

BARRIERS TO PATIENT PARTNERSHIP AND EQUITY

Help solve common barriers to patient engagement and equity in health and health services research



Ontario SPOR SUPPORT Unit
Patient Partner Working Group



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WELCOME!!



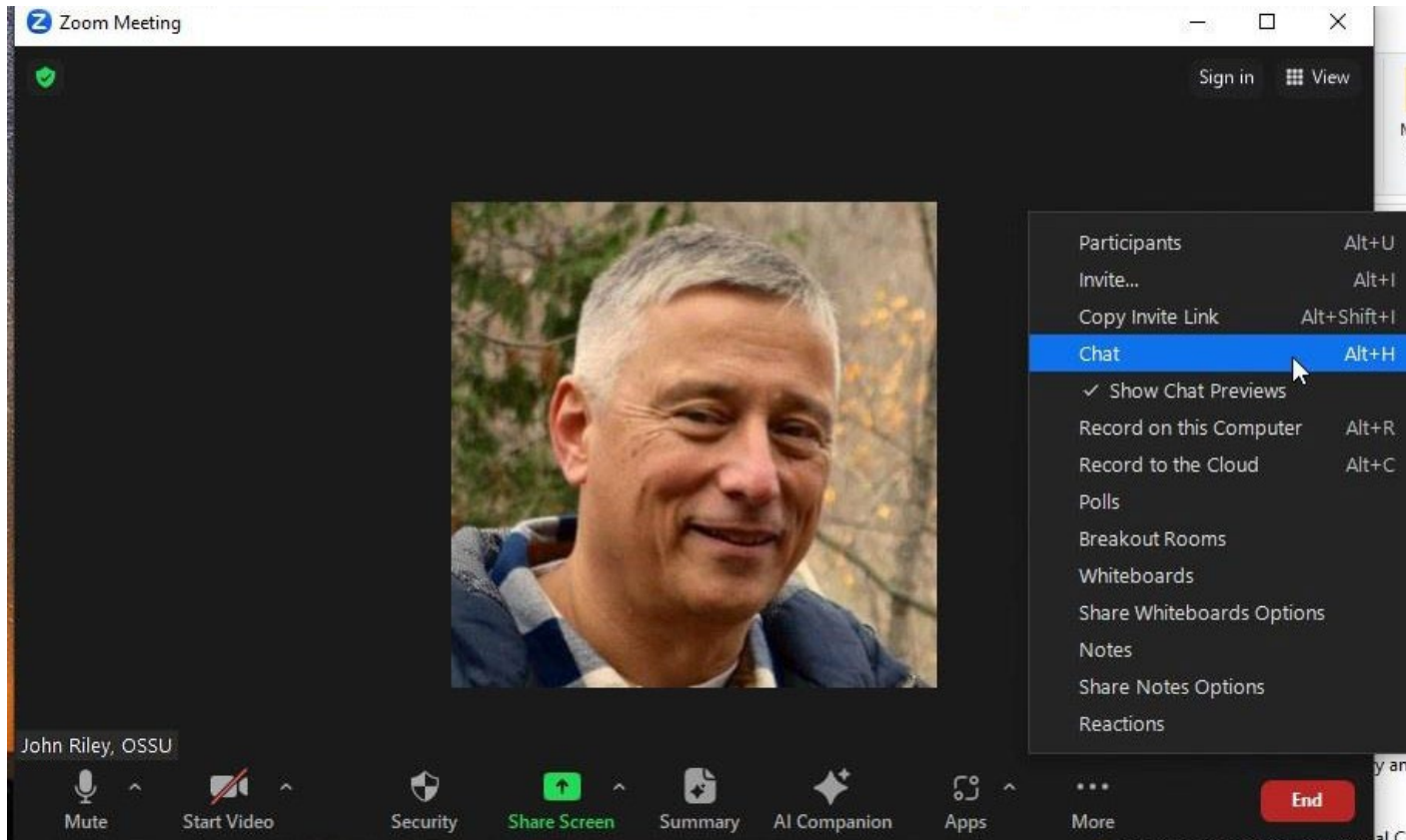


Land Acknowledgement

We acknowledge that OSSU is located on the land we now call Toronto and that OSSU operates across Ontario which is home to many diverse First Nations, Métis and Inuit peoples from across Turtle Island. Toronto is on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples; and is covered by Treaty 13 signed with the Mississaugas of the Credit.

