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

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Abstract

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

Methods. Patients with chronic kidney disease (CKD) were purposively sampled from four kidney dialysis and transplant centres in Australia to participate in nine focus groups (three each for pre-dialysis, dialysis and transplant patients), which were conducted from July 2006 to September 2006. Each involved 6–8 participants. Transcripts were coded and thematically analysed to identify recurrent research topics and the participants’ reasons for their choices.

Results. Participants suggested eight research priorities: prevention of kidney disease, better access to and improvement in kidney transplantation, reduction of symptoms of CKD and complications associated with treatment, new technological therapies, psychosocial aspects of living with CKD, whole body not organ-specialized care, and improvement in dialysis and caregiver support. Five major reasons for the selections were identified: normalization of life (developing therapies and regimens that fit into daily living), altruism (considering the welfare of others before personal needs), economic efficiency (channelling resources for maximum economic gain), personal needs (preferences based on feelings, values, personal needs) and clinical outcomes (improving health states and the physiological condition of patients with CKD).

Conclusions. A patient-focused research agenda is possible to elicit for CKD, and by inference for other healthcare issues. Unlike researchers who focus on specific interventions and questions, consumers think in terms of broad themes and quality of life outcomes. Effective methods for translating a patient-focused agenda into research priority setting and resource allocation are now needed.

Keywords: chronic kidney disease; decision making; patient involvement; qualitative research; research priorities

Introduction

Health research is largely community funded and ostensibly aims to improve outcomes for consumers. The inclusion of consumer perspectives in research priorities is widely advocated, yet research priorities are largely driven by professional agendas [1–3]. Consumers are rarely given a role in this decision-making process and the preferred mechanisms for consumer involvement remain unclear [4,5]. Consequently, the limited resources for health research may be directed towards research that consumers do not value as highly as researchers [2].

The experiences and knowledge of patients can complement those of clinicians, health professionals and researchers [6]. Patient involvement in identifying and prioritizing research topics may make practice and policy more relevant to consumers’ needs, leading to outcomes that include greater patient satisfaction, improvement in treatment adherence, better acceptance of research findings and reduced risk of litigation [3,7].

Research to identify patient priorities for health research is scarce [5]. According to a recent systematic review, most studies have not reported explicit and comprehensive details on how patient priorities were obtained [5]. Only three studies, involving osteoarthritis, asthma and spinal cord injury, have identified treatment-related research priorities of patients [8–10]. To our knowledge, no studies have explored the underlying rationales for patients’ decisions on research
priorities and no studies on research priorities of chronic kidney disease (CKD) patients are available.

This study was conducted to elicit priorities for research topics from patients who have CKD and to explore the reasons underlying their selection of research topics.

Subjects and methods

We conducted nine focus groups from July to September 2006. Each focus group lasted 2 h and was facilitated by one of the authors (S.C. or A.T.) who had had no contact with the participants before the study. One observer (B.H.) recorded field notes on group dynamics and interactions, participant characteristics, body language and the context surrounding the discussion. Ethics approval was obtained from the four institutions involved in the study (Princess Alexandra Hospital, Brisbane; Royal Prince Alfred Hospital, Sydney; Westmead Hospital, Sydney; and Royal Melbourne Hospital).

Participant selection

Patients were eligible to participate if they were English-speaking, 18–80 years of age, able to give informed consent and were in one of three CKD stages [diagnosed with CKD, but not currently needing dialysis (pre-dialysis patients), undergoing haemodialysis or peritoneal dialysis, and kidney transplant recipients]. We conducted three focus groups for each of the three patient types.

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 (A.T.). Participants were offered reimbursement for their time and transport expenses; three declined reimbursement.

Setting

The focus groups were convened in neutral locations external to the hospitals to encourage openness during discussion [11].

Data collection

We developed a list of preliminary questions, to pose to the focus groups, from a literature review and discussion among the research team. After input from 11 multi-disciplinary collaborators (nephrology, public health, health economics, qualitative research, social work and consumer representative), the schedule was finalized. Each focus group had three phases, preliminary questions about the participants’ experiences of CKD, specific questions about the participants’ research priorities and an exercise for the participants to rank priorities for research.

