



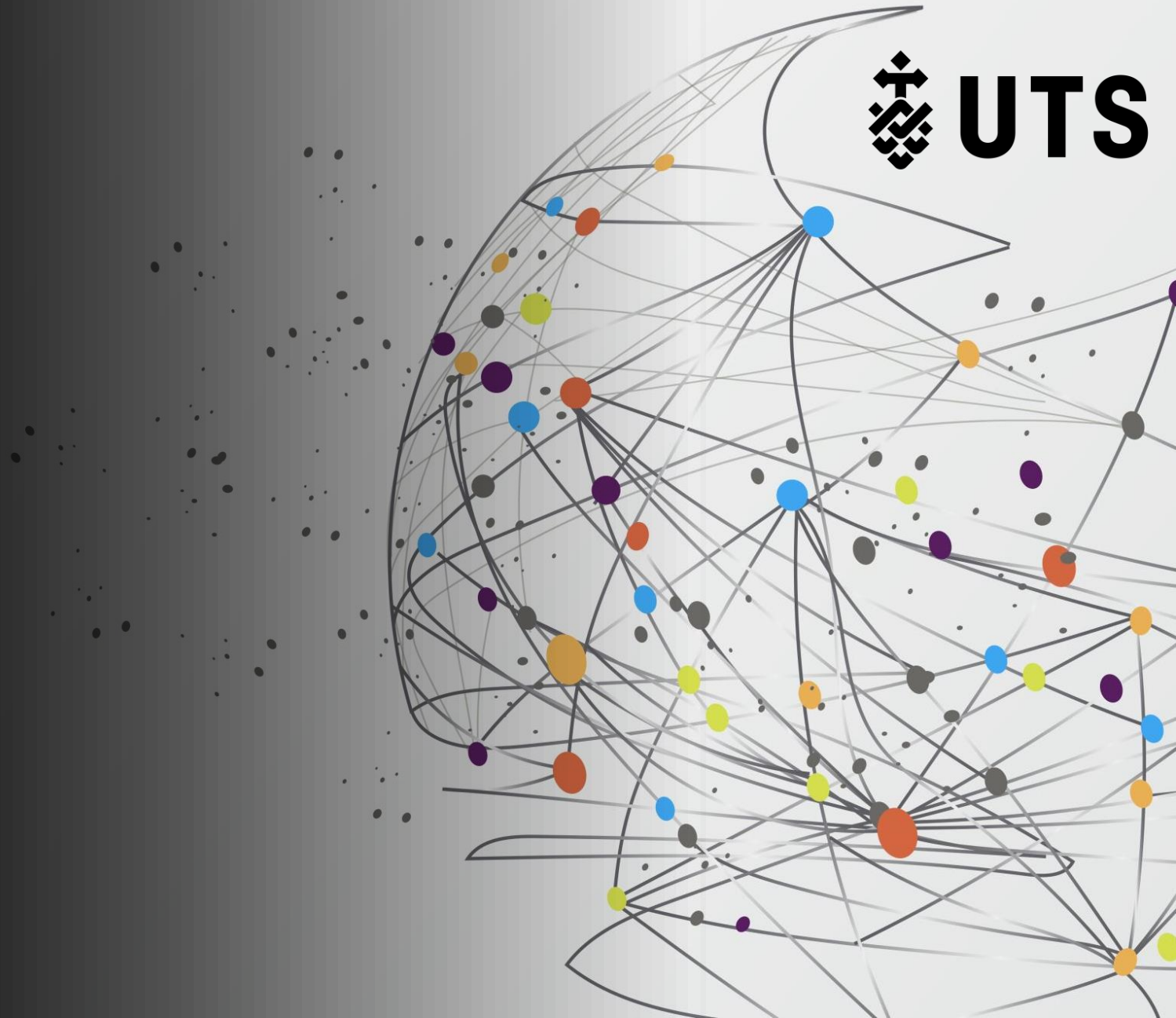
Complexity in Consent: Disability, Communication, and Inclusion

