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Childhood Cerebral Palsy
Discovery Network

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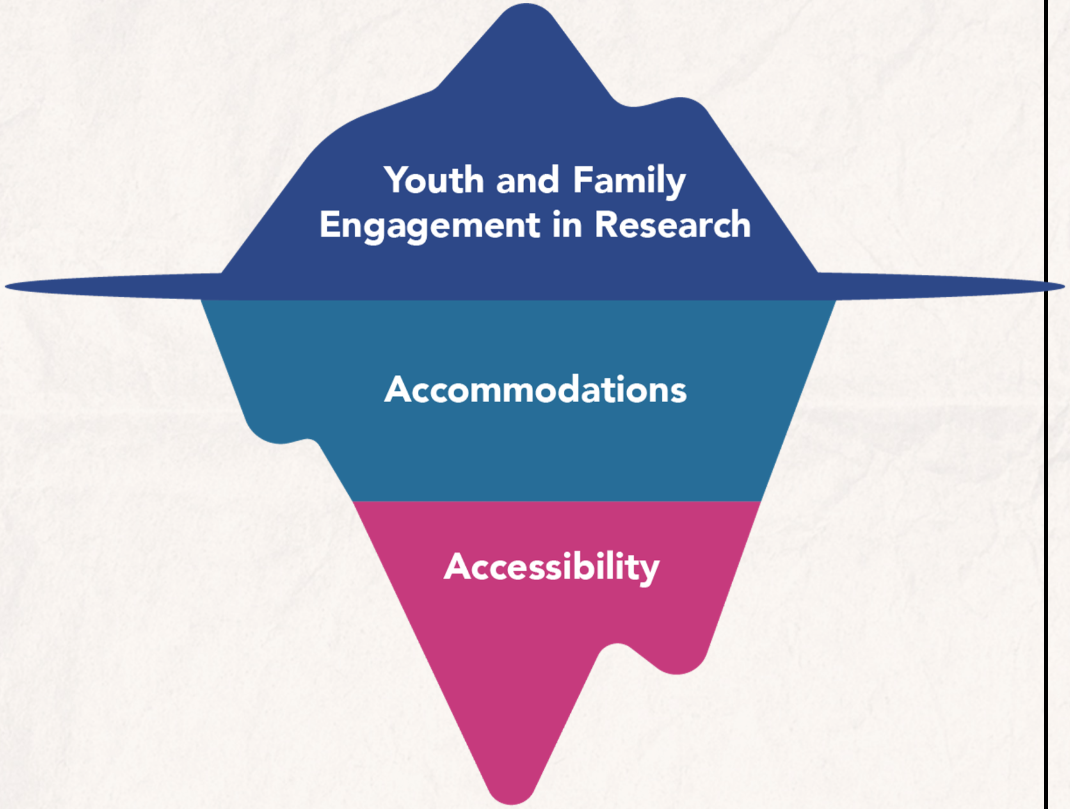
Nothing About Us Without Us!

Strategies for Equitable and Meaningful Youth Engagement



Presentation by **Amanda St. Dennis** and **Jessica Geboers**, on behalf of the Youth Engagement in Research Team, CanChild Centre for Childhood Disability Research

Our Agenda for Today's Presentation

1. Introductions
Your Speakers and the Youth Engagement in Research Team

2. Our Research Project:
A Very Brief Overview of Our Study

3. Reflections from Our Team's Research Process

4. So What?
Key Takeaways

1

Introductions

Your Speakers

Amanda St. Dennis – I am a disability and accessibility advocate, currently living in Toronto, Ontario who lives with mild/moderate right-side hemiplegic cerebral palsy, anxiety, ADHD and I am autistic. I am a patient advisor, co-investigator, and course developer with CanChild/CP-Net. When I can, I enjoy both being around and riding horses. Please feel free to contact me at: csi_hope@hotmail.com

Jessica Geboers – As a person with moderate cerebral palsy, I have a passion for disability advocacy and promoting disability awareness and accessibility through my work. I'm a patient advisor, co-investigator, and accessible documentation specialist for CanChild/CP-NET. I also love travel and live music. Feel free to contact me at: jessgeboers@gmail.com.

Youth Engagement in Research (YER) Team


Samantha Yimeng Dong


Linda Nguyen


Andrea Cross


Amanda Doherty-Kirby


Jessica Geboers


Dayle McCauley


Alice Kelen Soper


Amanda St. Dennis


Danny Steeves


Natasha Trehan


Jan Willem Gorter

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Our Research Project

A very brief explanation of what our project was about

Our Research Questions

1. What are the training needs for youth with neurodisabilities (ages 18-25) to enhance their knowledge, confidence, and skills, as research partners?
2. What are the benefits and challenges of engaging in a Patient-Oriented Research approach?

?

Patient-Oriented Research

Patient-Oriented Research (POR) is a “continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes,” according to the Canadian Institutes of Health Research.[1]

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[1] Government of Canada, 2019. *Strategy for Patient-Oriented Research - Patient Engagement Framework*. Canadian Institute of Health Research. Available at: <https://cihr-irsc.gc.ca/e/48413.html>

Project Phases

Phase 1: Interviews

November 2020 to August 2021: Youth with neurodisabilities (age 18 to 25) are consulted about barriers and needs in POR.

Phase 2: Virtual Symposiums

September 15 and 25, 2021: Youth and researchers from various neurodisability networks were invited to further discuss training needs , brainstorm delivery methods, and prioritize training topics.

