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## Aim

To describe the perspectives of patients, caregivers, and health professionals on the impacts of research that are important to patients with chronic kidney disease (CKD) and their caregivers.

## Background

Research impact has been defined as the demonstrable outcomes research has made to health, knowledge, economy, or society. In nephrology, little is known about what impacts of research are meaningful to patients and caregivers. Identifying these valued research impacts can help inform strategies for maximising the impact of research in way that is meaningful for patients and caregivers.

## Methods



Workshop with facilitated breakout groups

**27** Patients and caregivers

**54** Health professionals



Australia & New Zealand



Discussions transcribed and coded into themes reflecting research impacts

## Results

We identified seven themes (impacts) across all the discussions from the workshop.

### Preventing kidney disease and kidney failure

#### Promoting early detection

"Until you're about 60 or 70% [of kidney function], you actually don't feel any symptoms of CKD" – Patient

#### Slowing disease progression

"You prevent that whole cascade effect of people going on to dialysis, having to look at home haemodialysis or peritoneal dialysis, and then looking at transplant." – Health professional

### Improving access to care

#### Reducing geographical barriers

"In Adelaide, we have a transplant house, but it can only accommodate one rural family for a month. If we had three or four, we could get more people transplanted and well enough to go home and lead a more normal life." – Patient

#### Supporting advocacy for financial support

"Some people might have to put off dialysis or might not be able to come the right number of times because they can't afford the travel." – Patient

### Enhancing daily living

#### Reducing symptoms and complications

"What's important for consumers is that they feel less pain." – Patient

#### Prioritising mental health

"We've proven that people on dialysis are depressed and socially isolated... but how does that translate into actually making some changes within the health system." – Health professional

#### Minimising the burden of treatment

"Consumers are more keen to know if having 10 medications a day and having one can do the same thing." – Patient

### Strengthening agency in decision making

"Information that helps consumers make informed decisions about their care is going to be the most meaningful thing, whether it's a physical change or even their mental wellbeing." – Patient

### Offering hope for future generations

"Hope, it pulls you in... In a genetic issue, that can very much be generational like PKD, and you think, well it mightn't help me but it'll help my child." – Health professional

### Fostering societal understanding

"The big one for me is others' understanding... People just don't seem to understand and it's quite difficult managing that. You feel quite alone, very lonely in that place." – Patient

"Everyone can talk about stroke and heart disease, but we don't actually talk about kidney disease, it's not really an accepted topic." – Patient

### Achieving a breakthrough in treatment

#### Finding a cure

"Don't stop research when you've slowed cyst growth, you only stop when you find a cure" – Health professional

#### Making innovative advancements in dialysis technology

"When I first got diagnosed, I said, 'Oh, I'll be about 60 by the time I need to go on dialysis, and by then there'll be an artificial kidney so I won't need to go on dialysis'. I had 19 years between first diagnosed and going on dialysis, and then 29 years on transplant. And there was still no artificial kidney." – Patient

"I am just not keen on dialysis. Some of the things I've read and seen just really put me off." – Patient

## Conclusion

Preventing kidney disease and kidney failure, enhancing daily living, fostering societal understanding, improving access to care, strengthening agency in decision making, achieving a breakthrough in treatment, and offering hope for future generations were identified as impacts of research that are meaningful and important to patients with CKD and caregivers.

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