registration at a higher capacity than initially expected.
- Longer Q & A period (2-hour) as opposed to 1-hour. There were many great conversations but had to be cut short due to time.

CONCLUSION

- Research attains depth and relevance by prioritizing the perspectives of both patients and their families and recognizing the expertise of PWLLE. This approach contributes to advancing more effective and equitable mental health services, fostering a patient-centered approach that tailors interventions to individual needs, thereby promoting impactful and compassionate mental health care.

REFERENCES

- Johnston, J. N., Ridgeway, L., Cary-Barnard, S., Allen, J., Sanchez-Lafuente, C. L., Reive, B., Kalynchuk, L. E., & Caruncho, H. J. (2021). Patient orientated research in mental health: Matching laboratory to life and beyond in Canada. *Research Involvement and Engagement*, 7(21), 3–11. <http://doi.org/10.1186/s40900-021-00266-1>
- Ontario SPOR Support Unit [OSSU]. (2024). *What is SPOR?* <https://ossu.ca/about-us/what-is-spor/>
- World Health Organization [WHO]. (2022). *World mental health report: Transforming mental health for all.* <https://iris.who.int/bitstream/handle/10665/356119/9789240049338-eng.pdf?sequence=1&isAllowed=y>

ACKNOWLEDGMENT

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