

Disability Inclusion, Intersectionality, and Knowledge Translation

KTDRR's 2024 Virtual KT Conference

October 15, 16, and 18

Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

Nothing About Us Without Us: Creating Accessible Research Partnerships

Presented by Amanda St. Dennis, Jessica Geboers, Danny Steeves and Linda Nguyen

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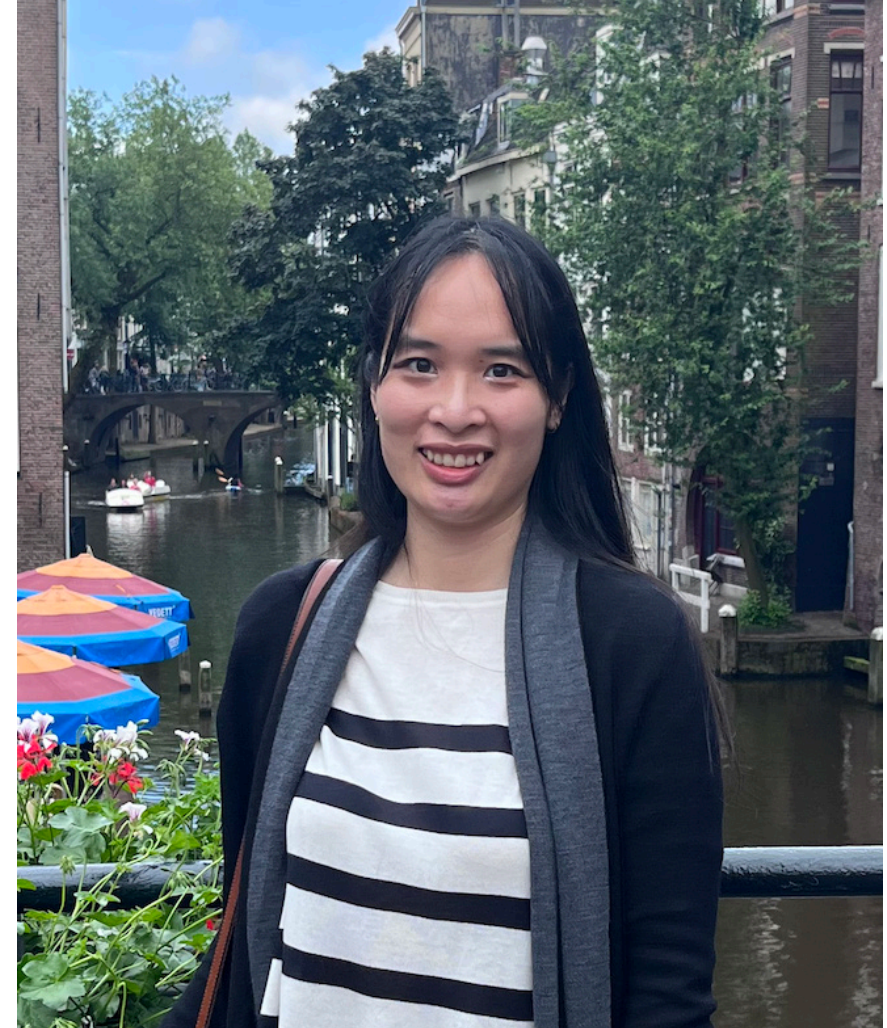
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Introductions

Amanda St. Dennis and Jessica Geboers



Danny Steeves and Linda Nguyen



Patient Oriented Research

And what was lacking from our experience

Patient Oriented Research... What is it?

- “A continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes.” (Canadian Institutes of Health Research, 2019).
 - ‘Patients’ include individuals with lived experience of a health condition and their informal caregivers, including family and friends.

What Did We Find Lacking in Research

One of the **Main** things that we found lacking in when partnering in research was an understanding of the importance of **accessibility** and therefore also the knowledge on how to provide that accessibility.

- We (Jessica, Amanda and Danny) were given the opportunity to take McMaster University's Family Engagement in Research (FER) Micro-Credential Course.
- The ongoing task of the course is to create a KT tool that highlights research partnerships/research process etc. as a group.
- In part due to our experience with the Youth Engagement in Research project we decided to make an accommodation booklet.



