

Patient Engagement in Research Community of Practice

July 2023: Engagement in Lab-based Research on a Rare Disease

This document provides a presentation summary about the engagement of a patient-led organization (PSC Partners) with lab-based researchers at UHN/U of T and SickKids studying Primary Sclerosing Cholangitis (PSC), a rare disease of the bile ducts of the liver.

Key Presentation Points

- People with lived experience of PSC provide feedback to research teams, support public outreach and knowledge dissemination, and leverage the registry developed by PSC Partners to support recruitment of research participants. The patient-led PSC Partners actively organizes and hosts conferences, leads focus groups, and develops and shares educational resources.
- Research teams engage PSC Partners in study planning and research updates, share protocols for feedback, generate tools to share data in accessible ways, create new avenues for collaboration, and provide information across organ research networks.

What did we discuss?

- **Benefits of engagement:** *For people with lived experience:* Engagement can help increase awareness of and access to available resources and supports including living organ donation program; *for scientists and research teams:* Engagement can help diversify and increase the research participant pool and the potential connections to other professionals. Patient engagement enriches the trainee experience.
- **Patient-led organizations:** Organizations such as PSC Partners can help other patients, family members, or care partners. Engaging with patient-led organizations can improve collaboration and create opportunities!
- **Engagement opportunities:** Conferences that have multiple audiences including scientists, people with lived experience, and others can increase chances of making connections and exploring future collaborations. Another opportunity is to provide open access to journal articles and share articles and summaries with patients and caregivers.
- **Dual perspective:** Often times, many initiatives are led by people who have multiple skills, perspectives, and knowledge, incorporating the skills of people with lived experience, beyond their lived expertise can increase the interest of funders and promote future opportunities for funding and research. It is important to note that patients may choose not to engage depending on their health conditions. Family members or care partners may choose to engage and share their perspectives on behalf of their loved ones.
- **Check-ins:** It is important to check-in with people with lived experience to see if the engagement is a good use of their time. Additionally, it is important to explain data and encourage people with lived experience to ask questions so they understand why and how the research is being done.

Relevant Resources on Patient Engagement in Research

1. [PSC Partners Seeking a Cure Canada](#): A website with information about PSC Partners Canada & their engagement.
2. [What the Cell? Exploring PSC on a Cellular Level, A Canadian PSC Partners Patient Event](#): An upcoming knowledge translation event (October 14-15, 2023) geared towards providing general PSC education and support with specific focus on communicating the single cell projects of the patient-partner collaboration between the UHN/UofT/SickKids team and PSC Partners.

