









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



The KINDER study




Kidney Inequalities: Needs, Data, Experiences, Response

Study Information Sheet – Specialist Care


 <p>1495 UNIVERSITY OF ABERDEEN OILTHIGH OBAR DHEATHAIN</p>	<p>Who are we?</p> <p>Hello! This study team has medical doctors, people who study health care, people with kidney disease, and other experts who care about people with kidney disease. The University of Aberdeen is organising this study.</p>
	<p>What is this study about?</p> <p>To hear people's experiences with having kidney disease, we are reaching out to patients from general practices and kidney clinics, and kidney patients' communities. We will also talk to staff working at general practices.</p> <p>We would like to hear about your experiences with having kidney disease or condition and the kidney care you have received.</p>
	<p>Why is this study important?</p> <p>If kidney disease or condition is not treated, it can make a person very sick. Find kidney issues early, and it is easier to treat them, but people in some areas get kidney care later than in others. We want to understand why this happens and what it means. We are particularly keen to hear if people think they have</p>

	<p>had problems getting a diagnosis, health care or support because of where they live, who they are, or their financial situation. This will help us to do something about it.</p>
	<p>Who can take part?</p> <ul style="list-style-type: none"> ❖ People aged 18-65 years. ❖ Having kidney disease or condition. ❖ Living in the NHS Greater Glasgow and Clyde or Grampian areas.
	<p>What will happen to me if I decide to take part?</p> <p>We will talk with you.</p> <p>The talk might last for up to 1 hour.</p> <p>Either using</p> <p>Telephone</p>  <p>Or</p> <p>Video calling</p>  <p>Or</p> <p>Face-to-face</p> 

	<p>We will audio record this conversation. A company approved by the University will write down what you said. Once we receive and check it, we will delete the recording.</p>
	<p>Do I have to take part?</p> <p>No It is up to you.</p> <p>If you say 'NO', it will not affect your care.</p>
	<p>Are there any good things about taking part?</p> <p>You could be helping us to take actions that may help others.</p> <p>What about bad things?</p> <p>Talking about some things may make you feel upset.</p> <p>Tell us if you feel upset. We can stop and offer you support.</p>
	<p>What happens to my information?</p> <p>We will keep your information only to ourselves.</p> <p>Your information will only be seen by people in the research team like us and people who check the research is being done properly.</p>

	<p>We will not use your name or anything that tells who you are in anything we write about this study.</p> <p>Information will be kept for ten years after the study ends.</p>
	<p>Will I get any help when I take part?</p> <p>To say, “thank you”, we will give you a £25 shopping voucher.</p>
 	<p>What happens next?</p> <p>If you want to take part, please</p> <p>Phone us at 01224 438182 (available [8.30 am to 7 pm] - Mondays to Fridays)</p> <p>or</p> <p>Email us at kinder.study@abdn.ac.uk</p> <p>We will set up the talk.</p> <p>We will ask if you are okay with the rules for joining this study, which is called 'giving consent'.</p> <p>When giving consent, you will be asked if you agree to allow your kidney doctor to tell us your kidney health status, both now and at the time it was first recorded by your general practitioner (GP), including the date. This information will help us ask you relevant questions and explain our study findings. You can say 'no' to this and still join the study.</p>

	<p>Your kidney doctor may want to check if you agreed to this. In that case, we would securely give them a copy of your consent form, showing that you said it is okay for them to share information about your kidney health with us.</p>
	<p>How will what I say help other people?</p> <p>We will suggest actions to make kidney care fairer for everyone.</p> <p>We will share our results so that other people can read them.</p>
	<p>Who has approved this?</p> <p>NHS Health Research Authority and NHS Research Ethics (Office for Research Ethics Committees Northern Ireland 24/NI/0037)</p>
	<p>Can I change my mind?</p> <p>Yes. You can change your mind at any time, and you do not have to tell us why.</p> <p>If you stop, you will still get your normal care and help but we will keep the information about you that we already have.</p>
	<p>What if I need more information?</p> <p>You can check here www.hra.nhs.uk/information-about-patients/</p> <p>You can email us at kinder.study@abdn.ac.uk</p> <p>You can ring us on 01224 438182</p>

	<p>GDPR statement</p> <p>For details about your rights as a patient, providing feedback, or making a complaint about your health care visit: NHS Feedback, complaints and your rights NHS inform</p>
	<p>What if there is a problem?</p> <p>If you have concerns about this study, contact Magda Rzewuska-Díaz at 01224438148 or email at magdalena.rzewuska@abdn.ac.uk. She is looking after this study.</p> <p>You can complain if you are still not happy. To make a formal complaint please see: https://pass-scotland.org.uk/</p>