**Pregnancy choices with kidney disease**

**Participant Information Sheet**

We are undertaking a new research study to learn more about how women make decisions about having or not having children whilst living with kidney disease. We are interested in women’s views, attitudes and experiences of family planning and pregnancy (if applicable). We would like to invite you to take part in this study in order to help us learn.

**Introduction**

Who are we?

Our team includes people with different research expertise drawn from throughout Wales, including: The Wales Kidney Research Unit (WKRU, an All-Wales strategy for the study of diagnosis, prevention, treatment and social context of kidney disease, <http://www.kidneyresearchunit.wales>), Bangor University, Cardiff University, Cardiff Metropolitan University and Cardiff and Vale University Health Board. We have been funded by the British Renal Society and Kidney Care UK to undertake this important research. Cardiff and Vale University Health Board are sponsoring this study.

**Background to this study**

In this study we want to better understand the key factors that influence decision making from women’s perspectives. The information we collect will help us design new tools for healthcare professionals to better engage with and support women with potentially complicated and emotional decisions about having children.

**Why we are asking for your help?**

We know very little about this important topic. You have been asked to take part in this study as a woman living with kidney disease, and are aged between 18-50. Sharing your views and opinions will help us learn and improve care and support for women living with kidney disease in future.

**How can I help?**

By completing a short online survey. We will also be inviting a small number of women to take part in an informal interview over the phone or online video call.

We would like to hear from all women with kidney disease aged 18-50, it does not matter if you have children or not. We would especially like to hear from women whose kidney disease has had a direct impact on their pregnancy experiences or decisions about having children.

Learning from the multiple perspectives is vital if we are to develop ways to support women through complex decisions and experiences in future. We would like to hear from women who are currently pregnant, have non-biologically related children, are considering adoption, same sex couples, single parents and women who are not in a relationship. If you have sadly had a miscarriage or stillbirth we would still very much like to hear from you, but only if the time is right for you. We would also like to hear from women who have been pregnant or given birth over the COVID 19 pandemic.

**What does taking part involve?**

**Filling in an online survey:**

You will be asked to take part in an anonymous online survey where you will be presented with a series of questions. These questions will ask about your; kidney disease, current circumstances, choices about pregnancy, health and wellbeing, communication with healthcare professionals, information needs, impacts of COVID 19, and your support networks.

The whole survey will take approximately 20-30 minutes. Once you have completed the survey, you will be taken to a page with information on organisations and resources that may be of help.

**Informal interviews so that we can listen to your views and experiences in more detail:**

We would like to listen carefully to some women’s stories in more detail. At the end of the survey you will be asked if you would be interested in participating in a more detailed interview (approx.1 hour) with a member of the research team over the telephone, an online video call, or face to face meeting depending on which you prefer (face to face meetings will only be an option if and when it is safe to do so). If the answer to this is yes, you can enter your contact details and we may get in touch to arrange to talk at a time and in a way that suits you. With your permission, our conversation will be audio-recorded, but there will be no video recording.

You can also enter your details if you want to be kept updated about the study findings, news and other opportunities to take part in research on this topic. You do not have to complete this if you do not want and would rather remain anonymous.

**What will happen to the information I give?**

You can choose what you tell us. Our collaborators and partners have kindly agreed to send out an online link to this survey on our behalf. We do not know who has been emailed with this link and any healthcare professionals will not know who has replied to the survey.

The data you provide will be anonymised and analysed by members of the research team. Audio-recordings will be transcribed and anonymised by a transcription service employed by Bangor University, where a confidentiality agreement is in place. They will be stored on a secure password protected university hard drive for 5 years. Only members of the researchers team at Bangor University will have access to them. Anonymised quotes may be shared in research publications. It will not be possible to identify you from these quotes. Anonymised transcripts may be used for educational purposes such as an MSc or PhD student study

All identifiable data collected will be kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act. We will not share any of your details unless you tell us something that makes us seriously concerned about your or another person’s safety such as a child or vulnerable adult.

*Cardiff and Vale University Health Board (C&VUHB) is the sponsor for this study based in the UK. We will be using information from your surveys and interviews in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Bangor University will keep identifiable information about you for 5 years after the study has finished until September 2026.*

*Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.*

*You can find out more about how we use your information at* [*https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/*](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/) *or by contacting the research team.*

*Bangor University will collect information for this research study in accordance with our instructions. Bangor University will keep your name and contact details confidential and will not pass this information to C&V UHB. Bangor University will use this information as needed to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from C&V UHB and regulatory organisations may look at your medical and research records to check the accuracy of the research study. C&V UHB will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.*

**What are the possible benefits of taking part?**

We cannot promise that taking part will benefit you directly although many people welcome the opportunity to share their views and experiences. The information we gain will help us understand more about women who live kidney disease needs when planning to have children and to develop new shared decision making tools to improve their health and social care support in future.

