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Youth Experience Matters: Public and Patient Involvement (PPI)



BACKGROUND

- Participating in physical activity has huge benefits for health and wellbeing. Most young people with physical disability do insufficient physical activity, which negatively affects their future health.
- Interventions aimed at increasing physical activity in young people with disability are often not sustained due to multiple personal, social and environmental barriers to participation.
- The idea for the Youth Experience Matters research study came from conversations with young people with physical disability, their parents, and clinicians. We wanted to understand the priorities (“what matters most”) of adolescents with physical disability when it comes to physical activity participation.

WHAT WE DID

- With our clinical partner the Central Remedial Clinic, we set up an advisory group of young people with physical disability and their parents. They advised us on the questions to ask and how to ask them, what images to use, and they created the name “Youth Experience Matters” to give the project an identity.
- Together we developed our promotional video, featuring footage of some of the panelists being active.
- We engaged with the public through local disability events, school visits, clinical initiatives, radio interviews and presentations, as advised by our PPI panel.
- We developed our “Interactive wall”, a space where young people could write or draw freely and tell us what matters most, what activities they like, and who inspires them to be active.

WHAT DIFFERENCE DID IT MAKE

- As a result of our promotional video, we received national and international inquiries about our research, with over 10,000 views on Twitter/X.
- By immersing ourselves in the community, having casual conversations on the side-lines of sporting events, and school sports days, we gained knowledge and insight that may have otherwise been lost.
- Our “interactive wall” engaged and captured the imaginations of the public, the disability community, clinicians, parents, and young people. It became a conversation starter for physical activity and a unique way of engaging the community.

Understanding that successful research takes a village, and gaining support and enthusiasm across community, clinical and academic organisations is fundamental for success.