

## 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