Prof Bronwyn Hemsley

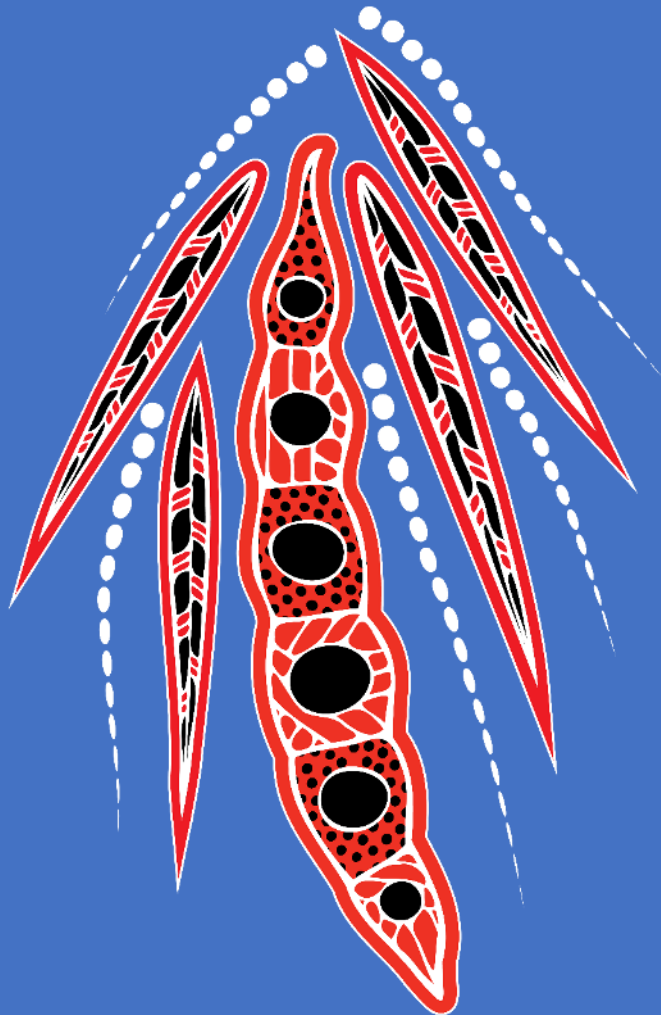
28th June 2023

Ethics Exchange online professional development session for
research ethics committee members

UNSW Online



Acknowledgement of Country



I acknowledge traditional owners of the land in which I'm presenting today, the Pambalong Clan of the Awabakal people, and the first nations peoples of the land where you are joining from.

I also acknowledge the Gadigal people of the Eora Nation as traditional custodians of knowledge on the lands where UTS stands.

I also acknowledge their elders past present and emerging as well as any Aboriginal and Torres Strait Islander people here today.

The Girra Maa (Indigenous Health Discipline at UTS) wattle seed artwork was produced by Wiradjuri artist Nathan Peckham. It signifies our unity and diversity.

Mapping Disability Research in Australia 2018 - 2020

1

Authors: Jennifer Smith-Merry, Gisselle Gallego, Angela Dew on behalf of the Research Agenda Project

National Disability Research Agenda Project

NDRA 4 Major Reports (open access)
<https://www.ndrp.org.au/researchagenda>

SURVEY



Setting an agenda for disability research in Australia: survey results

Phase 2a report

2

REPORT



Setting an agenda for disability research in Australia: co

Phase 2b report

29 AUG 2022

Mary-Ann O'Donovan, Bronwyn Hemsley, John Simon Darcy, Tadgh Mc

Jennifer Plumb, Gemma
PUBLISHER
Centre for Disability

3

REPORT



Setting an agenda for disability research in Australia: synthesis and refinement

Phase 3 report

29 AUG 2022

Angela Dew, Jennifer Plumb, Gisselle Gallego, Simon Garbellini, Christine Imms, Simon Darcy, Keith McVilly, Bronwyn Hemsley, Mary-Ann O'Donovan, Jennifer Smith-Merry

