

# **Research Participant Information Statement: Interviews**

Dignity Project: understanding patient perspectives on dignity in the rehabilitation context to improve satisfaction

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Research Team			
	Dr. Dinesh Palipana Principal House Officer, Emergency Department, Gold Coast University Hospital		Kelsey Chapman Academic Lead, The Dignity Project, MHIQ, Griffith University
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	Angel Dixon, Citizen Scientist, The Dignity Project, Griffith University	Susan Jones, Nurse Unit Manager Neurosicence, Rehabilitation Unit, Gold Coast Hospital and Health Service	
	Professor Elizabeth Kendall Griffith Inclusive Futures, MHIQ, Griffith University		

#### What is the study about?

We want to understand more about dignity in rehabilitation settings from the perspective of patients and staff. If we can understand dignity better, including what is 'good' practice and what the barriers to dignified care are, we expect that we can support rehabilitation staff to provide the best possible care experiences for patients.

#### Who can participate?

You were invited to participate in this study because you are either:

- 1. A person who was an in-patient or out-patient of a rehabilitation unit or clinic at Gold Coast Hospital and Health Service (including Robina Hospital, Gold Coast University Hospital, and other outpatient clinics); OR
- 2. A rehabilitation staff member or staff member who interacts with rehabilitation patients, with Gold Coast Hospital and Health Service (in-patient or outpatient settings) for at least 3 months; AND
- 3. You are 18 years old or older





#### What do I need to do?

If you are interested, we will be asking you to complete a 30-45 minute interview via phone, virtually or in-person with a researcher to share about your experiences either working in rehabilitation or as a patient in rehabilitation. We will be asking you about your perceptions of dignity. If you have been a patient in a rehabilitation unit, we will be asking about what dignity means to you and about your experience of dignity during your admission to the rehabilitation unit. If you are staff, we will be asking you about what dignified care means to you and the barriers and facilitators that impact the dignity of care that you provide. The time and date will be agreed upon together by you and a member of the research team.

The research team can accommodate diverse ways of participating and can provide interpreters, live captions, or any other support you may need to comfortably participate. The research team can also provide support through the hospital liaison officer for First Nations participants, as required. Please let the research team know about what support you may require, by emailing <a href="mailto:dignityproject@griffith.edu.au">dignityproject@griffith.edu.au</a>.

#### Do I have to participate?

No. This research is voluntary and you do not have to participate. Once you have consented to participate, you can also pause or end your interview at any time and stop participating in the research without giving a reason and without penalty. Once the interview is completed, you will not be able to withdrawal your data from this research.

#### What is the benefit to participating?

Participants who were patients will be offered a \$50 gift voucher for their time. Staff cannot receive gift vouchers. This research will benefit clinical staff and patients in rehabilitation by providing a way to better understand dignity experiences.

#### How can I trust this research is safe for me?

This research is being conducted by experienced research staff from Gold Coast Hospital and Health Service and Griffith University. The research team will work with you to make the process as comfortable as possible.

If you are concerned about your physical, emotional, or mental safety by participating in this research, please talk to one of the research team members about any support you may need. We encourage you to discuss participation with members of your support network.

If you are a staff member at Gold Coast Hospital and Health Service, you may be concerned about sharing anything negative about your employer or employment setting. Your interview will be conducted by a Griffith University staff member only. This staff member will be responsible for de-identifying and analysing your data. No Gold Coast Hospital and Health Service staff member will have access to your data or will know about your participation unless you tell them. Your confidentiality will be protected.

All interviews will be audio recorded and transcribed into text. Your confidentiality and privacy will be protected at all times. Your personal information will be kept safe and will be





removed from any data. Only the research team will have access to your data. Any data that is shared through publication or reports will be done in a summary format and if necessary, will include a pseudonym.

Any information that is collected in connection with this research will maintain your confidentiality and data will only be disclosed with your permission, except as required by law.