Source: Family Engagement in Research Team, McMaster University

Our KT Tool

And Examples of Accessibility in Action via The Youth Engagement in Research (YER) project

What Is It and How to Use It?

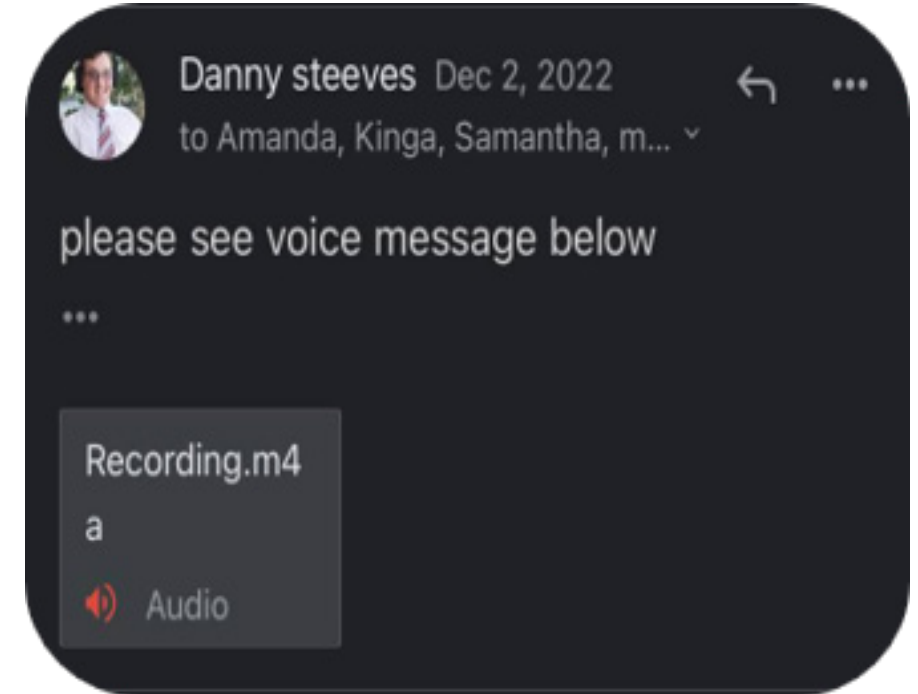
- Our tool is a booklet that we hope is used to aid both researchers and those with disabilities who are partnering in research.
- Our hope is that it is used to help start and continue conversations around access needs.

Source: Dong, S., Geboers, J., St. Dennis, A., & Steeves, D. (2023).

Examples of Accessibility in Research Partnerships

Communication

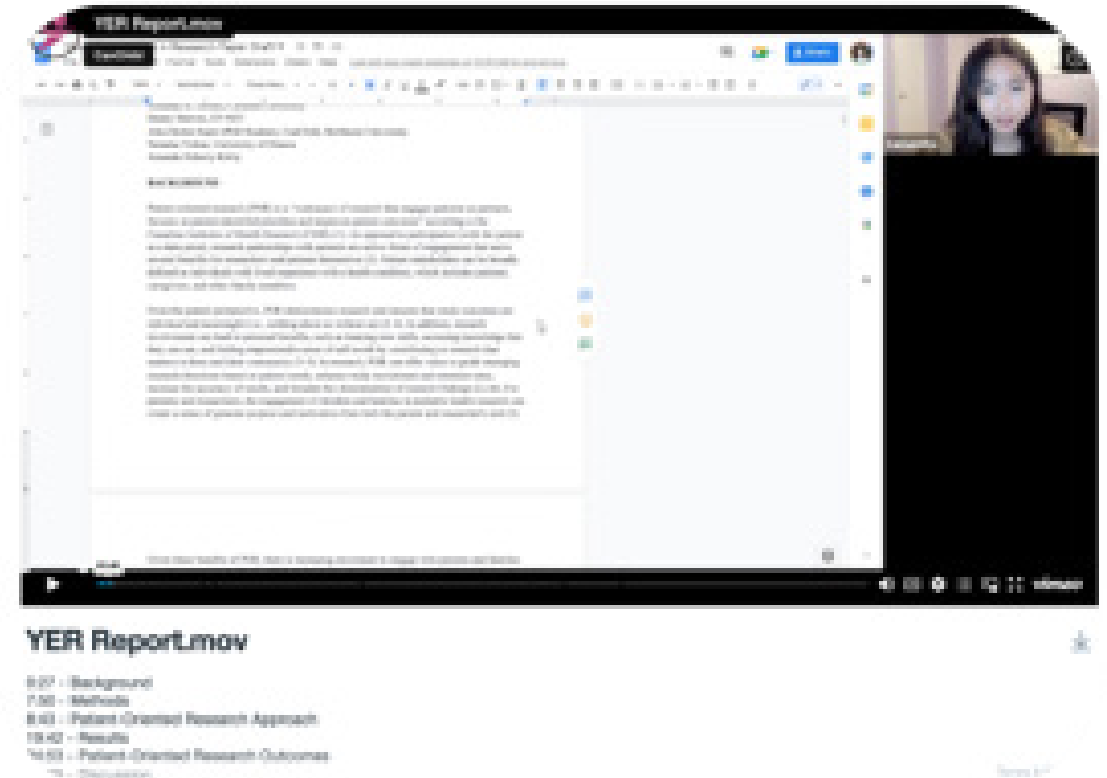
- Audio notes and other alternative forms/modes of communication
- Communication partner
- Plain language



