

A young adult kidney patient involvement group has provided valuable insights into how the research design should be conducted

Involvement of young people in a qualitative study that seeks to explore experiences of renal replacement therapy choice selection

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INTRODUCTION

- Patient and Public Involvement (PPI) promotes research questions that reflect the priorities and concerns of the relevant population.
- PPI in research can develop outcomes that are important to patients (INVOLVE, 2012; Hickey et al., 2018).

METHODS

- Involvement group meeting was set-up with 3 young adults in receipt of a kidney transplant.
- Brainstorming with researcher of potential current needs of young adults and possible research ideas.
- Research method and recruitment of participants was discussed.
- Follow-up discussions continued via email.

RESULTS

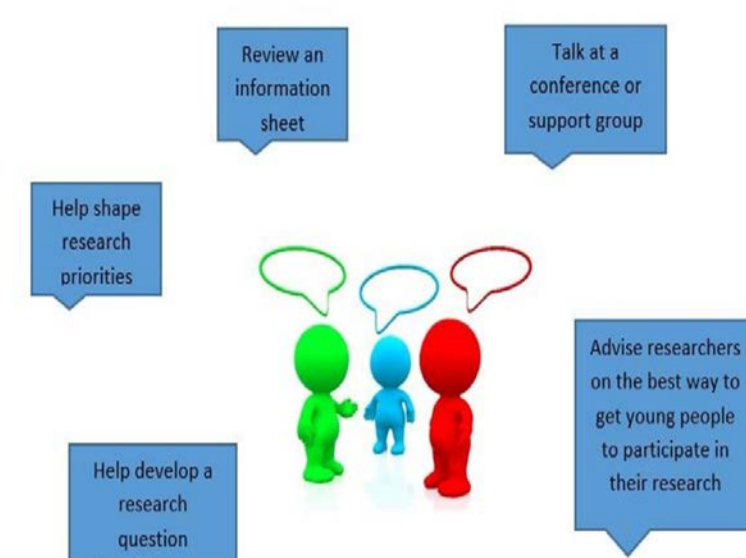
The involvement group highlighted the *emotional and psychological difficulties* experienced by young adults during treatment decision-making.

The involvement group subsequently

- firmed the research question and study objectives
- reviewed participant information sheet and consent form
- developed a poster advert and video to aid recruitment.

DISCUSSION

Research conducted will have address the question of what matters to young people with kidney disease who are making a dialysis or transplant decision.



Courtesy of PPI children's liver disease foundation

Recruitment Advert



Invitation to take part in a research study

Who can take part?

- Are you 18 to 30 years old and have kidney disease?
- Have you had to make a choice about dialysis or transplant between December 2017-December 2018?
- Do you live in the UK?

What is the study about?
The aim of the study is to understand your experiences of making a dialysis or transplant choice.

What will I have to do?
You would be invited to attend an interview, provided an information sheet and sign a consent form. If you'd like to take part then you would be invited to meet with the researcher at the university in central London. The interview would take around 3 hours. Travel expenses would be reimbursed on the day of the interview.

When will the study take place?
The study will run from March to September 2019.

Sharing your experiences will give us an understanding of what matters to you and enable the renal community think about how young people can be supported to during choice selection.

If you would like to take part in the study
Email Sarah on sarah.ansah@lsbu.ac.uk or text on 07535116777.

Young Adult kidney Involvement Group and recruitment video



Carl

[Vimeo.com/321959132](https://vimeo.com/321959132)

References

1. Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S et al.(2018). *Guidance on co-producing a research project*. Southampton: INVOLVE.
2. INVOLVE. (2012). *Briefing notes for researchers: involving the public in NHS, public health and social care research*. Eastleigh: INVOLVE.

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