During both **Phase 1** and **Phase 2** **Qualitative Content Analysis** took place

Phase 3: Knowledge Translation

Ongoing

Results: Barriers and Facilitators and Training Topics

Barriers:

- Lack of or difficulty finding opportunities
- Disability stigma in academia
- Unfamiliar, dense or triggering research language
- Negative perceptions of research

Facilitators:

- Accessible and flexible engagement methods with ongoing support
- Positive and equitable team dynamic
- Inclusive disability justice lens
- Clear communication on research roles and expectations
- Knowledge of the benefits
- Compensation

Prioritized Training Topics:

1. Communication training between youth and researchers
2. Research roles and responsibilities
3. Finding research partnership opportunities

Where to Find Out More

The Journal of Research Involvement and Engagement

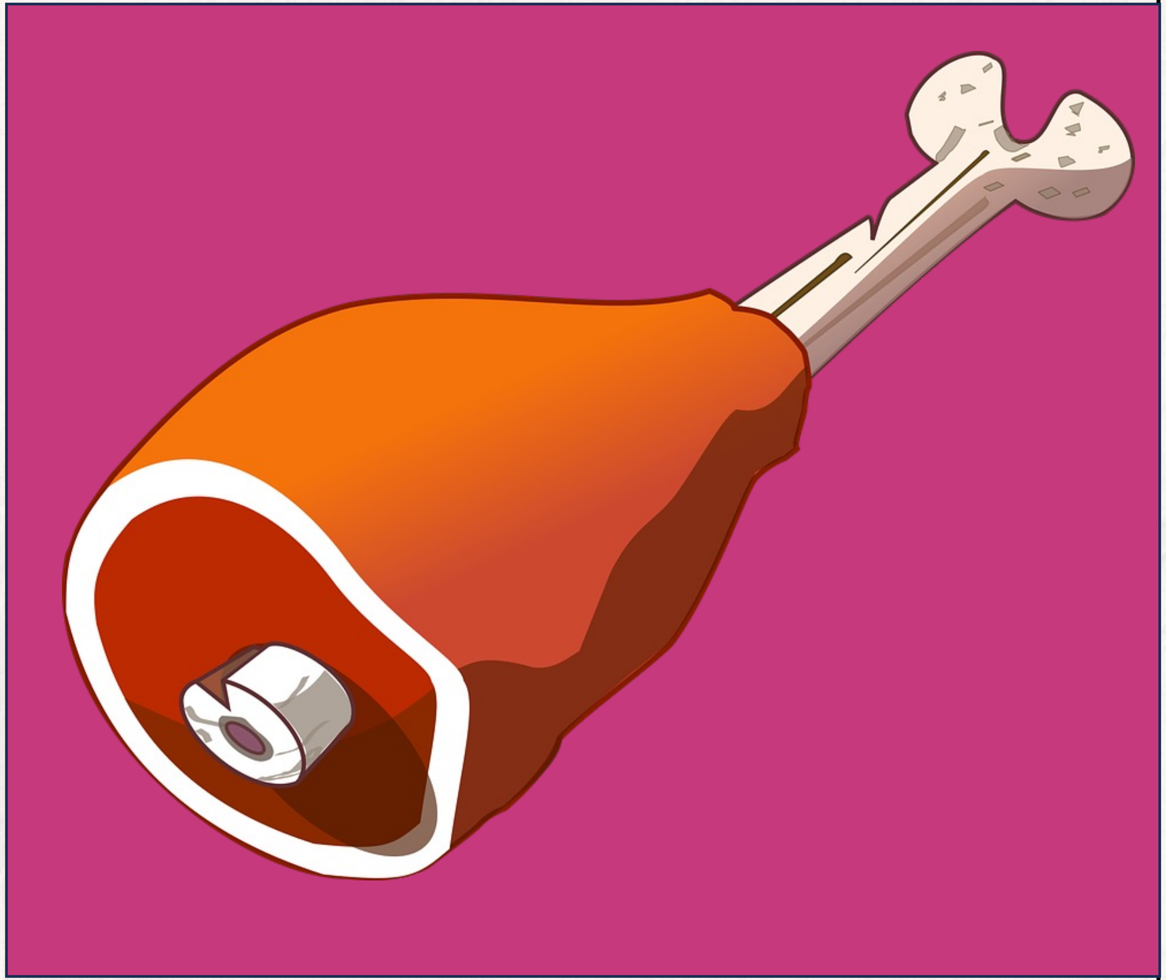
Please feel free
to **Scan the QR Code.**

3

Reflections

Our team’s lessons from engaging in Patient-Oriented Research throughout the research process – preparation, execution, to knowledge dissemination.