To maximize participant engagement, an activity was developed [12] for the third phase of the focus group that enabled participants to allocate ‘money’ between competing research priorities. For each of five ranking exercises, participants were given a sheet of paper on which were listed several research topics (see the appendix). Ten counters (each representing one million dollars) were provided to each participant. The facilitator explained, ‘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.’ We were not seeking consensus or a quantitative score for each list. Rather, we were aiming to understand how participants came to allocate resources, and to record their interactions around their allocations. For this reason, we encouraged debate and allowed participants to change their distribution of money during the discussion. All sessions were digitally audio-recorded and transcribed in full.

Analysis

The transcripts were entered into QSR Nvivo 7, a software program used to assist with storage, coding and searching of data. The transcripts were reviewed line-by-line by a single author (A.T.) who searched for concepts, themes and ideas, and developed a preliminary coding scheme. Transcripts were read and coded by three authors independently (A.T., B.H., P.S.) who compared and discussed their individual coding choices. Any disagreements were resolved by discussion. The coding scheme was revised based on these discussions to develop a final coding structure that adequately captured desired and relevant information. Through a process of careful analysis and comparisons (between individuals and groups), we inductively developed two categories of descriptive themes from the data. The first category of themes examined the research priorities expressed by the participants. The second category differentiated the ways in which participants explained their research prioritizations, i.e. the reasons for their choices.

A summary of our preliminary findings was mailed to the study participants in June 2007, to enhance the developing analytic framework and to ascertain whether the account made sense to participants with different perspectives. We received feedback from 18 out of 63 participants. Participants appreciated the summary and some commented further on their individual priorities, suggested that the summaries should be sent earlier and requested information on how the study would make an impact on the research agenda.

Results

The nine focus groups involved 63 participants (88% attendance rate), aged from 20 to 78 years (mean 52.3 years); 30 (48%) were male. Of the 63 participants, 50 (79%) were Caucasian and 13 were from nine different national backgrounds. Reasons for non-attendance included work commitments, illness-related problems and difficulty in arranging transport.
The participants valued the opportunity to engage with one another. Participants shared their experiences of coping with their illness, and the facilitators were careful to ensure that they were able to achieve this goal in the group. However, participants also engaged enthusiastically with the issue of research priorities. Participants suggested a wide range of topics and desired research outcomes based on their experiences, what was important to them and what they thought could be improved.

**Research priorities**

From the analysis of transcripts and field notes, we identified eight main research areas that participants nominated as priorities (Table 1). Additional quotes for each research topic are provided in Table 2.

**Prevention**

Primary and secondary prevention of CKD were nominated frequently as the highest priority in all focus groups. The participants were averse to undergoing dialysis and transplantation and frequently stated that prevention was of higher priority than treatment or a cure. For prevention of CKD, participants suggested that research should focus on raising the public profile of CKD in the community, health promotion and discovering the causes of CKD.

I would like them to try and stop the renal disease becoming so prevalent. (Female, 50s, transplant)

Research on screening for detecting CKD and non-medical treatments of early CKD such as lifestyle factors, including dietary control and complementary medicines, and devising ways of putting the disease into remission were all identified as priority areas.

**Complications and symptoms**

Research to reduce complications and symptoms relating to CKD and the side effects of dialysis and transplant treatment were very important to the participants. They described a range of symptoms, complications and side effects that they experienced personally including cancer, heart disease, bone disease, fatigue, cramping and vomiting. All groups discussed the importance of research focused on eliminating the need for immunosuppressants and developing better treatments to reduce symptoms and complications.

**Transplantation**

While most participants perceived quality of life to be better after transplantation compared with dialysis treatment, some expressed a preference for dialysis. Rather than face the uncertainty and trauma of kidney rejection and
immunosuppression, the minority favoured the predictability of the dialysis routine once they learned to integrate the regimen into their lifestyle. All participants recognised the current limitations and problems in transplantation (e.g. graft rejection, immunosuppression, lack of donors) and felt that research should aim to increase the availability of organs and donor numbers, reduce the time spent on the kidney transplant waiting list, improve matching between patients and donors, prolong graft survival and reduce post-transplantation drugs. Although xenotransplantation was discussed, it was considered of low priority due to the high risk of infection.

