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PARTICIPANT INFORMATION AND CONSENT FORM

Operationalising Epistemic Injustice in Healthcare: Extending the Illness Invalidation Inventory (3*I-H)

Invitation to Participate

You are invited to take part in a research study exploring how adults living with chronic physical health conditions experience communication and understanding in healthcare settings. Chronic physical health conditions refer to conditions that are ongoing (typically lasting three months or longer) and require ongoing management.

This research project is being conducted by Jesse Wheeler under the supervision of Professor Naomi Sweller, School of Psychological Sciences, Macquarie University, to meet the requirements for the degree of Master of Research and is funded by the Macquarie University Research Excellence Scholarship (MQRES).

Before deciding whether to participate, please read the information below carefully. Participation is voluntary. You may download or print a copy of this Participant Information and Consent Form for your records before proceeding.

What is the purpose of this study?

This study aims to better understand how people with chronic physical health conditions experience communication and understanding in healthcare interactions. This includes a range of experiences, from feeling understood and supported to feeling misunderstood, dismissed, or not taken seriously by healthcare professionals.

Previous research has shown that some patients report negative experiences in healthcare interactions, particularly when symptoms are difficult to explain or measure. This study builds on an existing validated questionnaire and includes new survey questions designed to better capture these experiences.

The findings may inform future research examining patient experiences in healthcare. Participation is limited to adults aged 18 years or older residing in Australia. Participants must also have sought care from a healthcare professional for a suspected or confirmed chronic physical health condition.

What does participation involve?

If you choose to participate, you will complete an **online survey** hosted on **Macquarie University's secure REDCap platform**.

The survey takes approximately **15-20 minutes** to complete and includes:

- questions about experiences of feeling understood, misunderstood, or dismissed by healthcare professionals
- general background questions (e.g., age, level of education)
- an optional open-ended question where you may provide general comments about your healthcare experiences.

You may skip any questions you do not wish to answer and may stop participating at any time before submitting the survey.

Do I have to take part?

No. Participation is entirely voluntary.

If you decide not to participate, or if you begin the survey and later change your mind, this will not affect your healthcare, your relationship with Macquarie University, or your relationship with any healthcare provider.

The survey does not collect your name, contact details, IP address, or other direct identifying information. While the survey is designed to be anonymous, the information collected will be treated as de-identified, as there is a small risk that individuals could be indirectly identifiable based on combinations of responses.

Because no direct identifiers are collected, it will not be possible to access, correct, or withdraw individual responses after submission.

Are there any risks?

This study involves **minimal risk**.

Some questions may prompt you to reflect on past healthcare experiences that you found frustrating or upsetting. If you feel uncomfortable, you may skip any questions, take a break, or stop participating at any time.

If you experience distress, you may contact:

- Lifeline: 13 11 14 or text 0477 13 11 14
- Beyond Blue: 1300 22 4636
- MindSpot Digital Mental Health Clinic: mindspot.org.au
- Your GP or local healthcare provider.

Support service information will also be provided at the end of the survey.

Are there any benefits?

You may not receive any direct personal benefit from participating. However, your responses may help improve understanding of patient experiences in healthcare and inform future research.

Will I be paid?

There are no costs associated with participating.

As a thank-you for your time, participants may **optionally enter a random prize draw to win one of ten \$100 gift cards.**

Entry into the prize draw requires providing contact details via a **separate online form**, which is **not linked to your survey responses**. Entering the prize draw is entirely optional and is not required to participate in the study.

Contact details collected for the prize draw will be deleted after the draw has been completed.

What will happen to information about me?

The survey responses do **not collect your name, contact details, IP address, or other direct identifying information**. Survey responses will be collected via REDCap and stored securely on Macquarie University SharePoint systems accessible only to the research team.

While the data are de-identified, there is a small risk that individuals could be indirectly identifiable based on combinations of responses.

If you choose to provide a written comment, you will be asked not to include names, locations, or other identifying details.

Because no direct identifying information is collected, it will not be possible to access, correct, or withdraw individual responses after submission.

Data will be analysed and reported in **aggregate form only**, meaning that individual participants will not be identifiable in any publications or presentations.

Your de-identified data may be shared in a research data repository where it may be accessed, reused, and reanalysed by other researchers or members of the public in the future. This means that your data may be used for purposes beyond the scope of the current study, including by individuals or organisations not involved in this research.

If you choose to enter the optional prize draw, you will be asked to provide contact details via a separate online form. These details will not be linked to your survey responses. Only the named researchers will have access to this identifiable information, which will be used solely for the purpose of administering the prize draw and will be deleted after the draw has been completed.

What if I have questions or concerns?

If you have questions about the study, please contact:

Jesse Wheeler
Master of Research (Psychology) Student
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jesse.wheeler@students.mq.edu.au
Phone: 0414 462 893

If you have concerns about the ethical conduct of this research, you may contact:

Director, Research Ethics & Integrity
Macquarie University
Email: ethics.secretariat@mq.edu.au
Phone: +61 2 9850 4430

Ethics Approval:

This study has been approved by the Macquarie University Human Research Ethics Committee - **Reference No: 520262034167529**.

Consent

By clicking “**I consent**” and proceeding to the survey, you confirm that:

- You are 18 years of age or older
- You have read and understood this information
- You consent to the collection and use of your de-identified survey responses as described in this form.
- You voluntarily agree to participate in this study.