We are deeply grateful to the generations of People – past and present – who have tended this land and acknowledge the abiding wisdom of the Dish with One Spoon treaty to share and care for it. As settlers, we are thankful for the opportunity and privilege to meet and work here. We seek to move forward with humility, respect, gratitude and meaningful relationship building.

Add your questions to the chat.



Open the Chat using Zoom or by pressing

ALT + H keys



Ron Beleno

BARRIER

The current methods of introducing, educating, and onboarding potential and new diverse patient partners are limiting and restrictive.

Popular tools and strategies such as the use of technology through online and virtual means creates a digital divide that does not allow for equitable access and engagement. Especially for new patient partners to properly engage in research, the early support about what it means to be engaged, how to be engaged, and the impact that their diversity brings to research is lacking and inconsistent.

STRATEGY(IES)

We are building relationships... it's not a simple transactional exchange

Developing diverse quality patient partnerships requires a period of time to nurture.

Understanding from all the stakeholders involved that it is about **growing relationships** to create a greater impact and to provide sustainable capacity with different diverse patient partner groups. (Tip: Find Champions)

Peer Mentoring and Onboarding Programs for new or interested Patient Partners

Invest upstream and earlier to improve the narrative and education of patient engagement in research.

Invest in other strategies such as “Boots on the ground and in the communities” for a greater ROI over time.

Continue to invest in peer mentoring programs and activities with other patient partners.



Shilpa Raju

BARRIER

One of the benefits patient partners bring to health research is the sharing of their lived experience and perspective. Unfortunately, the pool of self-identified patient partners is sociodemographically homogenous composed predominantly by white, university educated women. Such a narrow range of perspectives potentially limits the benefit of improving the value and relevance of health research evidence through patient engagement especially for research focusing on racialized and vulnerable populations.

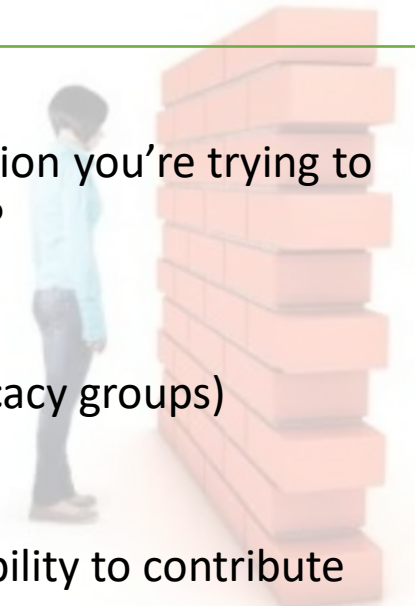
How can we address barriers to engaging with diverse patient partners?

STRATEGY(IES)

Consider the breadth of people impacted by the research, or the question you're trying to answer – are they adequately represented at the table, and if not, why?

Identify potential barriers limiting participation and address them

- Recruitment strategies (e.g. community organizations, advocacy groups)
- Scheduling of meetings (e.g., during/outside of work hours)
- Language considerations
- Onboarding process to improve patient partners' comfort/ability to contribute



Dr. Nav Persaud

BARRIER

Three suggestions:

- Disparity between grand statements about addressing equity and practical steps (e.g. funding) related to equity;
- Fears about things going wrong; or,
- Systemic opposition to equity focus activities.

STRATEGY(IES)

- Decide to actually focus on equity
- Be specific about how equity will be addressed
- Be upfront and honest about how input will be incorporated



Laura Ferreira-Legere

BARRIER

Researchers or clinician scientists can feel apprehensive about incorporating patient engagement in their research due to perceptions that the work can be time-consuming, costly, and challenging to execute effectively. This apprehension can translate to poorly conducted engagement or a lack of engagement entirely.

How can we continue to promote and support patient engagement, especially engagement that is equity-centered, to researchers who are apprehensive or unfamiliar to the benefits of this work?

STRATEGY(IES)

Individual level: Emphasize the importance and benefits of meaningful engagement for researchers and patients (e.g., competitive grants, data requirements, increased accessibility of research, bridging gaps between patients/communities and their data).

Organizational level: Guide researchers to existing tools, supports, training and resources, including examples of co-designed and partnered research. Create a repository of resources and support knowledge sharing.

System level: Support engagement as a priority area, promote budget allowance that makes engagement opportunities more accessible for equity-deserving communities (e.g., covering costs for transportation, child care, meals, a central venue, etc.).

