

Enriching your Research with Lived Experience Partnerships

Effective Strategies to Engage Lived Experience Partners

- 1) Engage lived experience partners throughout the entire scientific process
- 2) Provide clear expectations and role
- 3) Recognize lived experience co-researchers as experts and equals
- 4) Provide equitable compensation and support
- 5) Provide appropriate training and resources
- 6) Allow and anticipate flexibility and plan for unpredictability
- 7) Promote diversity in lived experience and expanding pool of lived experience experts
- 8) Reflect and evaluate on lived experience engagement throughout project

Helpful Resources

General Information

- Lived Health Experience in Research (*www.LivedHealthExperience.org*)
- Child Bright Network (<u>https://www.child-bright.ca/</u>)
- CYSHCNet (<u>https://cyshcnet.org/</u>)
- Family Voices- Family Engagement in Systems Toolkit (<u>https://familyvoices.org/familyengagementtoolkit/</u>)
- Compensation
 - CYSHCNet-A Standard of Compensation for Youth and Family Partner
 - Child Bright Compensation Guide
 - Novak-Pavlic M, et al. Patients and Families as Partners in Patient-Oriented Research: How Should They Be Compensated? J Patient-Centered Res Rev. 2023;10(2):82-90. doi:10.17294/2330-0698.1975

Training

- Fyreworks (https://fyreworkstraining.com/)
- Patient Oriented Research Curriculum in Child Health (https://porcch.ca/)
- PCORI Research Fundamentals (https://www.pcori.org)