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## **Quality of life, decision-making, costs and the impact on carers in people managed without dialysis: A study protocol**

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## **When patients decide not to dialyse: the PACKS study**

### **Abstract**

**Background:** As more people with advanced kidney disease make the decision not to embark on dialysis there is a need to understand the patient and carer trajectory and the impact on quality of life whilst receiving a conservative care approach. Conservative kidney management includes ongoing medical input and support from a multidisciplinary team. There is limited evidence concerning patient and carer experience of this choice. The study was funded by the National Institute of Health Research commencing December 2013 and the study protocol is presented.

**Methods:** The design is a mixed methods longitudinal study. Patients, who have made the decision not to embark on dialysis, will be recruited from seven sites in the UK by renal research nurses from Renal Clinical Networks. Carers will be asked to 'opt-in' with consent from patients. The approach includes longitudinal quantitative survey of quality of life, symptoms, decision making and costs and quality of life and costs in carers, with questionnaires administered 3-monthly over 12 months. In addition the decision making process will be explored via qualitative interviews with renal physicians/Clinical Nurse Specialists.

**Discussion:** The study is designed to capture patient and carer profiles when patients with advanced chronic kidney disease forgo dialysis, understand trajectories of care receiving and care-giving and optimise palliative care for this population. It will explore the interactions that lead to clinical care decisions and the impact of these decisions on informal carers. Ultimately the aim is to improve clinical outcomes for patients and the care giver experience.