#### What will be done with my data?

Research results will be reported to Gold Coast Hospital and Health Service and may also be disseminated via journal articles, reports and conference presentations. Research data will be retained in a password protected electronic file at Griffith University for a period of seven years. Your de-identified data, if you consent, may be shared with future research studies that are similar in nature to this study. Additional research will have individual ethics approval numbers.

#### **Privacy Statement**

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal, or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes and studies. However, your privacy will be safeguarded at all times.

#### Who can I contact for further information?

You might want to discuss if this research is right for you, if you can accessibility participate, or if your mental and emotional needs may be met during this research. You might be unsure if you are eligible to participate or unsure about how the research process works. We encourage you to contact the research team on <a href="mailto:dignityproject@griffith.edu.au">dignityproject@griffith.edu.au</a> or via phone on 0424-868-998 to discuss this and anything else you may wish to talk about, including scheduling an interview time.

#### How can I receive information about the research results?

Participants will receive plain language summaries of each phase of the research results, at the end of that phase. If you would like to discuss this further with the research team, you can do so via email.

#### Who has approved this research?

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2018)*. All research is also reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This research has been reviewed and approved by the Gold Coast Hospital and Health Service HREC (Ref number:) and Griffith University HREC (Ref number).

This research is funded by the Gold Coast Health Collaborative Grant Scheme.





#### What can I do if I have a complaint or a concern?

Any concerns or complaints about the conduct of this study should be directed to the:

HREC Coordinator Gold Coast University Hospital 1 Hospital Boulevard SOUTHPORT QLD 4215

Email: GCHEthics@health.qld.gov.au

Phone: (07) 5687 3879

Research Governance Leader Gold Coast University Hospital 1 Hospital Boulevard SOUTHPORT QLD 4215

Email: GCHResearch@health.qld.gov.au

Phone: (07) 5687 3880

Any complaint will be investigated promptly and you will be informed of the outcome.

This information sheet is for you to keep.





### **Research Participant Consent Information**

#### **Participant Consent Statement**

At the start of your interview you will be asked to consent to participating. The interviewer will read this consent form and ask you for verbal consent, which will be audio recorded.

By verbally consenting, I confirm that I have read and understood the information package and in particular:

- 1. I understand that my involvement in this research will include one interview, lasting approximately 30-45 minutes;
- 2. I understand that the research will include audio-recording of my participation;
- 3. I have had any questions answered to my satisfaction;
- 4. I understand the risks involved;
- 5. I understand that I will be offered a \$50 gift voucher for my participation in this research (note: only applies to participants who are previous patients);
- 6. I understand that my participation is voluntary;
- 7. I understand that if I have any additional questions, I can contact the research team;
- 8. I understand that I am free to withdraw at any time, without explanation or penalty;
- 9. I understand that my name and other personal information that could identify me will be removed or de-identified in publications or presentations resulting from this research;
- 10. I agree to allow my de-identified data collected as part of this study to be utilised in a future study of similar focus;
- 11. I understand that any future study that uses the de-identified data collected as part of this study will have a separate ethics approval and approval number;
- 12. I understand that I can contact the HREC Coordinator or Governance Leader at Gold Coast Hospital and Health Service if I have any questions or concerns about the ethical conduct of this research;
- 13. I agree to participate in this research.





## **Research Participant Withdrawal of Consent Form**

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Palipana, Chapman et al.,	
Participant Withdrawal Consent You can withdraw your participation dignityproject@griffith.edu.au or by	n consent by advising the researcher verbally, via email to returning this completed form.
research proposal described above	hereby wish to withdraw my consent to participate in the and understand that such withdrawal will not jeopardise with the Gold Coast Hospital and Health Service, other professionals.
Name of Research Participant (First i	name and Surname)(Print)
Research Participant Signature	 Date
Name of Witness	Relationship of Witness to Research Participant (e.g., friend, sibling, parent, partner)
Witness Signature	Date
Please return this withdrawal form v	ia email to <u>dignityproject@griffith.edu.au</u>