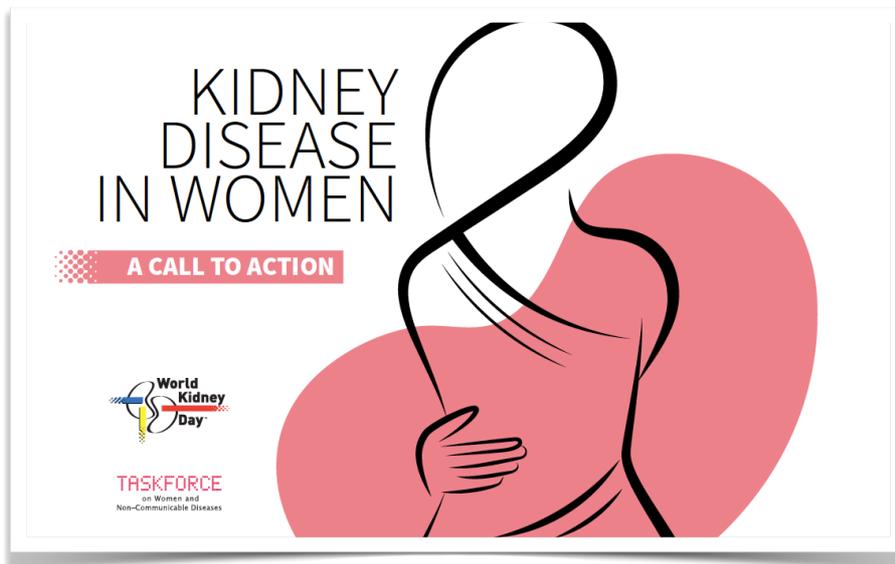


pregnancy choices with kidney disease

Welcome

To your first newsletter for the pregnancy choices with kidney disease study, learning more about women’s experiences of kidney disease, decisions about having children and their experiences of pregnancy and having children.

We are very pleased to report that we are now OPEN! Thank you so much to all of the kidney professionals and research and development support teams who worked to get this up during especially difficult and unique times for everybody. In this issue we introduce the study, highlight gaps in knowledge, showcase recent initiatives, introduce some of the research team and share how you can take part and/or help support recruitment into this important research. Have you heard about any of these, feel free to check them out:



RARERENAL.ORG/RADAR-REGISTRY/ RADAD

Information on rare kidney disease - pregnancy and CKD is considered a rare disease

RENAL.ORG/WP-CONTENT/UPLOADS/2019/09/FINAL-PREGNANCY-GUIDELINE-SEPTEMBER-2019.PDF

Clinical practice guidelines for pregnancy and kidney disease

WWW.KIDNEYCAREUK.ORG/ABOUT-KIDNEY-HEALTH/LIVING-KIDNEY-DISEASE/PREGNANCY-AND-CHRONIC-KIDNEY-DISEASE/

Kidney Care UK information for women who want to start a family or are pregnant

Did you know?



Kidney disease increases the chances of complications in pregnancy



Kidney infections are more common in women and the risk increases pregnancy



Women tend more often to donate kidneys and are less likely to receive them

Lupus Nephropathy

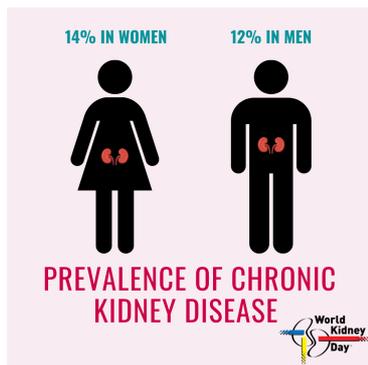


typically affects women

*content taken from WKD 2018 campaign

Background

An estimated 195 million women are affected by Chronic Kidney Disease across the globe, yet we know little about the current needs of these women. Previous research has tended to be very clinically led with little attention given to the lived experiences as told from women's perspectives.



