

Participant Information Sheet – People living with kidney disease

Understanding the service needs for renal patients in Aotearoa

You are invited to take part in a focus group to understand the services being provided to people living with kidney disease in Aotearoa. This Participant Information Sheet sets out why we are doing the project, what taking part would involve, and what the benefits and risks to you might be.

Before you decide whether or not to take part you may want to talk about the project with a project team member (contact details on page 2), or other people. If you agree to take part, please sign the Consent Form on the last page of this document. You will be given a copy of the fully signed Consent Form to keep. If you don't want to take part, you don't have to give a reason.

Purpose of this research

The main objective of the project is to better understand patient experiences of kidney disease services in Aotearoa and how these can be improved. The information provided will be integrated into recommendations designed to improve services for people living with kidney disease. A visual representation (or 'map') of the patient experiences will also be designed. This research is funded and approved by Kidney Health New Zealand, who have engaged an independent third party, Atlantis Health, to execute the project.

Who can take part in this research project?

To take part you must have been diagnosed with kidney disease and be able to speak and understand English.

What will my participation involve?

You will be invited to take part in an online focus group (approx. 1.5 hours). This will be conducted by members of the Health Psychology team from Atlantis Health and will be recorded to help us make accurate notes for analysis. All focus groups will be conducted in English. We will ask you about your experience and perceptions of support services provided to people living with kidney disease, especially at the point of diagnosis and when receiving dialysis, and for your ideas about improvements that might be useful. You may also be asked about your perspectives on equity and barriers to accessing support services.

What will happen to my information?

Only the researchers will have access to your identifiable information (e.g., your name, contact details and focus group recording), and this data will be deleted 1 month after the project has been completed. Non-identifiable, combined information will be kept by Atlantis Health in secure, cloud-based storage indefinitely. All storage will comply with local and/or international data security guidelines.

The research findings will be presented to the sponsor of this project (Kidney Health NZ) and they may share the findings with other renal service providers and funders. You will not be named or identified in any presentations or reports.

You have the right to request access to, correct, or withdraw your information held by the research team. Information relating to you can only be withdrawn up until the data are analysed, as at this point, your data will be combined with other participants' data to identify trends. If you have any questions about the collection and use of your information, please contact us. Full details of our Privacy Notice can be found here: <https://atlantishealth.com/privacy-notice>.

May I withdraw my consent from the research project?

Your participation is voluntary. You may withdraw from participating at any time, without penalty, by giving written notice. Please allow 30 days from receipt of your request for processing.

What are the possible benefits & risks of this project?

People sometimes feel a sense of relief after having the opportunity to share their experiences, and your input may help others living with kidney disease. To thank you for your time and participation, you will receive a \$75 Prezzy card. We will also send you a copy of the summary results, if you would like. The risk associated with participating in this project is low. Sometimes talking about your experiences can be distressing or make you feel low. If you do need support, you can text or call 1737 to reach the national counselling helpline.

Who do I contact for more information?

If you have any questions about the project at any stage, please contact us using the details below:

Email: kidneynz@atlantishealth.com

Phone: 09 363 4838

Consent to Participate in Research

Understanding the service needs for renal patients in Aotearoa

Please tick to indicate you consent to the following

I have read the Participant Information Sheet, and I understand it.	Yes <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this project.	Yes <input type="checkbox"/>
I have had the opportunity to discuss this project with others (e.g. the research team) and to ask questions, and I am satisfied with the answers I have been given.	Yes <input type="checkbox"/>
I understand that taking part in this project is voluntary (my choice) and that I may withdraw from the project at any time.	Yes <input type="checkbox"/>
I consent to the research staff collecting and analysing information I provide to them.	Yes <input type="checkbox"/>
I understand that the focus group will be recorded and that the recording and my personal identifiable information will be deleted 1 month after the end of the project.	Yes <input type="checkbox"/>
I agree that information collected from me will continue to be processed once the analysis has begun, but that I can ask for my information to be deleted before this time.	Yes <input type="checkbox"/>
I understand that my participation in this project is confidential and that no material which could identify me personally will be used in any reports on this project, unless I give my express consent.	Yes <input type="checkbox"/>
I know who to contact if I have any questions about the project.	Yes <input type="checkbox"/>
I would like to receive a copy of the summary results when they are available.	Yes <input type="checkbox"/> No <input type="checkbox"/>
I consent to my name & email address being provided to Kidney Health NZ so they can contact me about services and information/newsletters about kidney disease	Yes <input type="checkbox"/> No <input type="checkbox"/>

Signature:

I consent to take part in this project.

Name	
Signature	Date

Please state your region (e.g., Auckland):

Please tick to indicate your focus group preference:

- I identify as Māori and prefer to participate with other Māori participants
- I identify as Pasifika and prefer to participate with other Pasifika participants
- I do not identify as Māori or Pasifika (or have no preference for focus group)