

**Taking an active role in your own healthcare:
A Delphi Survey for key stakeholders to identify priority self-
management outcomes for Chronic Kidney Disease
(SM-CKD Delphi Study)**

Invitation

You are invited to take part in a “Delphi Survey” as part of a research programme conducted by the University of Leicester Kidney Lifestyle Team. This survey is relevant to:

- People who live with a diagnosis of Chronic Kidney Disease (CKD) in the UK
- Their close friends and families
- Healthcare professionals who look after people with CKD in the UK
- Anyone involved in designing, developing, managing, or commissioning CKD healthcare services in the UK
- Researchers interested in a topic related to self-management or CKD

People who fall into one of these categories are called “stakeholders”: this means that they have experience of kidney disease or kidney healthcare, and their opinions are important to our research programme.

We will invite representatives of all these groups to take part in our Delphi survey, to gather a range of stakeholder opinions.

Background information

What is Chronic Kidney Disease?

Chronic Kidney Disease (CKD) is a common health condition where the kidneys do not work as well as they should. Sometimes the kidneys fail completely and then the person needs dialysis or a kidney transplant. Most people with CKD never get complete kidney failure. Even so, living with CKD can affect overall health and wellbeing and requires regular healthcare from GPs or hospital kidney specialists.

For this survey, we are focussing on **people with earlier-stage CKD**, sometimes called non-dialysis CKD. In other words, these are people who have CKD but DO NOT need dialysis or a kidney transplant.

What is “self-management”?

It is well known that people with long term health conditions such as CKD do much better if they take an active role in looking after their own health, in partnership with their healthcare team. This can include things like:

- making healthy lifestyle choices (eg diet and exercise)
- reducing stress levels and sleeping well
- understanding and monitoring any medications
- checking their own blood pressure and blood test results

Taking an active role in your own healthcare is termed “self-management”

In order to successfully undertake self-management activities, people with CKD usually need some help and support to understand their condition and how to look after themselves. Over the last few years, there has been much more interest in the medical community about how best to provide education and support to patients so they can be successful partners in their own care.

What is a Delphi survey?

A Delphi survey is a process of finding out the views of a range of different people about a subject of interest, and identifying what the participants agree are the most important aspects.

What is this Delphi survey about?

We are interested in understanding your views on self-management for people living with CKD. In particular, we want to know what you think are the most important benefits (outcomes) of successful self-management. This Delphi survey has been designed to gather the opinions of a range of different people who are living with CKD or involved in caring for people with CKD (stakeholders). We will collect everyone's views together and identify the aspects that everyone agrees on. This is called a "consensus".

Our larger research programme is designing and testing an online resource to provide education and support about self-management for people with CKD. As part of this work, we need to know what different stakeholders think the most important benefits of self-management in CKD are. This is the purpose of the Delphi survey. We will use the important aspects we identify to measure success when we are testing our new resource.

Why have I been invited to participate?

You are invited to take part in this survey because you are an **adult aged 18 years or more**, you are **based in the UK**, and you have **experience or knowledge about CKD** in one or more of the following ways:

- you have Chronic Kidney Disease (CKD)
- you are a close friend or family member of someone with CKD
- you are a healthcare professional who looks after people with CKD
- you are involved in designing, developing, managing, or commissioning CKD healthcare services
- you are a researcher with an interest in CKD or self-management

Do I have to take part?

It is up to you to decide whether to take part in this survey. If you do decide to take part, please follow the link provided which will take you to the online survey. There is no separate consent form. Completing and submitting the survey implies that you consent to participation in the survey.

What will happen to me if I take part?

If you agree to take part, you will be asked to participate in 3 or 4 survey rounds, each one about 2-6 months apart.

Round One (now closed)

The Round 1 survey consisted of two parts:

1. **Five short items** about yourself (stakeholder group, gender, age range, ethnicity and postcode to identify approximate geographical location) so that we can describe the cohort who participated in the survey. No identifiable information about you will be reported
2. **Two questions** asking you about your views on self-management for people with CKD. For each question, we ask you to describe the **three** aspects that you think are most important.