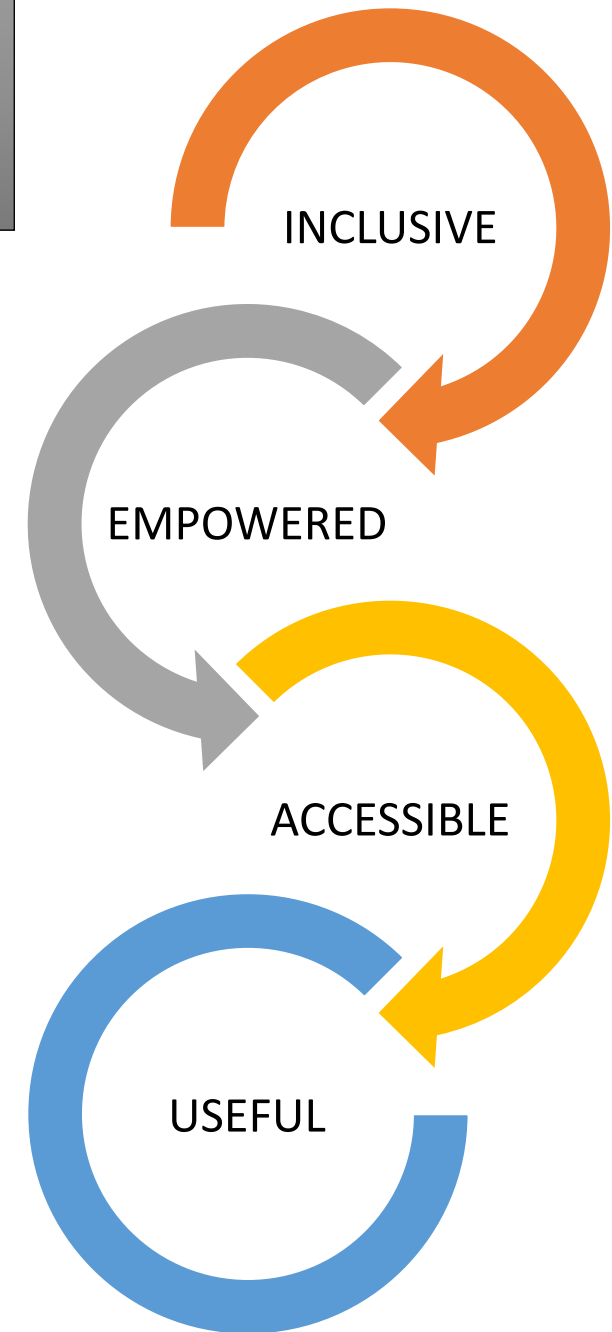
PUBLISHER
Centre for Disability Research and Policy

Community based participatory research Lived experience Disability People with disability
Australia