**Technological solutions**

Participants wanted current treatment to be revolutionized; they did not want to undergo dialysis, take immunosuppressants and depend on a donor for a kidney. Stem cell research, cloning and developing mechanical kidneys were considered important topics to include in the research agenda. Some participants wanted research to deliver an alternative to needles and the pain of dialysis.

**Psychosocial needs and support**

The need for more research on psychological and social support was discussed frequently. The participants felt that health professionals often overlooked the range of mental health and social problems prevalent in the CKD population. More specifically, the key issues they believed could be improved related to depression and poor coping, employment (how to re-enter the workforce, seek employment and improve employers’ understanding towards CKD patients), information needs and strengthening the family relationship.

Some patients who had received or were going to receive a transplant from a living donor faced tension within the donor–recipient relationship. For example, some felt obliged to accept a living donor kidney from their relative, at the same time feeling apprehensive about the health risks they felt they were imposing on that donor and about taking on the significant burden of being responsible for maintaining the donor’s kidney. The following interaction highlights the anguish that occurs with the loss of a donated kidney.

But we were both incredibly sad [after the kidney was rejected], that was what hit the most, it’s that dealing with losing that was harder for me than going on dialysis, because then I thought I did something wrong, and she gave me a gift. (Female, 40s, dialysis)

It’s like you broke her present. (Female, 20s, dialysis)

**Whole body care**

Some participants felt that clinicians tended to narrow their focus to individual health issues, rather than broadly examining and managing the problem as a whole. They believed that health professionals needed to approach health
research holistically and recognize the interdependence of health problems including heart disease, diabetes, obesity and lupus.

I think that’s sometimes partly the problem, that 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 etcetera because they’re so inextricably linked. (Female, 40s, predialysis)

Dialysis
Dialysis was reported to be a time-consuming and sometimes painful process that interfered with lifestyle and reduced quality of life. The participants identified many areas for improvement in both haemodialysis and peritoneal dialysis treatment. They wanted machines to be less cumbersome and easier to operate and treatment to consume less time. Participants who had experienced dialysis believed it was important to improve vascular access into the bloodstream and the medication required while on 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. (Female, 60s, dialysis)

Caregiver support
As CKD patients, the participants experienced the personal effects of the disease but they were also aware that CKD had a devastating impact on caregivers. Some described the trauma, emotional stress, feelings of neglect and poor coping of their partners or other family members who had to take on care-giving responsibilities. The participants suggested that it was important for research to focus on addressing caregiver needs and support.

Reasons underpinning participants’ research priorities
We identified five reasons that participants used to explain their choice for research topics: normalization of life, altruism, economic efficiency, personal concerns and clinical outcomes (Table 3). The five reasons were not mutually exclusive; some choices for research topics were supported by more than one reason.

Normalization of life
Developing therapies and treatment regimens that fit in with other aspects of daily living was important for participants. The diagnosis of CKD and the intensive, technically demanding regimen of dialysis disrupted participants’ lifestyles. The need for normality was more apparent in pre-dialysis and dialysis participants than transplant participants; transplantation allowed most participants a higher degree of normality and independence. A desire to reclaim a sense of normality frequently underpinned participants’ choices for research into better and more compact dialysis machines.

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)

Altruism
We coded as ‘altruism’ any talk in which participants identified research topics based on the consideration of the welfare of others, over and above the participants’ individual needs as a patient. In making decisions on which research topic was of higher importance, the tension of wanting both personal and population benefit posed difficulties for the participants. However, altruism was consistently observed across all three types of participant groups. The participants agreed that the reason research on prevention should be highest priority was because it would benefit the community and future generations.

Even though I’m in the dialysis stage, I think it’s more important to focus on the others. (Female, 20s, dialysis)

Also, participants considered the well-being of living donors and insisted that research focus on developing a cure or improving treatment so there would be no requirement for potential donors to jeopardize their own health by donating their kidney.

It isn’t worth someone going through what they have to go through to give a kidney. (Female, 30s, predialysis)

Participants thought that research to understand the psychosocial issues faced by patients was important because it would benefit patients undergoing, or about to undergo, similar experiences.

I think we need to learn more about the experiences of people like ourselves who’ve gone through the same thing, and that information needs to be passed on and gathered, and put to better advantage so that we can help others. (Male, 50s, transplant)

Economic efficiency
We coded as ‘economic efficiency’ any talk about channeling the available resources for maximum effectiveness or getting the best value for the money. Participants considered the long-term economic benefits and cost of conducting research when prioritizing their choices for research. For example, they agreed that resources would be better channelled towards research on prevention and transplantation than dialysis, which was perceived to be a less cost-effective treatment.

I think the main aim is to keep people off dialysis so if you’ve got a transplant, the aim is to keep it operating for as long as you can . . . dialysis is just so expensive. (Male, 60s, transplant)

Personal concerns
We coded as ‘personal concerns’ any talk in which preferences, feelings and values were given as reasons for participants’ decisions on research topics. The participants themselves recognized that their own individual experiences and...
Patients’ priorities for health research

Table 3. Reasons underpinning research theme prioritization with supporting quotations

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Illustrative quotes</th>
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<tbody>
<tr>
<td>Normalization of life</td>
<td>‘I’ve also put some money into the treatment because if people have gone beyond that level [dialysis], they do need better treatment, to make it easier. I have family who have been on all sorts of dialysis, peritoneal and overnight, and all of them have their down and upsides and they all take time and they all interfere with lifestyle.’ (Female, 50s, predialysis)</td>
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<td>‘Can they create a small machine that’s portable, that can travel with us so that we can manage as an individual, that we don’t lose our independence, or we lose a bit of independence but not completely? I think to me that would be really important.’ (Male, 50s, predialysis)</td>
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<td>Altruism</td>
<td>‘Well I’d like, not for me, I’d like to see them help prevent the occurrence of chronic kidney disease in future generations. That’s what I look forward to. I think I’m beyond, there’s no way I can look forward to a cure but I’d like to, along the lines of future generations, whether it’s through stem cell research or preventative measures, I’d like to see work in those areas I think, to prevent or cure it for people in the future. I think it’s too late for me.’ (Male, 60s, predialysis)</td>
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<td></td>
<td>‘But when you actually think about millions of dollars in research, that benefits everybody, common sense kind of tells you that you want to prevent something before it gets to that and my individual case kind of pales in significance to that, in comparison.’ (Female, 40s, predialysis)</td>
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<tr>
<td>Economic efficiency</td>
<td>‘I’d spend more money on prevention because it’s certainly better than the cure and the cure costs a lot more than prevention.’ (Male, 60s, predialysis)</td>
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<td>Personal concerns</td>
<td>‘I suppose in the predialysis stage, I found the thing that was the hardest to cope with was the lack of energy and something like Aranesp [iron supplement] was a great improvement to me but not really enough.’ (Male, 60s, dialysis)</td>
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<td></td>
<td>‘I looked at this and I feel there is only one way you can approach it and that’s looking at it through the way it’s affecting you. So if it’s affecting me, I’d like to see more money put into that area, a purely selfish sort of perspective, but that’s how I basically made [my decisions].’ (Male, 50s, dialysis)</td>
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<tr>
<td>Clinical outcomes</td>
<td>‘I’d put diabetes at the top of the list because I think diabetes leads to a lot of the kidney problems because diabetes ends up being a problem with the small blood vessels, and kidneys are just loaded with small blood vessels.’ (Male, 60s, transplant)</td>
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emotions often influenced their choices in a range of research areas. Personal concerns were linked to a range of research topics including complications, transplantation, psychosocial needs and support, technological solutions and whole body research.

I wish there was a better alternative to what’s currently available. In terms of research in the dialysis area, something that doesn’t take a lot more time but something that is not as cumbersome as I expect it to be and probably a lot more comforting. I think comfortig is the key issue I’m looking for right now. (Male, 50s, predialysis)

Participants diagnosed with CKD and who had not received dialysis treatment or transplantation felt that they were not being looked at holistically and emphasized the importance of the need for collaborative research across medical disciplines. During this earlier stage in the illness trajectory, the personal importance of other illnesses and problems (e.g. heart disease, diabetes, blood pressure, lupus) was comparable in magnitude to kidney disease. However, in the later stages, kidney disease became the dominant illness in the participants’ lives.

Clinical outcomes

We coded as ‘clinical outcomes’ any talk in which participants suggested research topics to improve clinical outcomes and the physiological condition of the people diagnosed with CKD. Participants’ knowledge of the clinical outcomes (e.g. risk of mortality, morbidity and adverse effects) influenced their choice of topics particularly within the area of complications and transplantation.

I think heart disease in chronic kidney disease is quite important because of the calcifications, because of the prednisolone (immunosuppressant) we were taking all those years ago, I think it’s terribly important because it can cause the calcification in your valve, in your arteries etcetera and I do find that quite important. (Female, 60s, transplant)

Discussion

Patients with CKD had eight priority areas for research: preventing CKD, reducing complications and symptoms, improving access to and outcomes of kidney transplantation, developing better technological solutions, developing better understanding of psychosocial needs, improving whole body care, improving dialysis treatment and developing caregiver support. Some of these priorities were not unexpected and perhaps overlap with professionally driven priorities, but we were able to demonstrate that elicitation of patients’ research priorities was feasible, and a coherent and comprehensive list of research priorities could be obtained. Many differences between a clinician-researcher and patient-generated list of topics are apparent. Patients think more broadly, are more thematic and focus on outcomes. Clinician-researchers think more mechanistically and focus on specific questions and interventions. How healthcare should be delivered, both to the patient and the caregivers, in a holistic way matters to patients, but appears not to be a priority of research funders who promote discovery-type and pharmacological research preferentially. Specifically, participants did not identify understanding disease processes as a priority topic, which underpins much basic scientific
research. Only basic science, which has a reasonable chance of contributing to better clinical outcomes, is implicitly valued. In contrast, the disciplines of health services research and qualitative research are implicitly needed if these priorities are to be realized.

A significant and novel contribution of this work is the identification of five reasons that patients used to develop their research priorities (normalization of life, altruism, economic efficiency, personal concerns and clinical outcomes). This aspect of patient’s research prioritization has not been reported previously. It provides a framework for understanding the factors that influence patients’ decisions about research priorities, and is transferable to all healthcare topics and not limited to kidney disease. By generating these five reasons, participants in our study have explicitly demonstrated that they understand the inevitable tensions in research, such as between the good of the individual and the good of society. They have shown that they understand the values attached to good clinical outcomes that may vary across individuals. The recognition of economic efficiency in research is an important observation. Usually limited to allocation of competing interventions into clinical practice, our participants recognized that opportunity cost applied equally to research funding. Criteria for research funding, such as those specified in grant assessment criteria of major funding bodies [3–15], are typically weighted to the research productivity of the individual, which can be and is quantified. Our participants have advocated for a similar quantitative approach to the potential benefit of a study by trading off the cost of the study with the potential health gain. Usually this is captured under the domain of ‘significance’ but this is not explicitly quantitative nor does it have an economic perspective. Given the scarce resources of healthcare research, it should be.

Despite the policy of all major international research funding agencies to include consumers in the process of setting priorities for research [16–20], there are very sparse data on how this can be achieved. A recent bibliography identified 96 reports relating to patients’ priorities for research or health outcomes [21]. Almost all studies have focused on patient preferences for treatment, but we identified three that specifically explored the patients’ research priorities. Similar to these studies, patient priorities were identified and expressed by patients in terms of general research areas, including better medication to reduce side effects, prevention and psychosocial interventions. However, these studies did not provide insights into patient’s reasoning about research priorities.

The agenda for health research is influenced by factors beyond the patients’ reasons we identified. Researcher and reviewer interests, study feasibility, innovation, quality of the methods and ethical considerations influence both government and non-government funding for research. Commercial interests also affect decisions about what research should be funded; a significant amount of health research is sponsored by industry who often have an investment strategy embedded in studies designed to maximized profits [22,23]. These considerations are not necessarily inappropriate, simply incomplete. Including patient perspectives can broaden the research agenda and help to ensure that the limited resources are channelled towards research that optimizes the mix of benefits.

Our study demonstrates that if the right research methods are employed, the patients’ priorities for research can be elicited. These participants provided a set of research priorities and ways of reasoning that run parallel to, complement and may be quite different from the research priorities and means of reasoning used by other stakeholders, including governments, industry, health professionals and researchers. Health professionals and researchers draw on their own unique cultural norms and expertise when they construct research questions. They are informed by medical knowledge and the conventions of scientific inquiry, including the need to specify, in technical language, particular problems regarding aetiology, disease progression or intervention and management to investigate [24–26]. In contrast, these participants spoke in general terms and related research to hoped-for improvement to their own and others’ quality of life. This is unsurprising as it resonates with other findings concerning lay knowledge of health issues. We all use personal experiences, views about ourselves and others, and an in-depth understanding of the circumstances and social context in which we live to produce sophisticated and idiosyncratic frameworks of knowledge about our health and other aspects of our lives [27–29]. What has been missing, and what this study aims to provide, is a conduit through which these different ways of setting research priorities can influence one another.

Innovative methods are needed to better engage patients in agenda setting, rather than involving them in the same way as health professionals. We have demonstrated that focus groups and mock funding allocation exercises are feasible and productive and we encourage others to use similar methods for identifying priorities across different health conditions. Citizen juries provide a more deliberative approach, which, despite their added cost, may produce more sophisticated results. More detailed exploration of the patients’ reasons for choosing particular research priorities may, however, require in-depth face-to-face interviews, perhaps following involvement in a focus group or citizens’ jury. To be provocative, however, we would also contend that the inclusion of consumers in grant review panels for health research is a tokenistic approach. This study has demonstrated the richness and range of understanding that can come from engagement with the patients’ personal experiences of a particular illness. It is unlikely that a single ‘consumer’ on a panel could ever be adequately equipped to offer this depth and breadth of insight. Well-designed and reported qualitative research about priorities across a range of research areas would provide a more methodologically sound route for incorporation of lay knowledge into funding allocation decisions. The principles of reasoning generated in this study—normalization of life, altruism, economic efficiency, personal concerns and clinical outcomes—have particular potential: secondary analytic work across a large number of qualitative studies such as this one may, in the future, produce principles of reasoning that could be applied across research areas.
Although this study was conducted with CKD patients from four centres, the findings are applicable and transferable across settings and health disciplines. A patient-focused research agenda was possible to develop, was thematic and the outcomes were focused and could be used to refine and prioritize specific topics proposed by health-related researchers. The five reasons underlying the patients’ research priorities demonstrate that they understand the tensions in prioritizing research, the variation in disease course and clinical outcomes between patients and recognize that opportunity cost applies to research funding. Decision-making processes for selecting research topics should be made explicit. This study presents a model by which these decisions can incorporate consumer values and perspectives, facilitate active and effective consumer participation and avoid tokenism.

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Conflict of interest statement. None declared.

Appendix. Ranking exercises

Research about the:

pre-dialysis stage of chronic kidney disease
dialysis stage of chronic kidney disease
transplant stage of chronic kidney disease

Research that aims to:

discover the causes of chronic kidney disease
help to prevent chronic kidney disease
lead to better diagnosis of chronic kidney disease
improve treatment for people with chronic kidney disease
understand the experiences and needs of people with chronic kidney disease

Research that aims to:

understand how chronic kidney disease works in the body

discover more effective treatments for chronic kidney disease
prevent chronic kidney disease in the community
help clinicians and hospitals to provide better services to people who have chronic kidney disease

Research about:

bone disease in chronic kidney disease
cancer in chronic kidney disease
blood pressure in chronic kidney disease
anaemia in chronic kidney disease

heart disease in chronic kidney disease

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