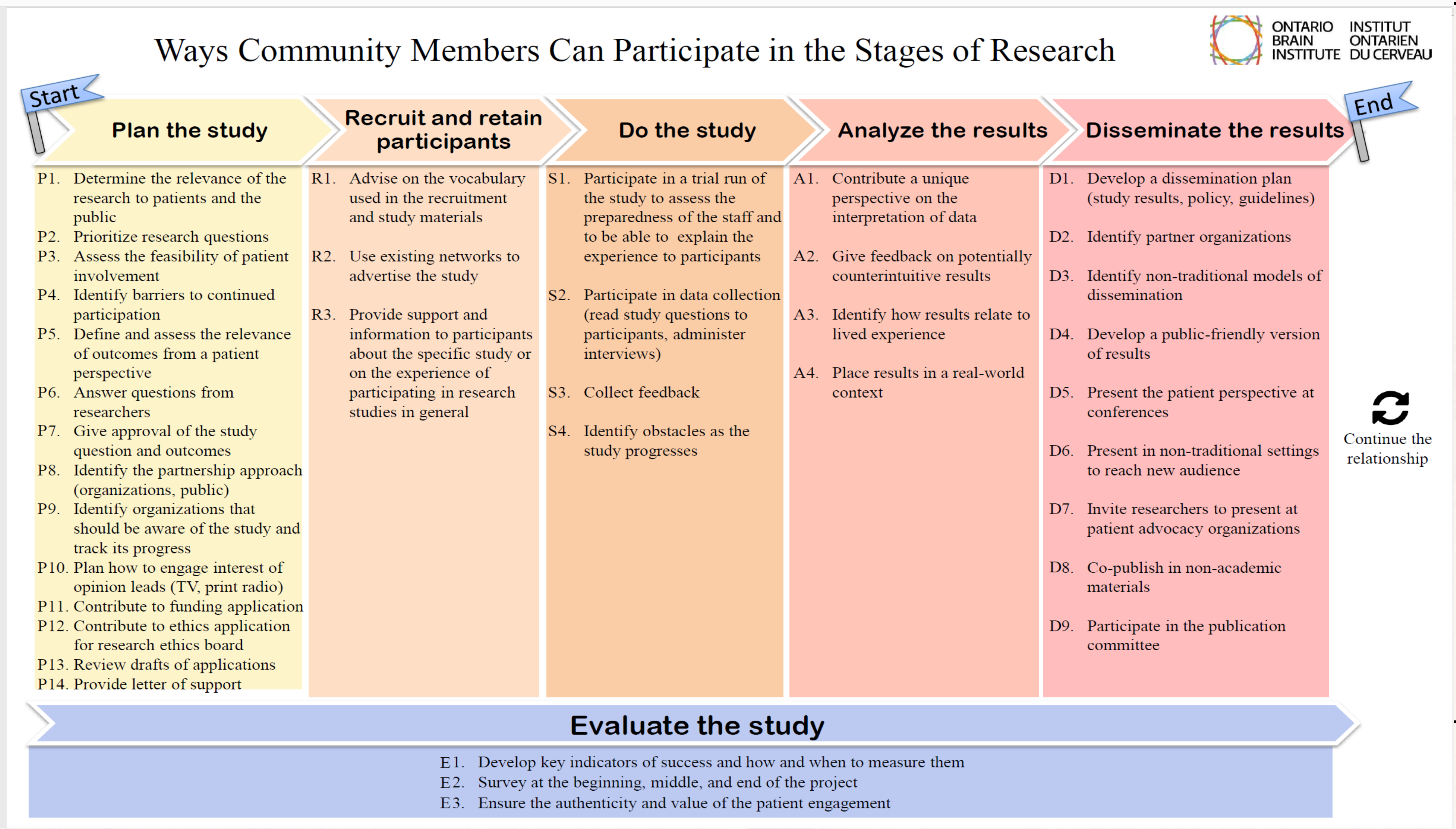
The Meat of Our Presentation



Background and Research Process

- This project came out after a CP- Net Stakeholder meeting when young people with neurodisabilities recognized that there was both a need and a lack of Patient-Oriented Research training available for researchers and youth with neurodisabilities.
- Using a Patient-Oriented Research approach allowed for us to build in access needs as needed.

Important Tools Used That Also Ensured Access



Ways Community Members Can Participate in the Stages of Research

Plan the study

P1. Determine the relevance of the research to patients and the public
P2. Prioritize research questions
P3. Assess the feasibility of patient involvement
P4. Identify barriers to continued participation
P5. Define and assess the relevance of outcomes from a patient perspective
P6. Answer questions from researchers
P7. Give approval of the study question and outcomes
P8. Identify the partnership approach (organizations, public)
P9. Identify organizations that should be aware of the study and track its progress
P10. Plan how to engage interest of opinion leads (TV, print radio)
P11. Contribute to funding application
P12. Contribute to ethics application for research ethics board
P13. Review drafts of applications
P14. Provide letter of support

Recruit and retain participants

R1. Advise on the vocabulary used in the recruitment and study materials

R2. Use existing networks to advertise the study

R3. Provide support and information to participants about the specific study or on the experience of participating in research studies in general

Do the study

S1. Participate in a trial run of the study to assess the preparedness of the staff and to be able to explain the experience to participants

S2. Participate in data collection (read study questions to participants, administer interviews)

S3. Collect feedback

S4. Identify obstacles as the study progresses

Analyze the results

A1. Contribute a unique perspective on the interpretation of data

A2. Give feedback on potentially counterintuitive results

A3. Identify how results relate to lived experience

A4. Place results in a real-world context

Disseminate the results

D1. Develop a dissemination plan (study results, policy, guidelines)

