

## Understanding Health Literacy Needs for People with disability

### Participant Information – What to expect

You are being invited to take part in a project that aims to understand how health literacy is currently supported and how it could be improved for people with disability in the ACT.

Your participation is voluntary. This means that you do not have to take part, and there are no consequences to you if you choose not to take part.

Before you decide it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully.

#### Why is this study being done?

This is a quality improvement study that will provide an understanding of the strengths and weaknesses in health literacy for ACT disability communities and focus areas for action. HCCA will share this information with ACT Health to support future actions under the [ACT Disability Health Strategy 2024–2033](#) and [ACT Disability Health Strategy First Action Plan, 2024-2026](#). This project will inform the work of the ACT Health Directorate, Canberra Health Services and other health and social care organisations, by providing advice and recommendations for where future projects and resources may be targeted to improve the way health systems support the health literacy of people with disabilities.

#### What is involved?

If you agree to participate in the study, a staff member from HCCA will contact you to arrange a time to interview you about:

- Your understanding of health literacy in practice
- Your experiences working with people with disability and the people who support them
- How you meet the needs of people with diverse communication needs
- Organisational policies and procedures you might use
- Some of the barriers to meeting patient needs in this area
- Some opportunities and key enablers to achieving this

### **Are there any risks?**

You may experience emotional discomfort when discussing your experiences as a service provider. Attending an interview may also be an inconvenience. To address this, the interview will be arranged at a time and location that is convenient to you. You are able to stop the interview at any time and/or withdraw from the study. If you would like to take part, you will receive a list of questions we may discuss before we speak. You can prepare for the interview by thinking about anything you'd like to talk about, and you can let the HCCA researcher know if there's anything you *don't* want to discuss.

If you do experience emotional discomfort, you may wish to contact Lifeline on 13 11 44.

### **What about confidentiality?**

If you consent to participate in this study HCCA will keep your name and contact details on record to arrange the interview. This information will be deleted at the conclusion of the project.

With your consent HCCA will utilise your job title and/or the setting or type of organisation you work in will be included in a final report that will be shared with the ACT Health Directorate which may be made public following ACT Health Directorate approval.

With your consent HCCA will take an audio-recording of the interview. The recording will be stored on a secure computer server, with one back up recording stored on an external hard drive which is stored in a locked filing cabinet for the length of the study. The audio-recording will be destroyed after they have been transcribed. HCCA will transcribe the audio-recording, removing any personally identifiable text, and will store a copy of these on a secure computer server, separately from your name and contact information.

De-identified information from this study will be included in a final report that will be shared with the ACT Health Directorate and will be made public following ACT Health Directorate approval. Results may also be shared in publications and presentations that will be shared with the public.

### **Questions or Concerns?**

If you have any concerns about the conduct of the research, please contact the Acting Executive Director of HCCA, Kate Gorman on (02) 6230 7800. If you have any questions about the project or the interviews, please contact the project research officer, Shivana Chandra at 02 6230 7800 or via email at [shivanachandra@hcca.org.au](mailto:shivanachandra@hcca.org.au)