4

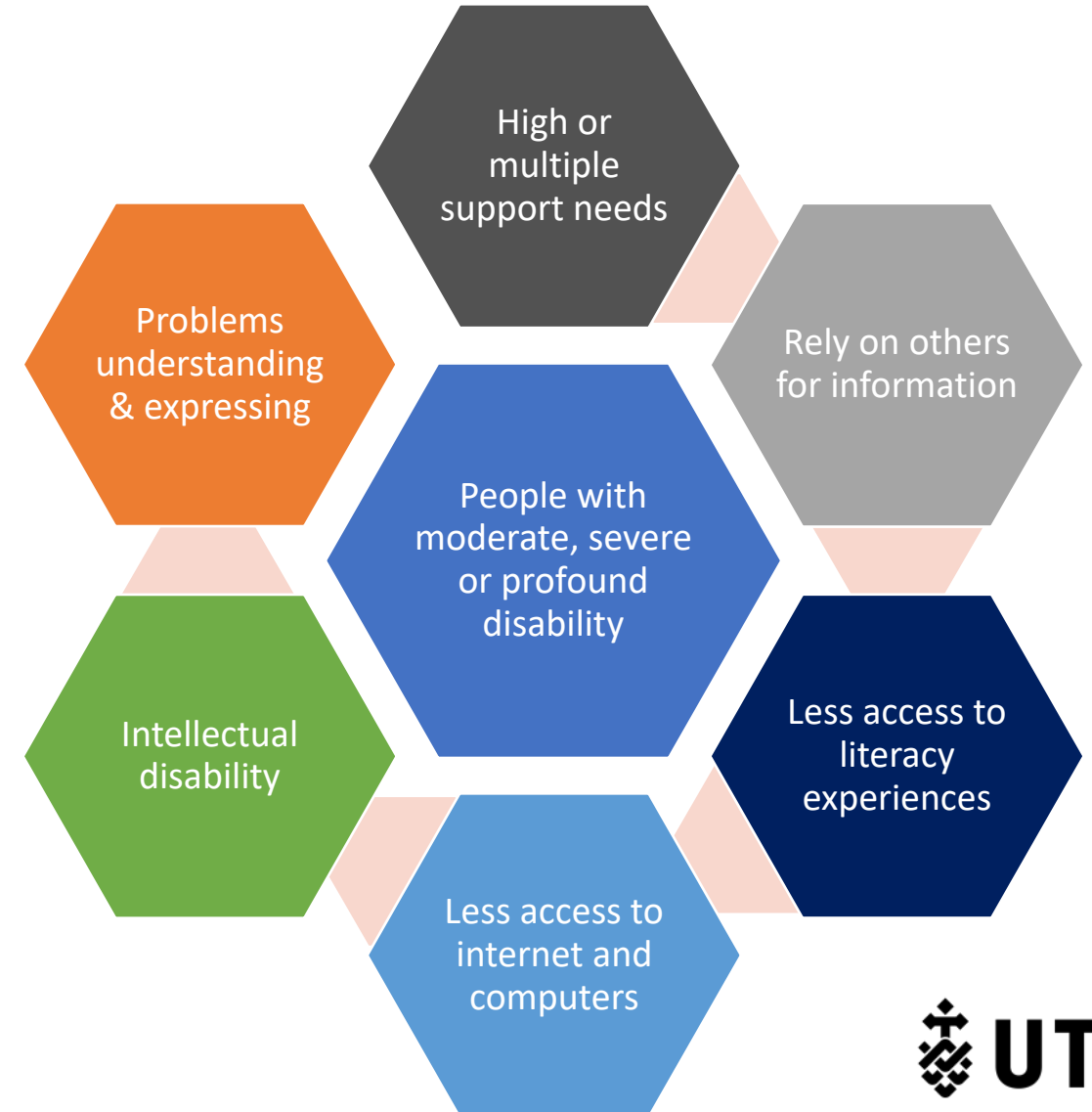
DISABILITY RESEARCH SHOULD BE ... to improve people's lives

1. **INCLUSIVE:** and much more inclusive than it is at present.
2. **EMPOWERED:** People with disability should be driving research and research priorities.
3. **ACCESSIBLE:** be inclusive by being accessible to all.
4. **USEFUL:** created and distributed in ways that all people with an interest in disability research can use in their lives and work (i.e., not just a summary, a journal article, a seminar!)



Participants with significant disabilities

- Cerebral palsy, intellectual disability, brain injuries ... multiple health conditions
- High proportion of communication disability impacts on research participation
- Supported by (a) family members (often parents, sometimes siblings) or (b) direct support workers (often low income, multilingual, low health literacy, low literacy) -
→ 45% of Australians have low levels of literacy
- Are therefore at risk of (a) being actively excluded from research, and (b) not having good access to research recruitment information (and less access to participation)
- Obvious implications for simplifying information sheets
- An example of 'Video Support' to a PIS for people with ID and communication disability (Harmony Turnbull, PhD Candidate UTS)
- An example of visual supports to text



Disability can impact the process of both informed consent and participation

- Procedures for ensuring informed consent
 - Must be multi-modal in terms of methods of communicating the information (text, video, picture supports, verbal explanation)
 - Must ensure the person understands all elements (e.g., ‘teach back’ procedure)
 - Is the person the one giving informed consent?
 - Who is to give consent on their behalf, if they are unable to give their own informed consent?
 - Information is not only needed for consenting, people have a right to know what it involves

Disability can impact the person's actual participation, after consent

Online surveys – with a support person?