D2. Identify partner organizations

D3. Identify non-traditional models of dissemination

D4. Develop a public-friendly version of results

D5. Present the patient perspective at conferences

D6. Present in non-traditional settings to reach new audience

D7. Invite researchers to present at patient advocacy organizations

D8. Co-publish in non-academic materials

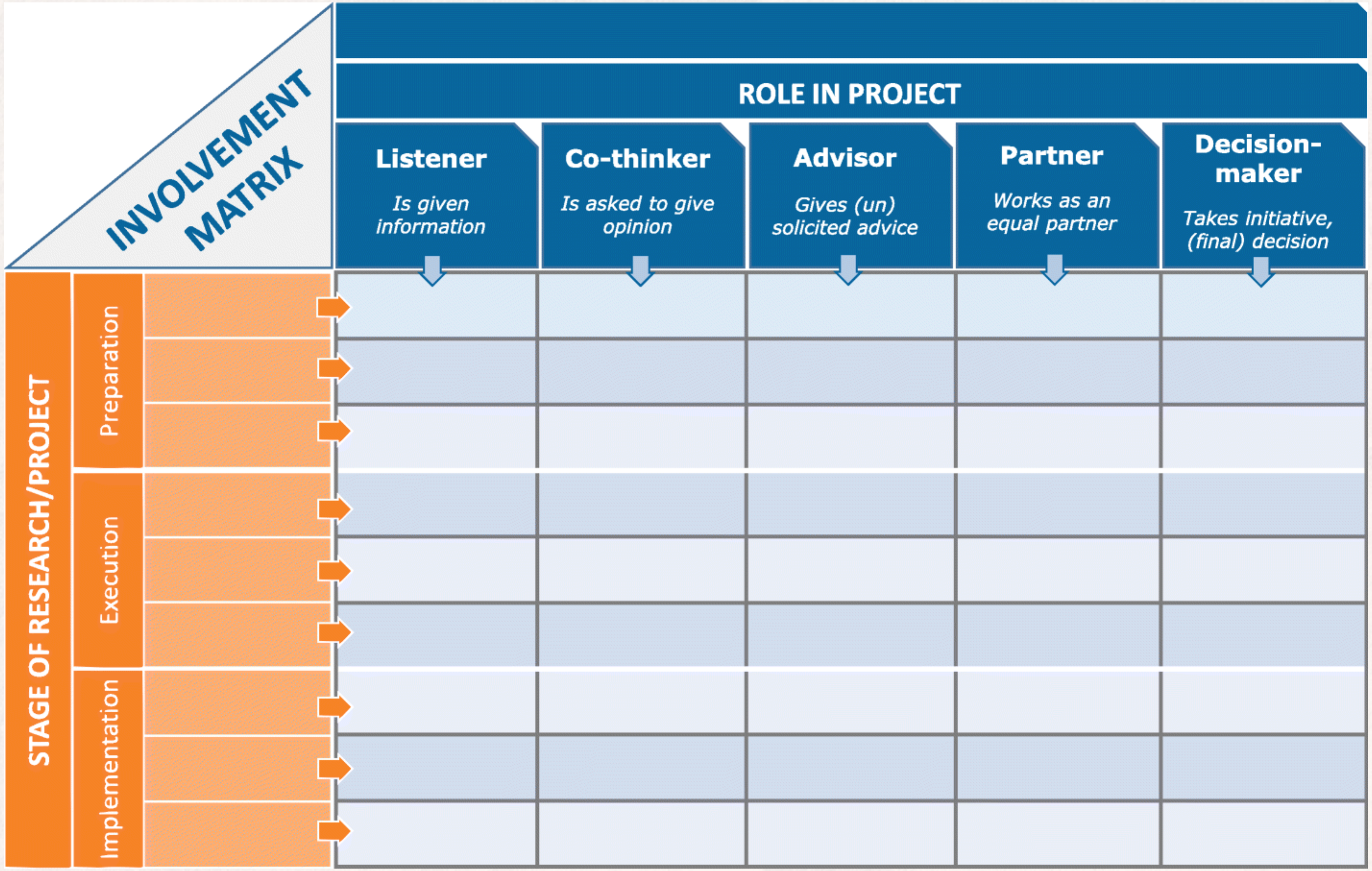
D9. Participate in the publication committee

Continue the relationship

Evaluate the study

E1. Develop key indicators of success and how and when to measure them
E2. Survey at the beginning, middle, and end of the project
E3. Ensure the authenticity and value of the patient engagement

Important Tools Used That Also Ensured Access



INVOLVEMENT MATRIX

ROLE IN PROJECT

STAGE OF RESEARCH/PROJECT		**Listener** *Is given information*	**Co-thinker** *Is asked to give opinion*	**Advisor** *Gives (un) solicited advice*	**Partner** *Works as an equal partner*	**Decision-maker** *Takes initiative, (final) decision*
Preparation						
Execution						
Implementation						