**What are the possible disadvantages and risks of taking part?**

This is a low risk study nonetheless some of the questions ask you to think about topics which may be sensitive to you for example if you have had a complicated pregnancy, miscarriage or still birth. You may find this upsetting or distressing. You do not have to answer any question you do not want to. We have provided contact details and links to relevant support agencies at the end of the survey and at the bottom of this information leaflet.

**What if I have concerns about this study?**

If you have a concern about any aspect of this study, you should ask to speak to a member of the research team who will do their best to answer your questions. The Chief Investigator is Dr Sian Griffin, email [sian.griffin2@wales.nhs.uk](mailto:sian.griffin2@wales.nhs.uk). You can also contact us on any of the channels provided at the end of this sheet. If the research team are unable to resolve your query and/or you would like to speak to somebody outside of the research team you can contact the Cardiff and Vale Research manager on [CAV\_research.development@wales.nhs.uk](mailto:CAV_research.development@wales.nhs.uk).

**What will happen to the results of the research study?**

We will share the results of this study via newsletters, presentations, academic papers, reports and visual graphics with the multiple key stakeholders including; researchers, multi-disciplinary health and social care workers, policy makers, people living with kidney disease, charity partners, research participants and other key stakeholders. Findings will also support the development of new shared decision-making tools and future research into the field. It will not be possible to identify any individuals from reports or presentations.

**Do I have to take part?**

No, it is entirely up to you. Even if you agree to take part, you can opt out at any time. You do not have to give a reason for opting out. You can choose to skip any questions that you would prefer not to answer. You can opt out from the survey at any time by exiting the browser. Your responses will be anonymous, so we will be unable to withdraw your data once you have completed and submitted your questionnaire.

If you take part in an interview, you can skip any questions you would rather not answer or stop at any point if you do not want to continue. You will be able to ask that your interview, or specific sections of your interview, be withdrawn for 14 days after your interview by contacting the research team. After this point, your responses will be anonymised for inclusion in the analysis and it won’t be possible to withdraw your data. Our contact details are below. We look forward to receiving your completed surveys and contact forms and learning from your opinions and experiences.

**What’s next if you would like to help?**

Thank you. Please click on the following link which will take you to the consent FORM C and the online survey FORM D. [**https://cardiff.onlinesurveys.ac.uk/ckd-engage**](https://cardiff.onlinesurveys.ac.uk/ckd-engage)

**Further information and contact details**

**Please visit our website, Twitter and Facebook pages for project information, updates, and contact details for the research team.**

Twitter: @Kidneypregnancy

Facebook: [www.facebook.com/Pregnancy-choices-with-kidney-disease-106902844446942](http://www.facebook.com/Pregnancy-choices-with-kidney-disease-106902844446942)

Website: [www.kidneyresearchunit.wales/impact-case-studies.htm?id=34](http://www.kidneyresearchunit.wales/impact-case-studies.htm?id=34)

**SURVEY DIRECT LINK:** [**https://cardiff.onlinesurveys.ac.uk/ckd-engage**](https://cardiff.onlinesurveys.ac.uk/ckd-engage)

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You can also contact the research team directly

Dr Leah Mc Laughlin ([l.mclaughlin@bangor.ac.uk](mailto:l.mclaughlin@bangor.ac.uk)) (Tel. +44(0)2921848469)

This is study funded by the British Renal Society and Kidney Care UK.

**Sources of support**

If you have any concerns about your health and well-being, please talk to your GP or a member of your usual kidney care team. Here is a list of external organisations you may also find useful:

* Paul Popham Renal Fund, <http://paulpophamfund.co.uk>
* Kidney Care UK, <https://kidneycareuk.org>
* Kidney Wales, <https://www.kidneywales.cymru>
* Relate: Relate specialises in relationship support throughout the UK. https://www.relate.org.uk
* Mind: Mind campaigns to improve services, raise awareness and promote understanding' of mental health issues. http://www.mind.org.uk/
* British Infertility Counselling Association (BICA). BICA aims to aid those with fertility problems at any stage of their life. http://bica.net/
* SANDS: <https://www.sands.org.uk/> for support with stillbirth & neonatal death