At the end, we also ask you to provide your email address. This will be used **ONLY** for two purposes:

- To send you an email inviting you to take part in the next round of the survey. This is optional and you can choose not to take part if you prefer
- To send you a summary of the results at the end of the survey

We will not use your email address for any other purpose, and we will not share it with anyone else. We will store it in a secure password protected file in the university IT system and only the research team will have access to it.

It should take no more than 10 minutes to complete the Round One survey. When you have answered the questions, click on the “Finish” button and your replies will be sent to the research team.

What will the research team do with the responses to Round One?

When we have received the survey responses from all the participants, we will look at the answers to each of the two questions, and organise them into “themes” or groups with similar meaning. This will identify the most popular aspects chosen as important by everyone who took part.

Rounds Two and Three

Using the themes from Round One, we will create the Round Two survey, which lists the most popular choices and asks you to rate them in order of importance from your own point of view. Using these results, we will then reduce the list to just the few most important items and ask you to rate them again in Round Three.

Usually, three rounds of a Delphi survey are enough to reach “consensus”. However, if there is a lot of disagreement between the answers we receive, a further Round Four may be required.

All the surveys will be short, and none should take more than 10 minutes to complete. The surveys are all online and can be carried out on any internet-enabled device, such as a desktop or laptop computer, tablet, or smartphone.

What are the possible disadvantages and risks of taking part?

The risks associated with taking part in this survey is very low, as there is no physical or psychological harm associated with taking part. Although unlikely, if a particular question is causing you discomfort you may skip this question.

What are the possible benefits of taking part?

Taking part will not provide any direct benefits to you. Your responses to the survey will be beneficial for research purposes and the development of future self-management resources. Your responses may inform assessments and commissioning for future CKD programmes tailored for service users.

What data will you collect about me?

We ask some simple demographic questions about you (which stakeholder group(s) you are in, your gender, age group, ethnicity and postcode to identify approximate geographical location). You will also be asked to provide your email address so we can contact you about the subsequent survey rounds (all optional) and send you a copy of the results. No other personal or identifiable information about you is required and your responses are all anonymous. This information, and your survey responses, will be kept confidential on a password protected University computer.

Will what I say in this research project be kept confidential?

Individual participant or organisation names will not be mentioned in any reports or publications arising from this work. Information and responses collated during this survey will be kept on a password protected computer and will be strictly confidential. Email addresses will only be used for communication purposes for each survey round and to send you a copy of the results at the end.

How will you look after the data you collect about me?

Data will be stored on a secure server in a folder to which only the study researchers have access.

At all times this project will comply with the General Data Protection Regulations (GDPR, 2018) approved by the EU parliament on 14 April 2016 and passing into UK law with effect from 25 May.

What will happen to the results of the research project?

At the end of the study we will prepare a report of the findings and email it to all the participants. The results will also be used as part of a PhD thesis, and may be submitted for conference presentations, scientific or medical journal publications or other relevant academic outputs. We will also disseminate the findings widely to the kidney community via social media channels and other relevant platforms. All data will be anonymised, and no participant or organisation will be identifiable.

What should I do if I want to take part?

If you wish to take part, please click on the link and respond to the questions in the survey. Please note that the completion and submission of each survey represents your consent to participate in each Delphi round and this study.

Who is organising and funding the research project?

This survey is part of the University of Leicester Kidney Lifestyle Research Programme, funded by a generous grant from the Stoneygate Trust. The research programme is led by Professor Alice Smith, and this survey will be coordinated by PhD student Naeema Patel and Research Associate Dr Courtney Lightfoot.

What if something goes wrong?

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

Who has reviewed the research project?

This project and associated documents have been approved by the University of Leicester Research Ethics Committee

Please do not hesitate to contact the study coordinator (Naeema Patel, np313@leicester.ac.uk) if you have any further questions.

If you have any concerns or queries about the way in which this project has been conducted, then you should contact the Chair of the University Research Ethics Committee on ethics@le.ac.uk.

If you require more GDPR data protection information, then you can access this via the University's Information Assurance Services.

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Thank you for taking your time to read the participant information sheet.