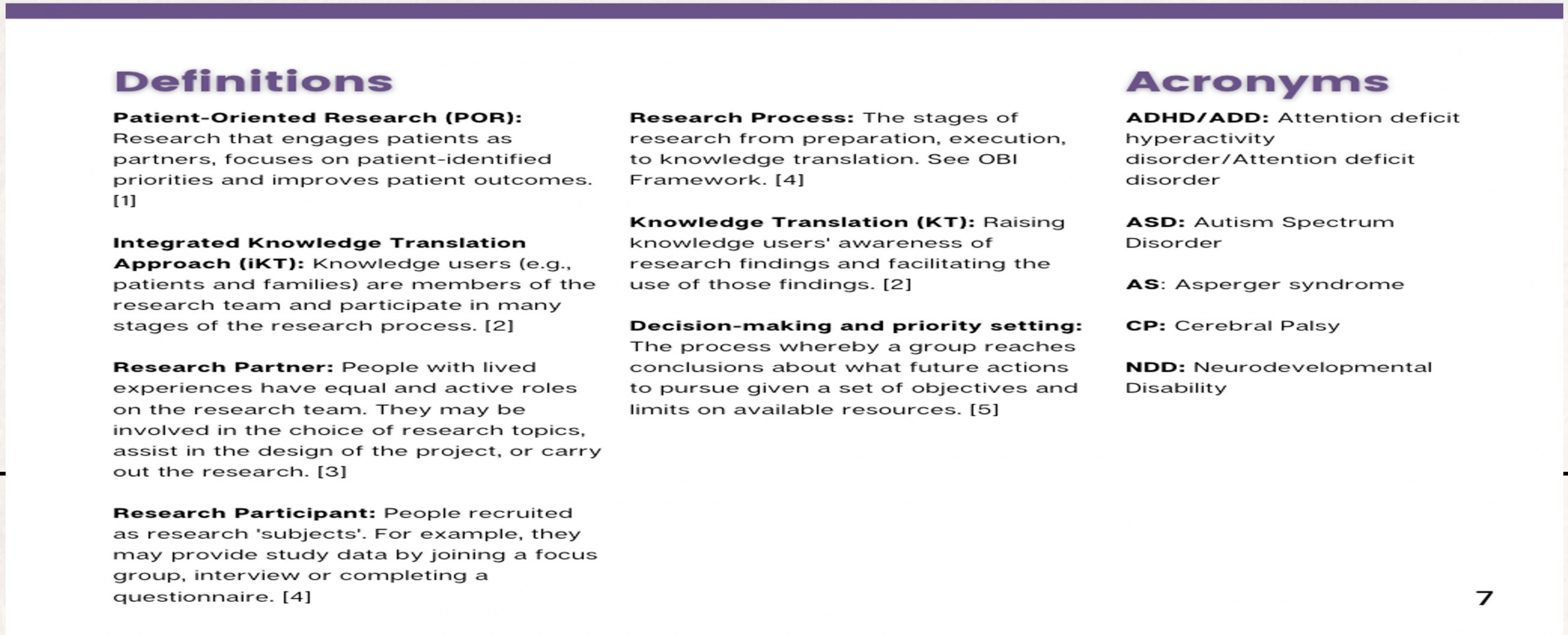
Involvement Matrix; www.kcrutrecht.nl/involvement-matrix. © Center of Excellence for Rehabilitation Medicine Utrechtr

Phase 1 From Grants to Interviews

- We ensured appropriate language surrounding disabilities when submitting research protocols, grant applications and research ethics board submissions.
- We utilized recruitment videos that we ensured were captioned and were made as accessible as possible with the budget that we had.
- Recruited participants by utilizing all our networks not just those of the ‘academic researchers.’
- Patient co-investigators were involved in the interviews in hopes of aiding in any possible power dynamic and assist in understanding disability culture and community.

Phase 2: Virtual Symposiums

- Every member of our team had a role that worked for them and their strengths and needs
- We as a team ensured that questions and discussion was worded in as plain language as much as possible.
- We ensured that it was not just ‘academic’ researchers visibly present. Many of our lived experience co-investigators were upfront with diagnoses/ disabilities.
- We held the symposium over 2 days and provided multiple ways as well as time for feedback to be given.
- We provided discussion questions and helpful acronyms and definitions ahead of time.



Definitions

Patient-Oriented Research (POR): Research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. [1]

Integrated Knowledge Translation Approach (iKT): Knowledge users (e.g., patients and families) are members of the research team and participate in many stages of the research process. [2]

Research Partner: People with lived experiences have equal and active roles on the research team. They may be involved in the choice of research topics, assist in the design of the project, or carry out the research. [3]

Research Participant: People recruited as research 'subjects'. For example, they may provide study data by joining a focus group, interview or completing a questionnaire. [4]

Research Process: The stages of research from preparation, execution, to knowledge translation. See OBI Framework. [4]

Knowledge Translation (KT): Raising knowledge users' awareness of research findings and facilitating the use of those findings. [2]

Decision-making and priority setting: The process whereby a group reaches conclusions about what future actions to pursue given a set of objectives and limits on available resources. [5]

Acronyms

ADHD/ADD: Attention deficit hyperactivity disorder/Attention deficit disorder

ASD: Autism Spectrum Disorder

AS: Asperger syndrome

CP: Cerebral Palsy

NDD: Neurodevelopmental Disability

Phase 1 and 2: Ongoing Qualitative Data Analysis

- Qualitative data analysis was done collaboratively with 2 academic researchers and 3 lived experience partners.
- This involved teaching lived experience partners how to code and what it meant to code.
- A video was created that was accessible to all research team members and involved captioning to ensure that we could refer to the video whenever needed.
- We met in small groups, and even one-on-one, to complete the coding.
- We worked with each other's needs and schedules.