Source: Dong, S. (2022-2023). *Screenshots from Youth Engagement in Research Project Partnership*. [Images]. Used with permission August 2024.

Documentation

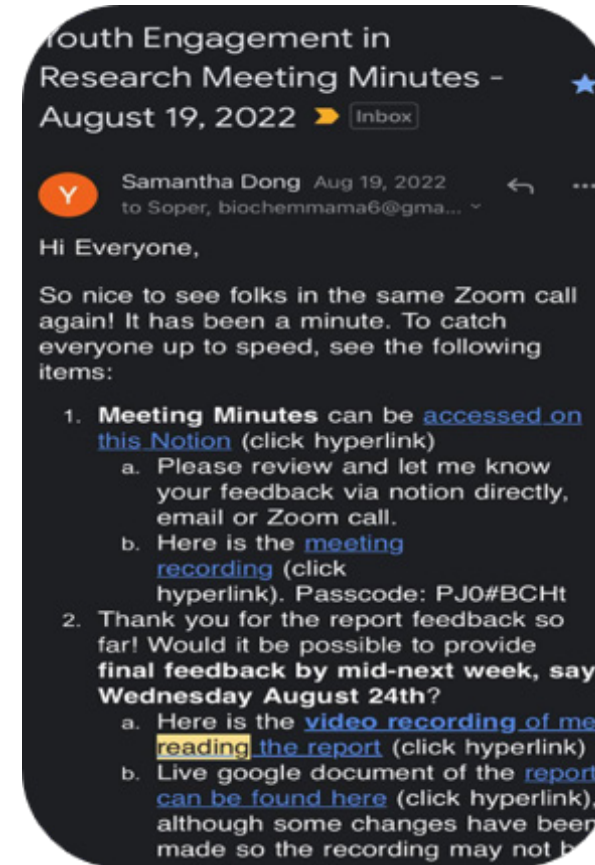
- How to make accessible documentation
- Recording large amounts of text
- Provision of documents to all.



Images : Dong, S. (2022-2023). *Screenshots from Youth Engagement in Research Project Partnership*. [Images]. Used with permission August 2024.