This study aims to address this gap by learning more about the values and preferences of women including their views on decisions about having children, weighing up pros and cons of starting a family, experiences of pregnancy and the impact of COVID 19 on any of the above. We are doing this via a survey - cardiff.onlinesurveys.ac.uk/ckd-engage and follow up interviews with a small sample of women.

“More women have kidney disease but more men are on a kidney replacement therapy”

It is so important that we better understand the key factors that influence decision making about pregnancy from women's perspectives. Examples could include; the impact of pregnancy on their health and of their kidney disease on their pregnancy, pressure from family, risk of passing on an inherited condition, miscarriages, anxiety and depression, feelings of shame and guilt, burden on relationships, and social care needs.

#butnotmaternity trended globally, were you affected? We are also interested women with kidney disease experiences during COVID 19 such as, lockdown, disruptions to care and support, and the influence of this on future decisions.

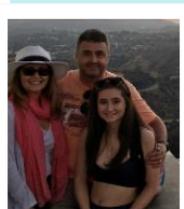
This is a UK wide study partnered with NHS Wales, Bangor University, Cardiff University, Cardiff Met and funded by Kidney Care UK and the British Renal Society. **if you are a woman with kidney disease resident in the UK aged 18-50 we want to hear from you. It does not matter if you do not want children or had your children sometime ago, as a women you will have an important perspective which we need to hear more about to address this global call to action.** If you would like to be more involved in this study even if you do not fit the inclusion criteria e.g. you are over 50, a kidney professional, or family member we would love to hear from you. Contact us via the details below.

Meet the team

“I didn't know what I didn't know, because no one asked me”

Helen has Polycystic Kidney Disease (PKD). She became a mother following fertility treatment in 2004 when she was 38. She says: “As a Nurse I had some understanding of PKD but also some misconceptions.” When Helen was pregnant, she found herself acting as the conduit of information between the obstetrics team in one hospital and the Kidney Team in another. “At the time, I felt that my thoughts, fears and wishes were not being listened to or considered. Both Consultants were experts in

their respective specialties, but I wasn't confident in my Obstetrician's knowledge of the potentially unique issues of pregnancy and delivery and Polycystic Kidney Disease. Helen is a core member of the research team. You view the full research team on the website below.



IN THE NEWS

You can HEAR all about this study on #diaryofakidneywarriors
[pen.spotify.com/episode/3a4jvZ3fckGV2OjBaO18aF?si=DIPNuwyUS4qEkZR3npe0GA](https://open.spotify.com/episode/3a4jvZ3fckGV2OjBaO18aF?si=DIPNuwyUS4qEkZR3npe0GA).
Follow the amazing @diaryofakidneywarrior for more about living well with kidney disease.

Diary of a Kidney Warrior Podcast

Living with Kidney Disease can be very challenging. Join Dee Moore a Stage 4 Kidney Warrior as she interviews guests and explores all aspects of Kidney Disease, Chronic Illnesses and Health. If you are a Kidney Warrior or the family or friend of a Kidney Warrior who wants to learn more about Kidney Disease, Kidney Disease prevention and be encouraged and uplifted, this is the Podcast for you.

Available on:



We are undertaking a study to learn more about women's experiences of kidney disease, decisions about having children and their experiences of pregnancy and having children.



pregnancy choices with kidney disease

Findings will help us develop new shared decision making tools to help better support women with the sometimes complicated and emotional decisions they may need to make about having children.

To hear more about this study, check if you are eligible to **take part and share your views you can get in touch** via any of the contact details below. You can also go directly to the **online survey via the link below or scan the QR code**. We look forward to hearing from you.

Survey link: <https://cardiff.onlinesurveys.ac.uk/ckd-engage>

Website: <http://www.kidneyresearchunit.wales/impact-case-studies.htm?id=34>

Email: l.mclaughlin@bangor.ac.uk

Tel: 02921848469

Twitter: @kidneypregnancy

