

Prepare for Kidney Care

Newsletter: Issue 1, Autumn 2019

Welcome and thank you for continuing to be part of the Prepare for Kidney Care study. We wanted to introduce a patient newsletter in order to keep you informed about study progress and as a way of conveying thanks. We hope you find this interesting and remember, we could not do the study without you!

The Prepare for Kidney Care study is growing!

Patients are now joining the study from 24 NHS sites around the UK, and the National Institute of Health Research is funding the study with £2.5 million to randomise 512 patients.

This map shows the UK sites currently taking part, and other sites are due to open shortly.



MESSAGE FROM Dr Fergus Caskey, Chief Investigator



Deciding on which treatment to have is very difficult. As well as talking to friends and family, most people rely on information from doctors and nurses. However, what people choose seems to depend on which kidney unit they go to. In some, almost all older people with other health conditions choose not to dialyse, whereas in others it's the opposite! In part this reflects the different support available in kidney units around the country, but it also reflects the weakness of previous research in this area. Prepare for Kidney Care is applying the most rigorous research methods so that people like you in the future can make better informed decisions. Thank you for taking part!

Why join the Prepare study?

Why would someone want to join a study where you are randomly allocated to a treatment? We know that people do so for lots of reasons.

We caught up with Yvonne, a kidney patient from Wiltshire, to ask her why she decided to join the trial. We even got to meet her handsome dog, Zeus!

Here is her story...



Yvonne at home with Zeus

When I was 17 I became a student nurse. After I finished my training, I sought out a job in Zambia, near the Rhodesian border. Here I worked with patients who had contracted malaria, typhus and dysentery amongst many other tropical diseases. The best advice I was given was 'if someone brings you a bag, don't look in it'. I had to learn why the hard way!

I heard about the Prepare For Kidney Care study after my consultant recommended me to the Bristol research team. I joined because I feel it is important for people trying to decide whether to have dialysis or responsive management should get given good information about what the treatments on offer mean for them. This means not only whether it will make them live longer, but how it will affect their symptoms, visits to hospital and state of mind—their whole quality of life. I think it's important that doctors think about their patients as a whole person and not just focus on the kidney problem, and I think Prepare for Kidney Care will help this.

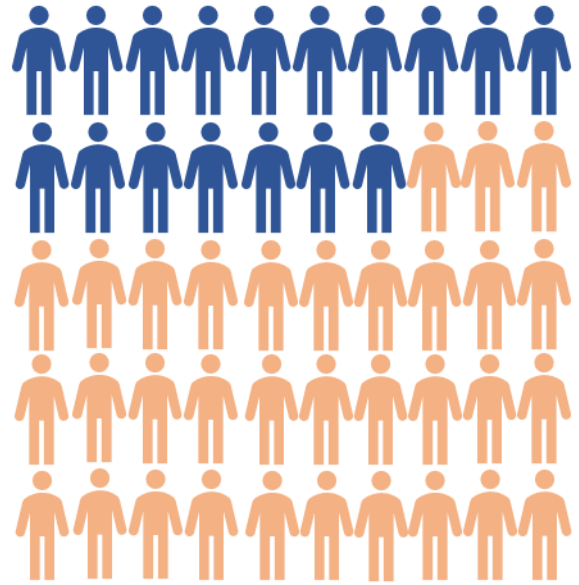
This is important to me due to my previous experience of dialysis. I looked after my husband when he had home dialysis, first peritoneal and then haemodialysis. Having the treatment placed a lot of strain on him and was stressful, but might have meant he lived for longer. I saw a lot of the team looking after him and this was important to both of us.

Now as I need to think about what might be right for me, I want good information to help me make this decision. I was originally set on a plan to only have dialysis if I really needed it; however when I found out about the study I was excited to participate and help improve care for future kidney patients, meaning I was happy to be randomised to either group.

Prepare Study Information

Recruitment to the study began in July 2017, and we are continuing to recruit patients to the study. At the last count an incredible 175 people had agreed to be randomised—34% of our target of 512. We are discussing with the funder to extend recruitment until June 2021 to help us achieve our target.

Recruitment to date



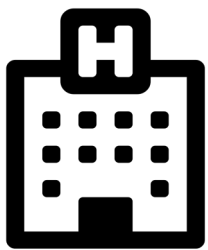
Data collection

Data Collection



Questionnaires

These tell us about your symptoms, feelings and quality of life. We want to see how these change over time. Thank you for filling them in!



Healthcare Data

We also collect data on your health and care both from you and electronically from hospital records. These tell us about your health.

This data is collected every 4 months. We are pleased to report average follow-up rates of 91%, and our first patients recruited have already submitted 20 months of follow-up data.

In March 2019, consultants and nurses working on the study came to a big investigator meeting held in London, from all over the UK. All 65 members of the team are enthusiastic about improving the care of older people with kidney problems.



You can follow us on Twitter [@PrepareKC](https://twitter.com/PrepareKC)

Prepare Study Bulletin Board

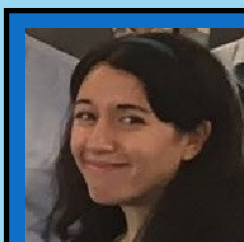
You can find out more about the Prepare for Kidney Care trial on our website. This includes news, site contacts and videos explaining the trial.

www.bristol.ac.uk/population-health-sciences/projects/prepare-kc-trial

You can also contact the central study team.....



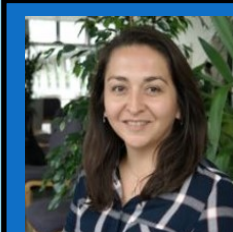
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If you have consented to be audio-recorded and interviewed about your experiences and acceptability of participating in the study, you may be contacted by one of our qualitative researchers above. Your input is very important –thank you.

This project was funded by the National Institute of Health Research Health Technology Assessment Programme (project 15/57/39). Department of Health and Social Care Disclaimer: The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HTA, NIHR, NHS or Department of Health and Social Care.

Other sources of information:



The UK's leading kidney patient support charity, providing practical, financial and emotional support.

Good for: diet and fluid advice, travel

01420 541424

Mon-Fri 9-5

www.kidneycareuk.org