

Newsletter

Summer 2024

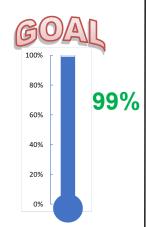
Prepare for Kidney Care Participant Newsletter

Welcome to our participant newsletter for the Prepare for Kidney Care study created to keep you up-to-date on our progress. You will receive one of these with each of your study questionnaires.

The whole study team would like to say a huge thank you for taking part in this vital work!

Aim: The Prepare for Kidney Care study aims to help people over the age of 65 with kidney disease make an informed decision between preparing to have renal dialysis should their symptoms progress, or follow a pathway where they will plan to have supportive treatment and care without dialysis.

Study Progress: Our 31 sites across the UK have recruited **442** patients to the study over the past 7 years, that is 99% of our new target of 446 patients! Our sites will continue to recruit more participants until the end of August 2024. After which, participants and their carers will continue follow-up visits and questionnaires until the end of August 2025.





Jona Guevarra (left), Prof. Aine Burns (middle) and Ellie Damian (right) at the Royal Free Hospital London are our top recruiters this year having recruited 21 patients to the study since the start of December!



Study questionnaires - quality of life matters

8 in 10 participants are returning their completed quality of life questionnaires. Thank you!

These questionnaires are so important for the research and assessing the quality of the treatment.



What happens next?

August 2024 — we will finish recruiting new patients into the study

August 2025 — all patients will finish their time in the study

Mid 2026 — we will have results and share them with you!



Please visit our website <u>www.bristol.ac.uk/prepare-kc-trial</u> for more information about the study including videos answering <u>frequently asked questions</u>.

You will be informed of the study results by newsletter once they are finalised!

Spotlight on....

Kidney Care UK and the UK Kidney Association have published their report on Patient Reported Experience of Kidney Care in the UK for 2023. 11,647 people completed a survey to compare experiences across renal centres. Overall experience scored 6.26 out of 7. You can see how your centre scored on the Kidney Care UK website by entering this link into your internet search bar or scanning the QR code below:

https://kidneycareuk.org/getinvolved/kidney-patient-reportedexperience-measure-prem/2023kidney-prem-results/



Previous Word Search Answers Renal Care Specialists:



Study Locations Word Search

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Meet our team!

Professor Fergus Caskey, a consultant nephrologist at Southmead Hospital in Bristol, is leading the study.

The study is supported by a dedicated team including:

- Kidney doctors and research nurses across the UK
- **Patients**
- Experts in clinical trials

The study is managed by the Bristol Trials Centre, which is part of the University of Bristol.

Trial Managers: Alexandra Soundy & Jo Worthington

Lead nurse: Karen Alloway Trial administrator: Laurie Cox

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Prepare for Kidney Care: a randomised controlled trial of preparing for responsive management versus preparing for renal dialysis in advanced kidney disease. This project is funded by the National Institute for Health Research Health Technology Assessment Programme (HTA) (15/57/39). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HTA, NIHR, NHS or the Department of Health.











