THE UNIVERSITY OF SYDNEY

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Stakeholder consultation: Capturing patient disability information in a Voluntary Patient Registration scheme for General Practice in Australia

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to participate in a focus group to share your views on how patient disability information could be captured using a short set of questions on a Voluntary Patient Registration (VPR) form for General Practice in Australia.

The Australian Government plans to introduce VPR so that people can choose to register with their regular general practice and nominate their preferred General Practitioner. The VPR form will include optional questions to record selected information about patients, including disability.

It is important for multiple stakeholders to have input into how patient disability information is captured in the VPR form. The purpose of this research is to gather input from people with disability through their representative organisations, health consumers through their representative organisations, and a variety of General Practices and their clinical and administrative staff and Primary Health Network staff.

Focus groups will discuss:

- what form questions about disability in the VPR form should take;
- what explanatory information should accompany questions about disability on the VPR form;
- benefits and risks of providing disability information for people with disability;
- benefits to general practices and Primary Health Networks of having patient disability information available, and the type of information that would be most useful;
- practical issues concerning implementing disability questions in a VPR form;
- ability to capture patient disability information in clinical information systems used by GP practices;
- other important considerations, such as confidentiality, privacy, data quality.

The findings of this research will inform development of questions to identify patients with disability and an accompanying clearly-worded statement explaining why these questions are being asked and the benefits to patients of providing this information to their GP practice.

You have been invited to participate in this research because of the particular insights and perspectives you can contribute as a representative of one of the following stakeholder groups: people with disability; health care consumers; clinical or administrative staff working in a general practice or a Primary Health Network.

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 Nicola Fortune, Research Fellow, NHMRC Centre of Research Excellence in Disability and Health, The University of Sydney, Project Manager
- Ms Jodie Bailie, Research Fellow, University Centre for Rural Health, The University of Sydney
- Dr Julie Gordon, Research Fellow, Classifications Node, WHO Centre for Strengthening Rehabilitation Capacity in Health Systems, The University of Sydney
- Professor Gwynnyth Llewellyn, Co-Director, Centre of Research Excellence in Disability and Health, The University of Sydney
- Professor Richard Madden, Honorary Professor, Faculty of Medicine and Health, The University of Sydney
- Ms Imelda Noti, Classifications Business Coordinator, WHO Collaborating Centre, Faculty of Medicine and Health, The University of Sydney

This research has been commissioned by the Australian Government Department of Health.

(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 either face-to-face or via video conference. The focus group will be facilitated by Ms Jodie Bailie, another member of the research team and another researcher with lived experience of disability. The session will run for approximately 1 hour. You will receive a short background document in advance, which will contain information about the VPR scheme and some discussion points relating to how patient disability information could be captured in a VPR form. 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 face-to-face discussions in venues that are physically accessible to all participants, live videoconference captioning, or arranging for participants to provide input in writing or via phone or face-to-face 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 Braille.

You will be asked whether you consent to an audio recording being made of the focus group discussion (or interview) 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 4 weeks after you participate in Phase 1 above, we will invite you to complete an online questionnaire. This will ask you to:

- indicate your preferred set of disability questions (from two or three options given);
- indicate your preferred explanatory statement about including disability in the VPR form (from two or three options given);
- provide additional comments if you wish.

The options in the questionnaire will be developed following Phase 1 consultations and a review of relevant literature on disability questions in service registration forms and service data collections.

You may respond to the questionnaire via other means (e.g., over the phone) 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 1.5 hours, allowing an hour 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 in your own time (not as part of your paid work time as an employee of the organisation you are representing), you will receive a $50 voucher to recognise and thank you for your input.

Capturing patient disability information in the context of VPR is an Australian Government initiative that will affect all Australians. It is important that the views of relevant stakeholders inform the development of feasible and acceptable disability questions and accompanying explanatory information to be included in the VPR form.

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

By providing your consent, you are agreeing to us collecting your name and organisational affiliation (if applicable), and the views you express in the focus group (or in writing or via phone or face-to-face interview) and questionnaire. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

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. A list of organisations represented in the stakeholder consultation may be included in publications or presentations to convey the breadth of the consultation process.

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 Research Data Store, a secure, University-supported data storage 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. Hard-copy study materials (including participant consent forms) will be scanned and stored electronically; hard copy materials will then be destroyed. 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:

Jodie Bailie E-mail: jodie.bailie@sydney.edu.au Ph: 0428 601 559
Nicola Fortune E-mail: nicola.fortune@sydney.edu.au Ph: 0401 643 483
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 stakeholder consultation.

(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 2021/526). 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