

# The Next Generation of Lived Perspectives in Clinical Trials

Emily Chan MSW, RSW

[echan@hollandbloorview.ca](mailto:echan@hollandbloorview.ca)

**Holland Bloorview**  
Kids Rehabilitation Hospital

A world of possibility

# Introduction

- Social worker at Holland Bloorview Kids Rehabilitation Hospital
- Recent graduate from the MSW Program at the University of Toronto
- Youth Leader/Mentor at Holland Bloorview and other disability-related organizations for 10+ years
- Passionate about youth engagement and how youth with lived patient experience can inform the next generation of clinical knowledge

# Volunteer Work

- Client advocate for Muscular Dystrophy Canada's Accessibility Advisory Committee
- Former chair of Holland Bloorview Youth Advisory Council
- Former Co-Director of Equity, Diversity, Inclusion, and Accessibility for the Young Canadians Roundtable on Health
- [Lindsay S.](#), Chan E, Cancelliere S, Mistry M. (2018) Exploring how volunteer work shapes occupational potential among youths with and without disabilities: A qualitative comparison. [Journal of Occupational Science 25\(3\): 322-336.](#)
- Lived experience research student at Bloorview Research Institute

# Promoting Youth Involvement in Research

- Consider ways of making your study as accessible as possible
- Ensure you are recruiting diverse patient partners
- Listen to patient partners and report back regularly
- Harness social media
- Incentivize involvement
- Co-present with patient partners

# Key Takeaways



## Diversity

Include multiple youth with differing types of lived experiences



## Accessibility

Ensure accessible ways to participate in research



## Co-Design

Harness lived experience knowledge in the design of research



# Thank You!

[echan@hollandbloorview.ca](mailto:echan@hollandbloorview.ca)