

Patients' priorities for health research: focus group study of patients with chronic kidney disease



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Background

The inclusion of consumer preferences in prioritising research topics is widely advocated, but professional agendas largely drive prioritisation.¹

Objectives

To elicit priorities for research topics from patients who have chronic kidney disease (CKD) and reasons for their choices.

Methods

- 9 focus groups: 3 each for predialysis, dialysis and transplant patients (63 participants on total)
- July – September 2006
- 3 capital cities in Australia
- Thematic analysis

Table 2. Participant reasons for their choice of research themes

Reasons	Definition	Illustrative quotes
Normalisation of life	Developing therapies and regimens that fit into daily living	'I think if they can sink money into improving the dialysis and making it so that it works better and frees you up then that's good enough for me.' (Male, 50s, dialysis) [Dialysis] takes time and they all interfere with lifestyle.' (Female, 50s, CKD)
Altruism	Considering the welfare of others before personal needs	'Even though I'm in the dialysis stage, I think it's more important to focus on the others.' (Female, 20s, dialysis)
Economic efficiency	Channelling resources for maximum economic efficiency	'And it's the money, it's the government that saves in the long run, what it must cost for dialysis and what it costs for maintaining transplant.' (Female, 40s, transplant)
Intrapersonal concerns	Preferences based on feelings, values and personal needs	'I think comforting is the key issue I'm looking for right now.' (Male, 50s, CKD) 'So if it's affecting me, I'd like to see more money put into that area, purely selfish sort of perspective...' (Male, 50s, dialysis)
Clinical outcomes	Improving clinical outcomes and the physiological condition of patients with CKD	'I'd put diabetes at the top of the list because I think diabetes leads to a lot of the kidney problems.' (Male, 60s, transplant)

Table 1. Nine priority research themes identified by participants

Research area	Quotes
Prevention	'What I'd like research to do is to prevent people from getting chronic kidney disease, to be able to track it early enough so they don't have this chronic disease.' (Female, 60s, transplant)
Complications and symptoms	'I'd like to see more research on some of the side effects...' (Male, 60s, dialysis)
Kidney transplantation	'...no longer is the tissue matching so important as some of the new processes they have pre-transplant...more research in that area could clear the [transplant waiting] list.' (Male, 60s, dialysis)
Technological solutions	'I'd like to see a lot more stem cell research so you can grow your own kidneys.' (Male, 50s, transplant)
Psychosocial research	'All the medicos, they always forget that the psychological aspect of it has a huge impact...anxiety and depression are huge issues.' (Female, 40s, CKD)
Whole body	'I think that's partly the problem, they're not actually looking at the whole picture...I don't think it's easy to separate research on blood pressure, diabetes and heart disease because they're so inextricably linked.' (Female, 40s, CKD)
Dialysis	'There are lots of problems and lots of ways that [dialysis] could be improved like the big drama of getting access to the bloodstream...if anything happens to my access to the bloodstream, they've got to find another access and that causes a lot of heartache.' (Female, 60s, dialysis)
Caregiver / family support	'It affects your family as much as it does you...they suffer with you. I think at times the carers suffer more than the actual patients.' (Female, 70s, dialysis)
Health services	'...all the help the clinics and hospitals can get the better.' (Male, 60s, CKD)

Results

- Participants nominated themes not topics
- Participants suggested outcomes not interventions

Conclusion

A patient-focused agenda is possible to elicit for CKD. Unlike researchers who are topic, intervention focused, consumers think in terms of research themes, and health outcomes. Participants recurrently nominated primary and secondary prevention of CKD as a research priority.

References

1. Richards T. Patients' priorities. *BMJ* 1999; 318:277.

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