How To Start Coding

An Introduction Tutorial

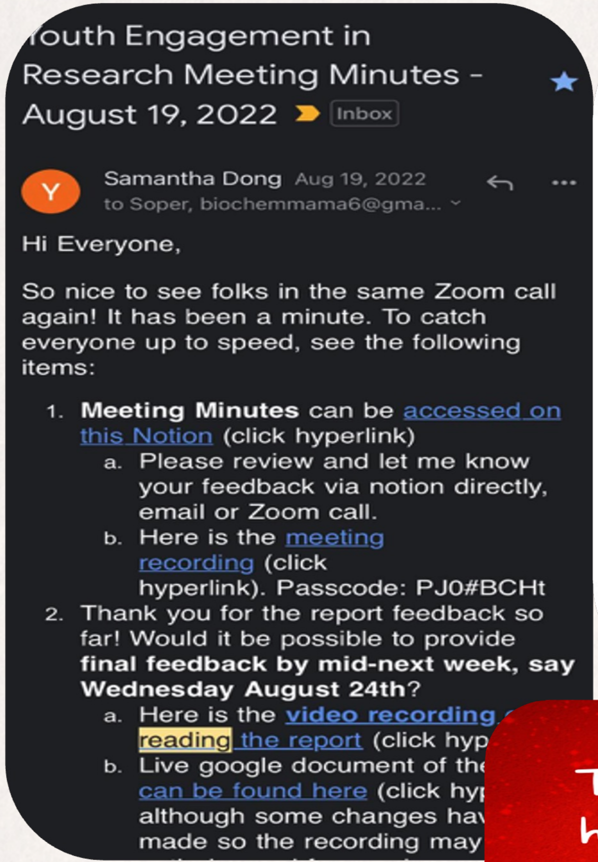
Today, I will be discussing about how to start coding as an introduction tutorial.

Phase 3 Knowledge Translation and Dissemination

- Those who have wanted to and been able to have been able to have been involved in presenting on our research at different conferences over the years… Including those of use with lived experience (e.g., CP-Net Science and Family Day, 2021, Children’s Healthcare Canada Conference November 2021, Empowered Kids Ontario Conference, May 2023).
- While preparing our manuscript for the already mentioned journal article, Sam recorded herself reading out the manuscript for those who needed to process it auditorily.
- We asked for extra time after our manuscript was peer reviewed so our entire team was able to respond to comments, considering access needs and processing times.
- Those of us with lived experience have been given the opportunity to take lead in next steps.

“I have had a blast being able to **co-present** on our results, our challenges and our triumphs.”

Other Reflections



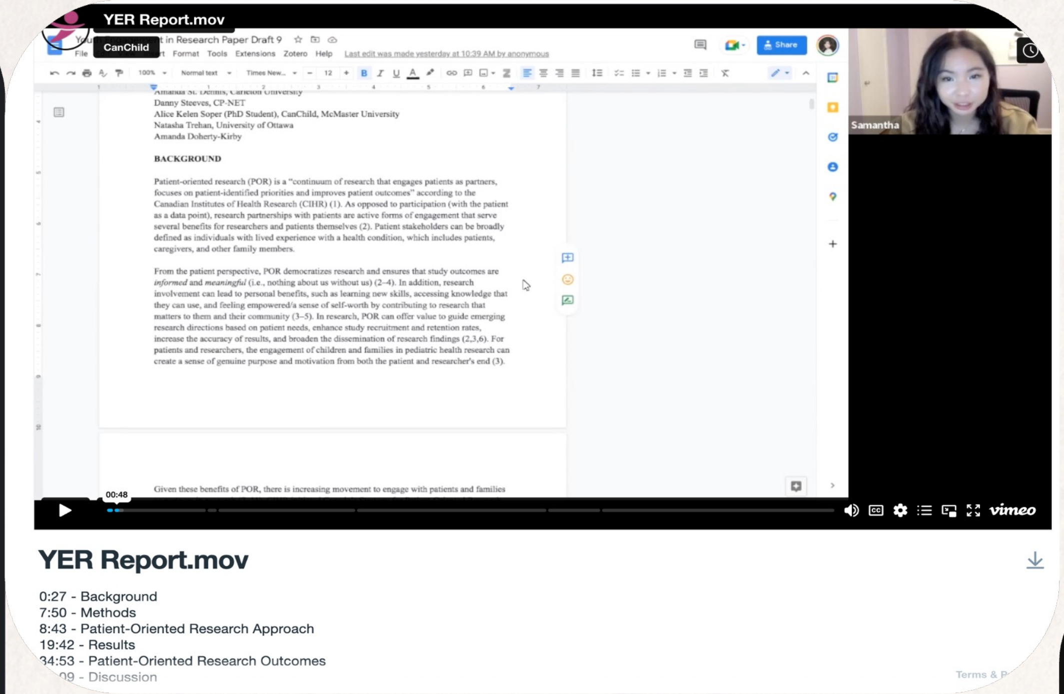
outh Engagement in Research Meeting Minutes - August 19, 2022

Samantha Dong Aug 19, 2022
to Soper, biochemmama6@gma...

Hi Everyone,

So nice to see folks in the same Zoom call again! It has been a minute. To catch everyone up to speed, see the following items:

1. **Meeting Minutes** can be accessed on this Notion (click hyperlink)
    a. Please review and let me know your feedback via notion directly, email or Zoom call.
    b. Here is the meeting recording (click hyperlink). Passcode: PJ0#BCHt
2. Thank you for the report feedback so far! Would it be possible to provide **final feedback by mid-next week, say Wednesday August 24th?**
    a. Here is the **video recording** reading the report (click hyp
    b. Live google document of the can be found here (click hy although some changes hav made so the recording may



YER Report.mov

Danny Steeves, CP-NET
Alice Kelen Soper (PhD Student), CanChild, McMaster University
Natasha Trehan, University of Ottawa
Amanda Doherty-Kirby