In-depth interviews – directly for themselves (independently) or with communication assistance?

Focus groups – with a support person? (Moderator skilled?)

With a communication aid – used independently?

With unclear speech – and any speech interpretation?

To what degree is the communicated message coming from the participant with communication disability? How will the researcher check this?

Whose voice is it?
Determining 'authorship' when 2 are involved

Photo review method (use of visual supports)

Not relying on spoken language or understanding (e.g., Body Mapping, Visual Methods, Talking Mats)

Participants: Criteria for inclusion

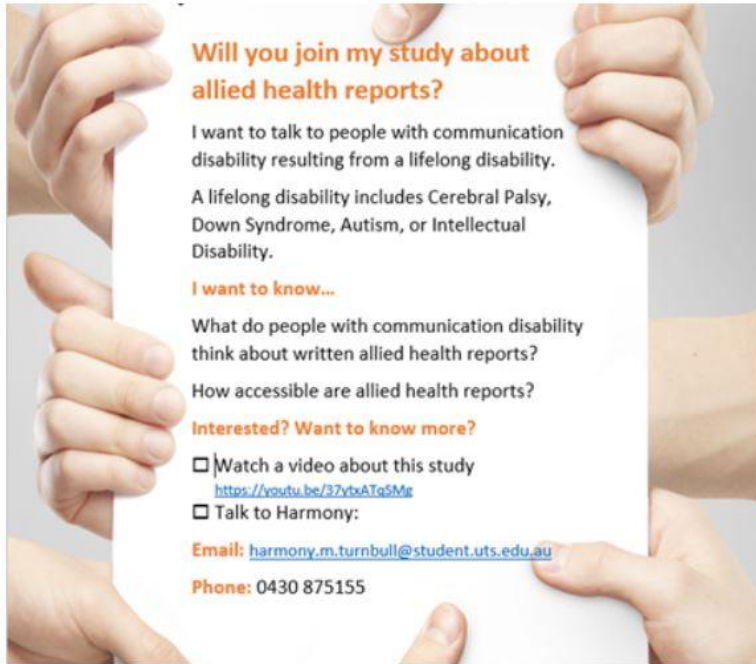
- The person must be able to communicate independently, even if using an assistant to help communicate in the session.
- The role of the assistant should be acknowledged.
- The person may need access to a communication aid to take part in the study.
- Study materials should provide relevant communication aids for inclusion.
- The researcher should have experience in communicating with people who have severe communication disability / intellectual disability.
- The research materials should be modified so that the person can understand

Problematic practices in communication

- Use of Facilitated Communication or Rapid Prompting Method
- If the study is of people with severe or profound non-verbal autism, how are they taking part?
 - Speech?
 - Pointing to pictures on a board?
 - Typing?
 - What is the role of the 'facilitator' in the message created?
 - There is no evidence that FC or RPM results in independent communication
 - Therefore, authorship testing should be used to determine any role or influence of a facilitator, if FC or RPM is used; and the influence should be ruled out prior to using these techniques to take informed consent

Will you join my study about allied health reports?

Posted On October 5, 2020












I am a PhD candidate at the University of Technology Sydney (UTS). I am doing a study about allied health reports written for and about people with communication disability.










   
Thank you for talking to me today.

 
My name is Kirsty.

     
I am a researcher at the University of Technology Sydney.


        
I talk to children about what they want disability researchers


to know.

        
I want to talk to you today with your parent.

    
It will take 30 minutes or one hour.

     
Your Mum or Dad will help.

    
Are you ready to start? Let's start.

<https://www.youtube.com/watch?v=37ytxATqSMg&t=82s>





Get some assistance with creating “Plain Language” or “Easy English” or adapted formats for Information Sheets

AI – ChatGPT – A quick way to transfer information into simpler formats.

