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Developing a Preference-based Wellbeing Index: The Disability Wellbeing Index (DWI)

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to participate in a focus group to share your views on the development of a disability wellbeing index (DWI) that will measure changes in various components of wellbeing over time. This measure

Monash University, the University of Sydney and Flinders University are collaborating to develop and validate a preference-based wellbeing index based upon the outcomes contained within the Australian Disability Strategy, the NDIS Outcomes Framework and other state-based Disability Inclusion Plans that can estimate the benefits and thus the cost-effectiveness of investments for people with disabilities. This index will also provide people with disability, including NDIS participants an easy signal as to how certain types of funded supports have improved the wellbeing of other participants.

It is important for multiple stakeholders to have input into how disability wellbeing is framed in the DWI. The purpose of this research is to gather input from people with disability to ensure that the domains and items in the DWI are relevant, of importance and accessible to people with disability.

Focus groups will discuss:

- The domains in the draft DWI about disability wellbeing
- The explanation of these DWI domains
- The items included in each domain
- Other domains or items that should be included
- Issues of concern (e.g., who will use the DWI, and for what purpose).

The findings of this research will inform development of a draft DWI that will be used in further testing and development to refine the index and ensure the accessibility and rigour of the DWI.

You have been invited to participate in this research because of the particular insights and perspectives you can contribute as a person with disability.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this document carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

This study is being undertaken by a research team at the University of Sydney:

- Dr Kim Bulkeley, Senior Lecturer, Centre for Disability Research and Policy, The University of Sydney, Chief Investigator
- Professor Emerita Gwynnyth Llewellyn, Centre for Disability Research and Policy, Co-Director, Centre of Research Excellence in Disability and Health, The University of Sydney
- Assoc Professor Gang Chen, Monash University
- Assoc Professor Dennis Petrie, Monash University
- Professor Anthony Harris, Monash University
- Professor Julie Ratcliffe, Flinders University
- Ms Imelda Noti, Faculty of Medicine and Health, The University of Sydney

This research has been commissioned by the Australian Government National Disability Insurance Agency and Monash University.

(3) What will the study involve for me?

There are two phases to this study. If you agree to participate, in Phase 1 of the study, you will be invited to take part in a focus group consultation, with approximately 4-8 participants, held via video conference. The focus group will be facilitated by a member of the research team and another researcher with lived experience of disability. The session will run for approximately 1 ½ hours. You will receive a short background document in advance, which will contain information about the DWI domains and items. You are welcome to provide further input in writing after the focus group discussion if you wish.

If you require, accessibility arrangements can be made to ensure that you can participate fully in the consultation process. Accessibility accommodations may include holding discussions using live videoconference captioning, or arranging for participants to provide input in writing or via phone or individual interview. Where required, documents can be provided in a form compatible with software used by participants who use alternative and augmentative communication devices, in Easy Read form, or in accessible screen reader formats.

You will be asked whether you consent to an audio recording being made of the focus group discussion (or interview if you are unable or unwilling to participate in a focus group) in which you take part. The discussion will be recorded only if all participants provide their consent; if not, one of the researchers will take notes on the views expressed during the discussion.

In Phase 2 of the study, between 1 and 2 weeks after you participate in Phase 1 above, we will invite you to complete a follow-up online questionnaire. This will ask you to:

- indicate your preferred set of domains and items from two or three options given

- indicate your preferred explanatory statement about the domains
- provide additional comments if you wish.

The options in the questionnaire will be developed following Phase 1 consultations. You will also be asked several questions about yourself. We anticipate the questionnaire can be completed in 10-15 minutes.

You may respond to the questionnaire via other means (e.g., over the phone, in person) if necessary to accommodate accessibility requirements.

(4) How much of my time will the study take?

Your participation will involve a time commitment of approximately 2 to 2.5 hours, allowing an hour and half for focus group (or interview) participation, and 30 minutes for email communications (e.g., providing your Participant Consent Form) and completing the online questionnaire.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by informing a member of the research team, verbally or in writing, that you no longer want to participate.

If you provide any written input, within two weeks of providing that input you can request that it should not be included in the research findings. After this time, it may not be possible to remove your responses from the analysis. If you participate in a focus group it may not be possible to exclude individual data once the session has commenced, however you are free to leave the focus group at any time.

(6) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

If at any stage during your participation in the study you become distressed, you can contact Lifeline's 24 Hour Crisis Support Service on 13 11 14.

(7) Are there any benefits associated with being in the study?

If you participate in a focus group or interview you will receive a $50 voucher to recognise and thank you for your input.

The proposed index will not provide a direct benefit to participants but has the potential to provide a preference-based measure that comprehensively covers the domains of interest to people with disability to enhance monitoring of both social equity outcomes and value for money in public spending.

(8) What will happen to information about me that is collected during the study?

Your information will be stored securely and your identity/information will only be disclosed with your permission, except as required by law. Study findings may be published and presented orally, but you will not be identified in these publications or presentations.

Audio recordings will be used solely to produce a transcript of the focus group or interview so that the researchers can analyse the views expressed by participants. No third parties will have access to the audio recordings or to any written input you provide as part of this study.

During the project, all study materials will be stored digitally on the University of Sydney Research Data Store, a secure system. All files that contain identifying information will be encrypted. Electronic files containing written input from participants and audio recordings will be labelled using participant and focus group codes, not participant names. Upon completion of the project, all study materials will be stored digitally on Research Data Store. Study materials will be retained for 5 years after project completion.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

When you have read this information, a member of the research team will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact a member of the research team:

Kim Bulkeley E-mail: kim.bulkeley@sydney.edu.au Ph: 0430 431 292
Gwynnyth Llewellyn E-mail: Gwynnyth.llewellyn@sydney.edu.au
Imelda Noti E-mail: imelda.noti@sydney.edu.au Ph: 0434 980 877

(11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You will receive a summary report on findings from the focus groups and follow-up questionnaires including in accessible formats.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (Project number 2022/318). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep