

Patients' Priorities for Health Research: Focus Group Study of Patients with Chronic Kidney Disease

Tong et al. (2008)
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For which topic were research priorities identified?

chronic kidney disease

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

The inclusion of consumer preferences in prioritizing research topics is widely advocated, but prioritization is driven largely by professional agendas.

What was the objective?

to elicit priorities for research topics from patients who have chronic kidney disease and to explore the reasons underlying their selection of research topics

What was the outcome?

a list of 8 research areas

How long did the research prioritization take?

July 2006 - September 2006

Which methods were used to identify research priorities?

focus group

How were the priorities for research identified exactly?

Step 1: 9 focus groups, 3 focus groups for each of the three patient types (pre-dialysis, dialysis and transplant patients), each focus group consisted of three parts: preliminary questions about the participants' experiences of CKD, specific questions about the participants' research priorities and a mock funding allocation exercise to rank priorities for research: participants were asked: There is a limited amount of money and resources for research and decisions have to be made. Please distribute your money to the different research topics written on the sheet of paper, and think about how you are making those decisions. Also, please add topics that you think should be included but are not listed on the paper, debate was encouraged, participants were allowed to change their distribution of money during the discussion. Step 2: data processing: thematic analysis, 8 research areas and 5 reasons that participants used to explain their choices were identified. Step 3: summary of preliminary findings sent to participants for validation

Which stakeholders took part?

Patients with chronic kidney disease. 63 participants.

How were stakeholders recruited?

Participants were purposively sampled for each focus group to achieve equal numbers of male and female participants from a wide age range and various cultural backgrounds. For each focus group, eight participants were approached either face-to-face or by telephone and invited to participate by the recruiting nephrologist or by the primary investigator.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.