

Participant Information Sheet

Title: Patient Perspectives of Quality Indicator Reporting in Kidney Failure Care: A Qualitative Study

Title: Patient Perspectives of Quality Indicator Reporting

HREC Reference: 16623

Principal investigator: Stephen McDonald – Executive Officer, Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), E-mail: stephen@anzdata.org.au

Study investigators: Emily Duncanson, Shyamsundar Muthuramalingam, Christopher Davies, Nicholas Gray

Location: ANZDATA Registry, South Australian Health and Medical Research Institute (SAHMRI)

1. Introduction

You are invited to take part in a focus group to share your opinions and views of reporting of quality indicator data in kidney care. Quality indicators include information of the outcomes of dialysis and transplant at different hospitals and kidney units (such as patient survival or peritonitis rates). This information may be used in deciding where to receive treatment and in evaluating and planning kidney health services. This information sheet will help you decide if you would like to participate in this study. Please read it carefully.

2. Who is undertaking this research?

This research is being undertaken by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). ANZDATA is a clinical quality registry that collects information about people receiving dialysis or kidney transplantation in Australia and New Zealand hospitals and kidney units. ANZDATA is located in Adelaide, at the South Australian Health and Medical Research Institute (SAHMRI).

3. What is the purpose of this research?

Each year, ANZDATA collects information from kidney units and hospitals and then produces a number of reports based on the data. These reports include information of the outcomes of treatments across different hospitals and dialysis units, such as patient survival, and rates of peritonitis infection and kidney transplantation. ANZDATA would like to know what patients think about the quality indicator data we report and how it influences their kidney care journey. We would like to know if this information is important to patients and how to make it more useful and accessible.

4. Do I have to take part in this research project?

This is a research project and you do not have to be involved. If you do not wish to participate, your medical care will not be affected in any way. Also, you may withdraw from the project at any time after you have commenced.

5. What does participation in this research involve?

You will be required to complete a brief 5-10 minute survey over the phone with a researcher, so we can collect some basic information about you. You will then participate in a focus group over Zoom with the researchers and 2-3 other patients with experience of dialysis or transplant. A focus group is simply a group discussion 'focused' on a particular topic. You will be asked to listen and talk to the other participants and the researchers. There are no right or wrong answers to the questions you will be asked. Two hours will be allocated for the focus group, though it may not take this long. In this focus group we will ask you about your perspectives of the importance of quality indicator reports in kidney care and using this information to assess the quality of kidney services and in healthcare decision-making. The focus group will be video recorded, so that the discussion can be transcribed and later analysed.

Some time after the focus group you will also be asked to review a summary of the key findings from the discussion and give your feedback on these to the researchers (via e-mail or telephone), to let us know if your views have been captured appropriately or if you would like to add anything. This should take approximately 1-hour of your time.

6. What are the possible benefits and risks of taking part?

While we hope this project will improve how ANZDATA reports quality indicator data and may improve healthcare for people with kidney disease in the future, it may not be of direct benefit to you. There are no foreseeable risks to you by participating in this research project. You do not have to answer any questions in the focus group that you do not feel comfortable answering. You will be offered a \$100 Prezzy gift card for your participation and time.

7. What will happen to information about me? Confidentiality and data security

The information collected from you via the phone survey and focus groups will be kept confidential on password protected computer servers. Once the focus group recordings are transcribed, all identifying information (such as your name and hospital where you receive your kidney care) will be removed. The de-identified information from all participants will be kept for 5 years post study completion. After this time, papers will be shredded, and recordings deleted. Your identifiable focus group transcript will not be available to anyone other than the study investigators. De-identified quotations and excerpts from transcripts will be included in presentations, reports and publications of this research, but you will not be identifiable in any of these.

In accordance with relevant Australian and/or South Australian privacy and other relevant laws, you have the right to request access to your information collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

8. Questions and information

This study is being conducted by researchers at the ANZDATA Registry. The researchers involved in the project are Prof Stephen McDonald (Director of Dialysis, Central & Northern Adelaide Renal and Transplantation Service; Executive Officer, ANZDATA Registry), Emily Duncanson (Research Officer, ANZDATA Registry), Shyamsundar Muthuramalingam (Research Officer – Consumer Engagement, ANZDATA Registry), Dr Christopher Davies (Senior biostatistician, ANZDATA Registry) and Associate Professor Nicholas Gray (Executive Member, ANZDATA Registry; Director of Renal Services, Sunshine Coast Hospital and Health Service). If you would like further information about this study, please contact:

Emily Duncanson: emily@anzdata.org.au | (08) 8128 4768

Shyamsundar (Shyam) Muthuramalingam: shyam@anzdata.org.au | (08) 8128 4596

9. Complaints and contacts

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) incorporating all updates. This statement has been developed to protect the interests of people who agree to participate in human research studies. The study has been approved by the Central Adelaide Local Health Network Human Research Ethics Committee. If you wish to speak to someone about the conduct of this study, please call Prof Stephen McDonald (08) 7074 2618 stephen@anzdata.org.au

If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the CALHN HREC.

Reviewing HREC approving this research, HREC Executive Officer details and Complaints Contact HREC

Name: Central Adelaide Local Health Network Human Research Ethics Committee
(CALHN HREC)

Contact: HREC Support Officer

Telephone: (08) 7117 2229

Email: Health.CALHNResearchEthics@sa.gov.au