Executive Functioning

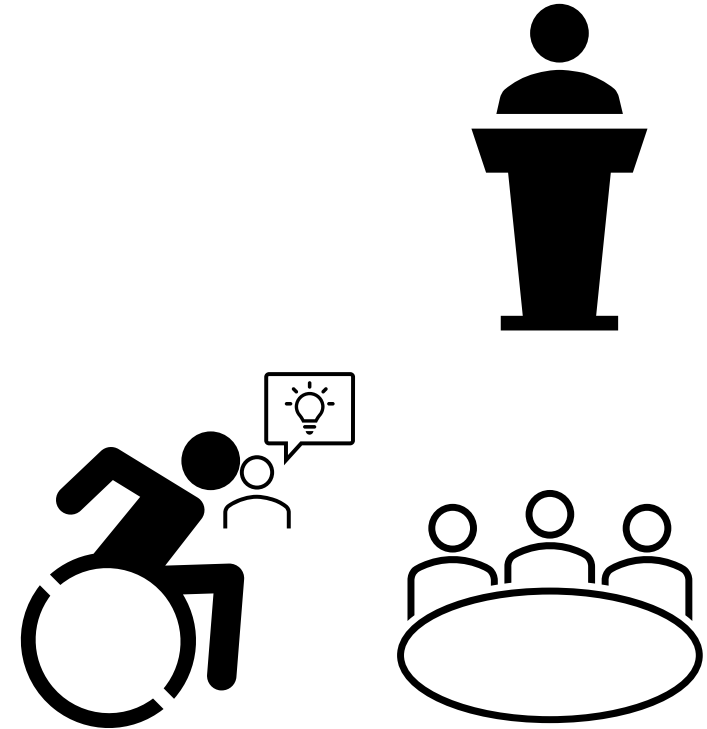
- Extra Time
- Chunking of tasks
- Clear frame of reference
- Check-ins
- Meeting summaries
- Recording of meetings



Dong, S. (2022-2023). Screenshots from Youth Engagement in Research Project Partnership. [Images]. Used with permission August 2024.

Conferences

- Conference presenters
- Work with disabled partners to assist in needed accommodations
- Communication
- Costs
- Quiet place to take a break



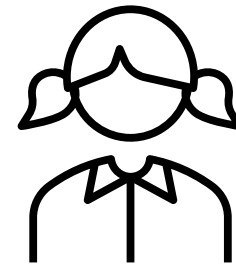
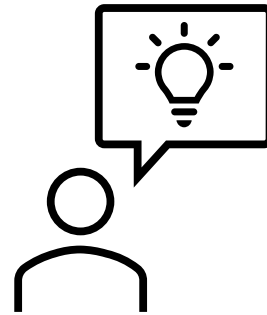
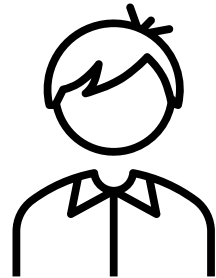
All Icons from Microsoft 's Powerpoint built in Icon Library, Accessed 8/21/2024

Partnerships and Accessibility

Viewpoints from a Researcher

3 Lessons Learned

1. Working with youth and/or disabled individuals.
2. Giving them space to learn and experience.
3. See their worth and believe in them as researchers and colleagues.



Source: All Icons from Microsoft 's Powerpoint built in Icon Library, Accessed 8/21/2024

What Comes Next

For Us as People and For Our Tool....

For Us...as Individuals and As a Team

- Conferences and co-presentations.
- Leadership roles in research as patient partners.
- Continuing to host Possibilities podcast.
- Continued employment as Accessibility Champion and as a Co-Instructor with the FER program.
- Continued employment with CanChild as Accessibility Remediation Specialist
- Assistant professor focused on engagement with youth in research

What is Next...for Our Tool

- Continue to share our resource
- Update and add to the resource



Please utilize the QR Code to access our [Youth Engagement in Research/Accessible Research Resource Linktree](#)

Thank You and Feel Free to Contact us:

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Linda Nguyen - linda.nguyen1@ucalgary.ca

References and Sources

Canadian Institutes of Health Research (CIHR). (2019). *Strategy for Patient-Oriented Research – Patient Engagement Framework*. <http://www.cihr-irsc.gc.ca/e/48413.html>

Family Engagement in Research (2023) *Family Engagement in Research Logo*,

Dong, S. (2022-2023). *Screenshots from Youth Engagement in Research Project Partnership*. [Images]. Used with permission August 2024.

Dong, S., Geboers, J., St. Dennis, A., & Steeves, D. (2023). *Accessibility Accommodations in Patient-Oriented Research Partnerships*. Unpublished manuscript. McMaster University.

Microsoft Stock Images. Accessed August 2023.



Q&A

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