

Information for consumers – patients, carers and family members affected by kidney disease

THE BENEFITS FOR CONSUMERS

Consumers may get involved for a variety of personal and social reasons:

- To make a difference by improving trials that in turn, improve the health and well-being of future patients.
- To give something back to the health system.
- To turn a negative experience into something positive.
- To develop skills that are useful for further employment - such as research skills, computer skills, experience working in a team and document writing skills etc.
- To make use of existing skills.
- To have a voice that influences processes that affect people's health or healthcare.
- To have something interesting and challenging to do.
- To meet new people, share experiences and learn new things.
- To increase confidence and self-esteem by developing new skills.
- To develop knowledge of, and insights into their disease condition.
- To be a voice for those who are voiceless.
- To achieve the inner satisfaction of knowing that they are adding something to the work of the research community.

THE BENEFITS FOR THE COMMUNITY

Consumer involvement and engagement brings many benefits to the community:

- Ensures research being conducted that is relevant to community needs.
- Ensures research generates knowledge that could improve health, treatment or care
- Improves public awareness of, and support for, science and research.
- Facilitates effective translation of research to deliver improved health outcomes.
- Increases public confidence in research through enhanced openness and transparency in the conduct of research.
- Increases public confidence in research through improved accountability over the use of public funds.
- Helps develop a greater understanding and awareness of research.

Why get involved in research?



You can be involved in all stages of the research process:

Study design

- Identifying and prioritising research topics and questions – what questions should be asked?
- Co-design methods – how should we try and answer them?
- Assist in selecting and trialling data collection tools, (e.g. interview questions, questionnaires)

Preparation for the study

- Co-write participant information sheets and consent forms
- Assist with writing ethics applications and detailed study protocols
- Develop 'update' tools for participants involved in the study

Collecting and analysing data in a study

- Interpreting the results
- Writing

Disseminating research findings and information

Implementation

Monitoring and evaluation