BACKGROUND

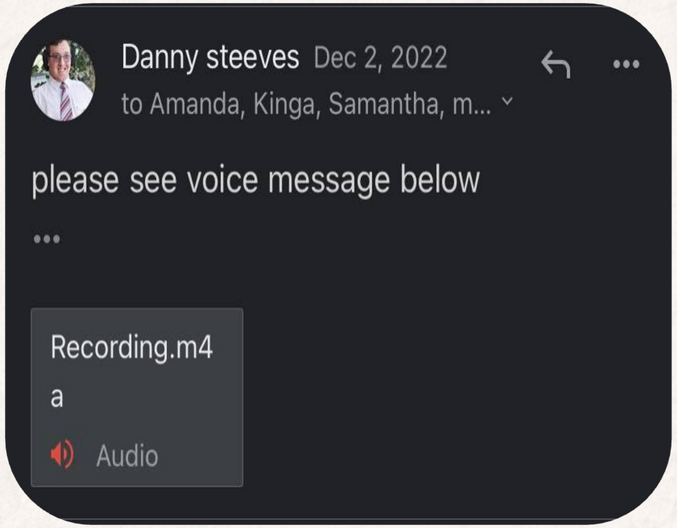
Patient-oriented research (POR) is a "continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes" according to the Canadian Institutes of Health Research (CIHR) (1). As opposed to participation (with the patient as a data point), research partnerships with patients are active forms of engagement that serve several benefits for researchers and patients themselves (2). Patient stakeholders can be broadly defined as individuals with lived experience with a health condition, which includes patients, caregivers, and other family members.

From the patient perspective, POR democratizes research and ensures that study outcomes are *informed* and *meaningful* (i.e., nothing about us without us) (2–4). In addition, research involvement can lead to personal benefits, such as learning new skills, accessing knowledge that they can use, and feeling empowered/a sense of self-worth by contributing to research that matters to them and their community (3–5). In research, POR can offer value to guide emerging research directions based on patient needs, enhance study recruitment and retention rates, increase the accuracy of results, and broaden the dissemination of research findings (2,3,6). For patients and researchers, the engagement of children and families in pediatric health research can create a sense of genuine purpose and motivation from both the patient and researcher's end (3).

Given these benefits of POR, there is increasing movement to engage with patients and families

YER Report.mov

0:27 - Background
7:50 - Methods
8:43 - Patient-Oriented Research Approach
19:42 - Results
34:53 - Patient-Oriented Research Outcomes
09 - Discussion

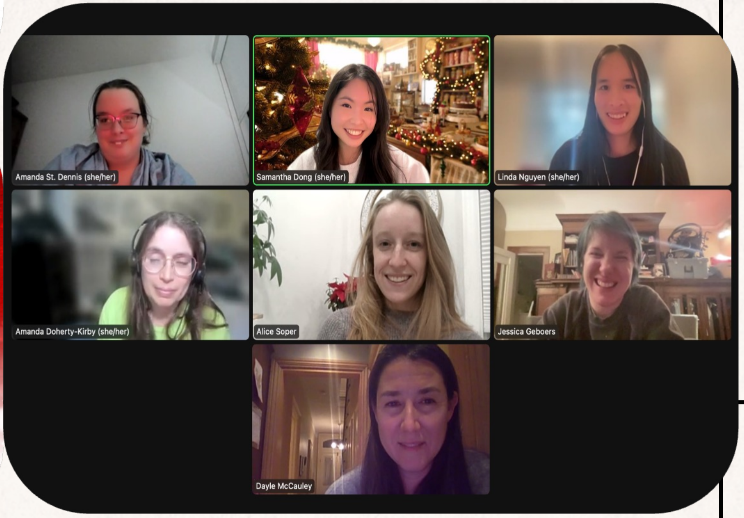


Danny steeves Dec 2, 2022
to Amanda, Kinga, Samantha, m...

please see voice message below

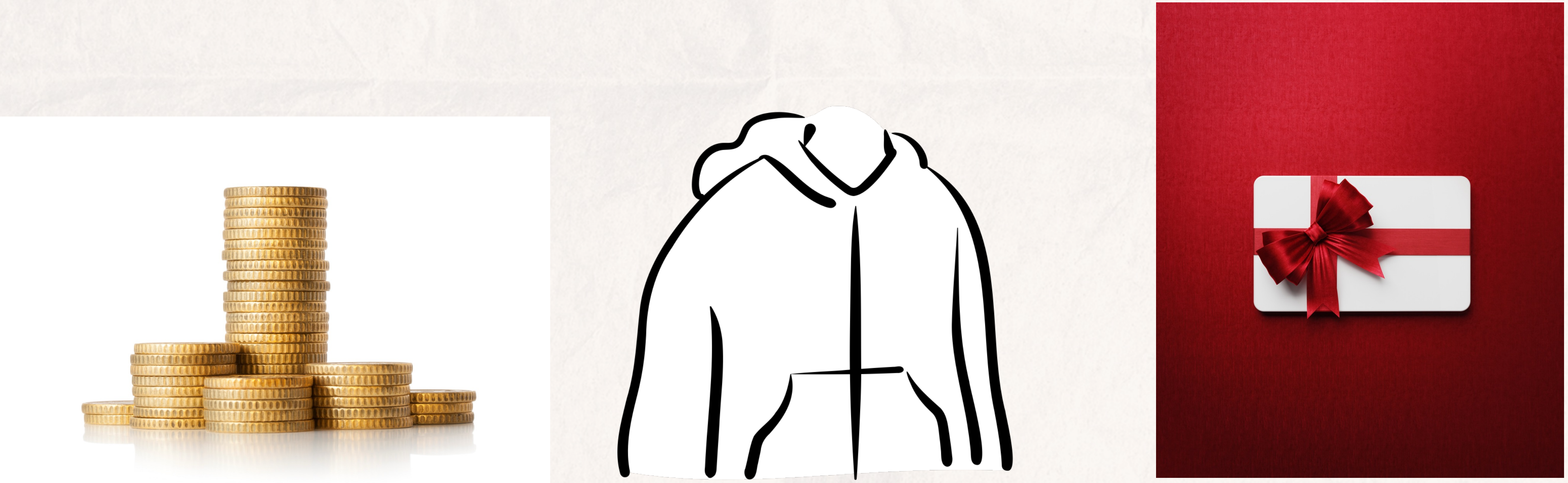
•••

Thank you for your generous support & hard work on the Youth Engagement in Research Project!



