# Understanding and reducing inequalities in kidney health care and outcomes in Scotland

## KINDER Study - Kidney Inequalities: Needs, Data, Experiences, Response

### Study Information Sheet

You are being invited to consider taking part in this study. Before you decide, please read this information sheet to understand why the research is being done and what it will involve.

**If you would like to take part, please get in touch with the project researcher directly - contact details are at the end of this information sheet.**

If there is anything that is not clear or if you would like more information, the project researcher will answer them.

## 1. What is the purpose of this study?

Kidney Inequalities: Needs, Data, Experiences, Response (KINDER) study is being organised by the University of Aberdeen with the help of medical professionals, people with kidney disease and a range of experts from across Scotland. This study seeks to address these recognised shortcomings in existing knowledge of kidney healthcare inequities in Scotland, by moving from the limited current understanding that inequalities in kidney care exist to a better appreciation of how and why they exist, and how we can best mitigate the harms.

## 2. Why have I been invited?

We are reaching out to people from kidney patient groups, general practices, public health, local government, and various organisations in Scotland who share our concern for the well-being and healthcare of individuals with kidney disease/condition in underserved areas. Together, we hope to develop big-picture solutions (‘strategies’) and decide which ones are the most important to reduce the healthcare challenges this population faces. This joint effort will lay the groundwork for actions to improve a situation or help solve a problem (‘interventions’) in the future.

## 3. Do I have to take part?

No. It is up to you whether you take part or not. If you do agree to take part and then change your mind, you can withdraw at any time without giving a reason. A decision to not take part or to withdraw will not affect your medical care, employment, or your legal rights. You can withdraw by contacting the project researcher – contact details are at the end of this study information sheet. Any data obtained prior to your withdrawal will remain part of the study.

## 4. What will happen if I decide to take part?

We will need 20 people in total. Our project researcher will contact you by email or phone to confirm if there are still available spots and to determine which stakeholder group you represent. If you then decide to participate, you will be asked to complete and sign a consent form online or give your consent verbally which will be audio recorded. If you agree to join this study, you will be invited to two linked online workshops involving five to ten participants. Before each workshop, we will ask you to complete a short 30-minute reading. It is to show you what we will be covering in the workshop. Each workshop will take up to 90 minutes, with breaks available throughout.

We will provide various time slots for you to pick what suits you best. The discussion will be audio recorded and typed up by an external typing company who will treat your data confidentially. Once we receive and check the transcription, we will delete the recording. This information will not identify you and will not be combined with other information in a way that could identify you.

You will also have the option to consent for us to retain your details to contact you about future relevant ethically approved studies. These details will be stored securely in line with the current UK Data Protection Laws.

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

You will not be disadvantaged in any way by joining this study.  You will be reimbursed for your time at a rate of £50 per workshop. Your views and experiences may help us to co-develop with patients and experts, practical strategies to reduce inequalities in kidney care.

## 6. What if I have concerns about the study?

If you have any concerns with any aspect of this study, please ask to speak to the project team who will do their best to answer your questions – contact details are at the end of this study information sheet.

If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance Team by emailing researchgovernance@abdn.ac.uk.

## 7. What will happen to the results of the study?

The results from the study will be published in scientific journals and presented at academic conferences. They will also be shared at public engagement events, and on our website and social media. We may quote what you said, but the information we report will be completely anonymous and will not identify you in any way. You will also have the choice to receive a summary of the results.

For study updates, please go to the website https://bit.ly/kinder-study

## 8. Who is organising and funding this research?

The study is funded by the Chief Scientist Office in Scotland. It is sponsored and run by the University of Aberdeen, in collaboration with a range of experts across Scotland and stakeholders, for example, Healthcare Improvement Scotland, Public Health Scotland, NHS

Education for Scotland, UK Kidney Association, Kidney Research UK, and Kidney Care UK.

The study is under the direction of the Chief Investigator Dr Simon Sawhney, a kidney doctor and researcher.

## 9. Who has reviewed this study?

This study has been reviewed and approved by the Office for Research Ethics Committees Northern Ireland, NHS Research Ethics Committee (24/NI/0037).

People with kidney disease and public partners are involved in the design and conduct of this study.

## 10. Will my taking part in this study be kept confidential?

### How will we use the information about you?

We will need to use information provided by you for this research project. This information will include your initials, name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. Others who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data for ten years, so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we will not be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using data saved from this study.

## Where can you find out more about how your information is used?

You can find out more about how we will use your information:

- by asking one of the research team
- by sending an email to dpa@abdn.ac.uk or

- by ringing us on 01224 272596.
- at www.abdn.ac.uk/about/privacy/

# Thank you for reading this Study Information Sheet.

# Please save it for future reference.

**To take part in our study,** or if you have any questions, please contact the study research team:

**Project researcher**

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Alternatively, you can contact:

principal investigator (magdalena.rzewuska@abdn.ac.uk)

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