- Reduce the word count
- Make it simpler
- Turn it into bullet points
- Use active case sentences only
- Include these headings: (give headings)
- Reduce the reading level
- Make it easier to read
- Remove all jargon
- Make sentences shorter
- Suggest pictures to go with the text
- Summarise this
- Give me the five main points
- Write me a video script explaining this in 2 min
- Suggest scenes, pictures, text, and transitions



I want to make a Participation Information Sheet easier to read in a variety of ways. Are you ready?



Absolutely, I'm ready to help! Let's make your Participation Information Sheet more readable and accessible. Please share the current version with me so I can suggest improvements. Here are a few general tips to get started:

1. **Plain Language:** Use simple, everyday language instead of technical jargon. Make sure the content is easy to understand for people with various literacy levels.
2. **Clear Structure:** Use headings and subheadings to organize information. This will help readers easily find what they're looking for.
3. **Bullet Points and Numbered Lists:** These make information easy to digest and remember.
4. **Use of Visuals:** If possible, use diagrams, infographics, or other visuals to illustrate complex information.
5. **Font and Size:** Ensure the font style and size are readable. A minimum of 12-point type is usually recommended.
6. **Whitespace:** Avoid cluttering the page. Whitespace improves readability by providing visual breaks for the reader.
7. **Highlight Important Information:** Highlight key points or use boxes for information that requires extra attention.
8. **Consider Accessibility:** Make sure your information sheet is accessible to those with visual or hearing impairments.
9. **Contact Information:** Make sure to include easy-to-find contact information for participants who may have further questions.

Now, if you share the specific text you have, I can provide more tailored advice.



Thank you for providing the detailed Participation Information Sheet. It is quite thorough and well-structured. Here are my suggestions to make it easier to read:



PARTICIPANT INFORMATION SHEET – Interviews

Project: Exploring AI in Teaching Health Professions

Code: ETH23-8115

Who's doing this study?

Prof. Bronwyn Hemsley, Assoc. Prof. Emma Power, and Ms. Fiona Given from UTS Faculty of Health.

What's it about?

We want to understand your thoughts on using AI language models like ChatGPT in health education. We're keen to learn about:

- How these AI models could help train health professionals.
- Any possible risks or opportunities with using AI like ChatGPT for assignments.
- Ways to reduce any risks and better understand how these AI models can be used in health curriculums.

Who can join?

You're invited if you're involved in teaching, learning, or researching in health fields in an Australian university. You don't need to be a full-time staff or a qualified health professional.

Who's funding this?

The UTS Faculty of Health Teaching and Learning Scholarship 2023.

What will you do?

If you join, we'll ask you to do a 45-60 minute online Zoom interview, talking about your use and views of AI like ChatGPT. The conversation is flexible, and you can skip any question you don't want to answer. We'll send you a summary to check and amend before we use it. For your time, we'll give you a \$50 gift voucher.





I want to make a 2 minute video with the same information, for people to watch if they cannot read very well. Could you write me a 2 minute script for the video with suggested scenes / narration?



Absolutely! I'd be happy to help you create a video script. Here's a suggestion:

[Scene 1 - Image of UTS logo or campus with upbeat music playing softly]

Narration: (Cheerful voice) "Hello! We're Prof. Bronwyn Hemsley, Assoc. Prof. Emma Power, and Ms. Fiona Given from the UTS Faculty of Health. We have an exciting study we'd love for you to join."

[Scene 2 - Slide showing AI interface, ChatGPT logo, or related images]

Narration: "We're exploring the use of AI, like ChatGPT, in health education. We're interested in your thoughts, experiences, and how it might impact the future of health training."

[Scene 3 - Images of diverse group of university staff, students, researchers]

Narration: "Whether you're a student, teacher, researcher, or staff member at an Australian university, and you're involved in health disciplines, we'd love to hear from you."

[Scene 4 - Image of a calendar or clock showing time frame]

Narration: "What does participation look like? Well, it's simple. You'll be invited for a casual 45-60 minute chat on Zoom, at a time that suits you."

[Scene 5 - Images of various people in conversation (illustrations, photos, animations)]

Narration: "You'll share your thoughts on AI like ChatGPT and how it might be used in health education. And remember, you can skip any question you're not comfortable answering."

Contact

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