Compensation

- Honorariums
- Gift cards
- Customized team sweaters
- Assistance with conference costs and needs.



Team Dynamic and Spirit

- Anti -”strictly business”
- Mutual respect and compassion.

> “I feel like I am **learning** so much. I consider many on the team to be **mentors**.”

Accommodation and Accessibility

- Openness to communicating needs
- Openness to trying new approaches
- Thinking outside of the box

What’s Next?

- Aiding in creating more accessible content for the Family Engagement in Research (FER) Course.
- Co-instructing a cohort of the FER course.
- Seeking continued employment within research.
- Continued engagement in research surrounding youth engagement in research.
- Attending conferences and aiding in creating space at these conferences for researchers and research partners with disabilities.
- Being hopeful for a future Youth Engagement in Research course and/or mentorship of some sort.
- Applying for a CIHR Grant Fall 2023
- Continuing to educate our colleagues and anyone else interested in accessibility and how to make research more accessible.
- Networking with colleagues.

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So What?

Key Takeaways for everyone

For Youth:

- Your lived experience is valuable and important.
- Understand your strengths and limitations. Explore and discover roles and skills within research.
- Continue to advocate for your accommodations.

For Parents:

- Involve your child in all discussions surrounding accommodations.
- Share decision making with your child: what do they want to do?
- Support your child to discover roles within community, including within research.

For Researchers:

- Accommodations: Be open and flexible.
- Accessibility: Consider multiple methods to learn and engage.
- Dedicate resources to build and sustain team rapport.
- Hire people with lived experiences and promote awareness.

For Everyone:

- Share personal experiences and reflections on patient-oriented research engagement.
- Be open to new viewpoints.
- See potential in everyone!
- Strive for more accessible and equitable research.

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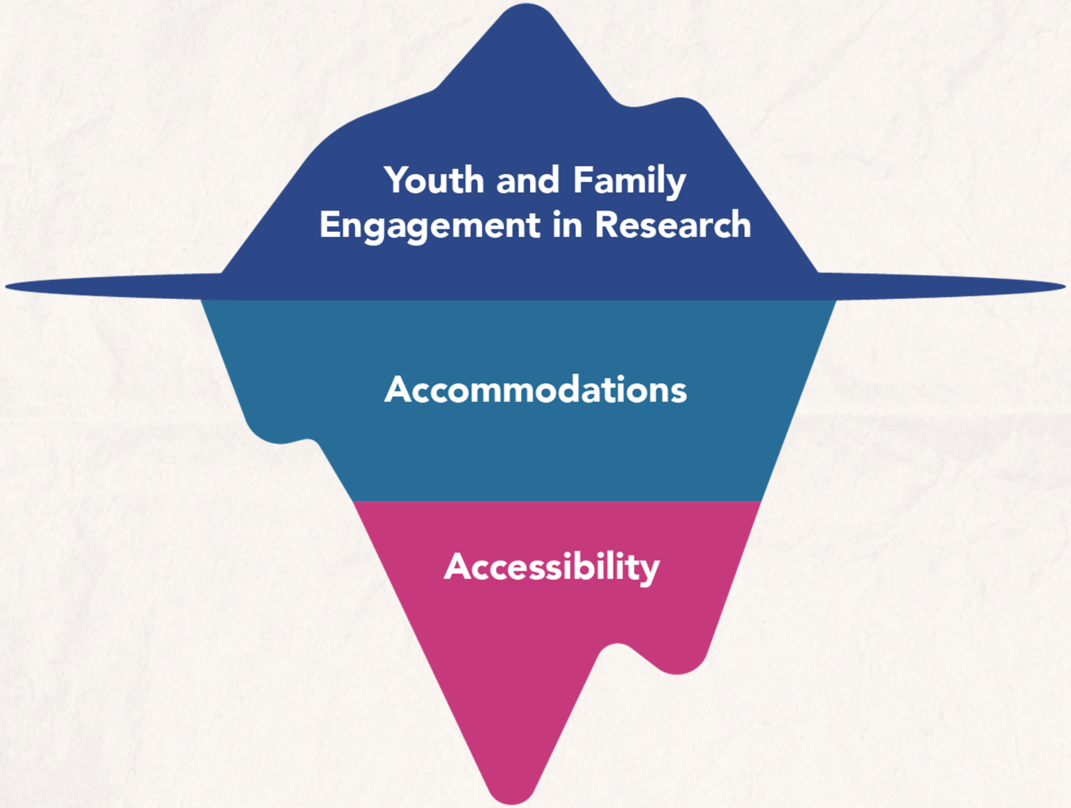
Thank You!

For more information about our project, visit our website:


Youth and Family Engagement in Research

Accommodations

Accessibility

Presentation by **Amanda St. Dennis** and **Jessica Geboers** on behalf of the Youth Engagement in Research Team, CanChild Centre for Childhood Disability Research