AJKD
Special Report

Research Priorities in CKD: Report of a National Workshop Conducted in Australia

Allison Tong, PhD,[1,2] Sally Crowe, PG Dip,[3] Shingisai Chando, MPH,[1,2] Alan Cass, PhD,[4] Steve J. Chadban, PhD,[5] Jeremy R. Chapman, FRCP,[6] Martin Gallagher, PhD,[1,7,8] Carmel M. Hawley, MBBS,[9,10,11] Sophie Hill, PhD,[12] Kirsten Howard, PhD,[1] David W. Johnson, PhD,[9,10,11] Peter G. Kerr, PhD,[13] Anne McKenzie,[14] David Parker,[13] Vlado Perkovic, PhD,[8] Kevan R. Polkinghorne, PhD,[12] Carol Pollock, PhD,[1,15] Giovanni F.M. Strippoli, PhD,[1,16,17,18] Peter Tugwell, FRCP,[19] Rowan G. Walker, PhD,[20] Angela C. Webster, PhD,[1,2,6] Germaine Wong, PhD,[1,2,6] and Jonathan C. Craig, PhD[1,2]

Research aims to improve health outcomes for patients. However, the setting of research priorities is usually performed by clinicians, academics, and funders, with little involvement of patients or caregivers and using processes that lack transparency. A national workshop was convened in Australia to generate and prioritize research questions in chronic kidney disease (CKD) among diverse stakeholder groups. Patients with CKD (n = 23), nephrologists/surgeons (n = 16), nurses (n = 8), caregivers (n = 7), and allied health professionals and researchers (n = 4) generated and voted on intervention questions across 4 treatment categories: CKD stages 1 to 5 (non–dialysis dependent), peritoneal dialysis, hemodialysis, and kidney transplantation. The 5 highest ranking questions (in descending order) were as follows: How effective are lifestyle programs for preventing deteriorating kidney function in early CKD? What strategies will improve family consent for deceased donor kidney donation, taking different cultural groups into account? What interventions can improve long-term post-transplant outcomes? What are effective interventions for post hemodialysis fatigue? How can we improve and individualize drug therapy to control post-transplant side effects? Priority questions were focused on prevention, lifestyle, quality of life, and long-term impact. These prioritized research questions can inform funding agencies, patient/consumer organizations, policy makers, and researchers in developing a CKD research agenda that is relevant to key stakeholders.
Am J Kidney Dis. 66(2):212-222.

INDEX WORDS: Research; clinical research; chronic kidney disease (CKD); priority setting; resource allocation; funding decisions; patient-centered care; patient; caregiver; health care worker; stakeholder; disease prevention; quality of life; renal replacement therapy; Kidney Health Australia (KHA).

Research aims to improve treatment and health outcomes for patients, but research priorities are usually determined by academics, clinicians, and funders, with little input from patients and their caregivers.[1-3] This discordance between doers and end users results in mismatches between topics of importance to patients and their families and the research that is funded and conducted.[3-5] Consequently, clinicians may focus on treatment issues to such an extent that the burdens associated with living with the disease and coping with treatment are not considered. Moreover, many potentially important

From the [1]Sydney School of Public Health, The University of Sydney, Sydney; [2]Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, New South Wales, Australia; [3]Crowe Associates Ltd, Oxon, United Kingdom; [4]Menzies School of Health Research, Charles Darwin University, Darwin, Northern Territory; [5]Royal Prince Alfred Hospital; [6]Centre for Transplant and Renal Research, Westmead Hospital; [7]Department of Nephrology, Concord Hospital; [8]Renal and Metabolic Division, The George Institute, Sydney, New South Wales; [9]Queensland School of Medicine, University of Queensland at Princess Alexandra Hospital; [10]Translational Research Institute; [11]Metro South and Ipswich Nephrology and Transplant Services (MINTS), Brisbane; [12]Centre for Health Communication and Participation, La Trobe University, Melbourne; [13]Monash Medical Centre and Monash University, Clayton, Victoria; [14]Centre for Health Services Research, The University of Western Australia, Perth, Western Australia; [15]Renal Division, Kolling Institute, Sydney, New South Wales, Australia; [16]Diaverum Medical Scientific Office and Diaverum Academy, Lund, Sweden; [17]Division of Nephrology and Transplantation, Amedeo Avogadro University of Eastern Piedmont; [18]Department of Translational Medicine (Italy), University of Bari, Mario Negri Sud Foundation, Bari, Italy; [19]Department of Medicine, University of Ottawa, Ottawa, Canada; and [20]Department of Renal Medicine, The Alfred Hospital, Melbourne, Victoria, Australia.

Received December 11, 2014. Accepted in revised form February 6, 2015. Originally published online May 3, 2015.

Address correspondence to Allison Tong, PhD, Centre for Kidney Research, The Children's Hospital at Westmead, Westmead NSW 2145, Sydney, Australia. E-mail: allison.tong@sydney.edu.au

0272-6386
http://dx.doi.org/10.1053/j.ajkd.2015.02.341

topics are neglected even when a substantial amount of research is publicly funded.[4,6,7]

Recently, the lack of partnership among researchers, clinicians, and patients has been recognized in many jurisdictions, and major new initiatives have been forged to fill the gap.[8,9] In the United States, an important element of recent health care reform was the formation of the Patient-Centered Outcomes Research Institute (PCORI), which has a mission to produce and promote high-integrity research that is "guided by patients, caregivers, and the broader healthcare community."[10] In the United Kingdom, the James Lind Alliance was launched in 2004 to unite patients, caregivers, and health care providers in prioritizing treatment uncertainties for research.[11]

Research prioritization exercises with an explicit process are uncommon in chronic kidney disease (CKD), and those that exist often do not engage key stakeholder groups, including patients and caregivers, in a partnership approach.[12-17] The notable exception is an exercise completed in Canada that focused on advanced CKD and dialysis and involved physicians, allied health professionals, and patients receiving or nearing dialysis.[18] The top 10 priorities arising from this exercise addressed patient-provider communication, dialysis modalities, itching, access to transplantation, heart health, dietary restrictions, depression, and vascular access.

Research priority-setting partnerships provide an opportunity for equitable involvement of patients, caregivers, and health care providers, which can improve the relevance, quality, and implementation of research.[19]

NATIONAL PRIORITY-SETTING WORKSHOP

Context

Australia is among the world's 20 largest economies, with a gross domestic product of approximately US $1 trillion. In the Australian health care system, some services are funded by the government and others are funded by private health insurance. Medicare is the Australian government's universal health insurance scheme and provides free or subsidized treatment to patients in public hospitals. Costs of dialysis and kidney transplantation are covered by Medicare. However, patients may choose to dialyze as a private patient at a private renal unit that is funded by private health insurance schemes.

A national priority-setting workshop was convened on February 7, 2014, to generate and prioritize research questions in CKD in Australia. The intent of the workshop was to develop a prioritized research agenda across the entire spectrum of CKD that is relevant to all key stakeholders: patients, clinicians, policy makers, and research funders.

Workshop Participants

Participants were eligible if they were patients with CKD (CKD stages 1-5, 5D, or 5T), family caregivers, or health professionals with experience in CKD (nephrologists, surgeons, nurses, allied health professionals, and researchers); English speaking; 18 years and older; and able to provide informed consent. Participants were recruited from 7 Australian states and territories (New South Wales, Victoria, Queensland, Northern Territory, South Australia, Western Australia, and the Australian Capital Territory).

Patients and family caregivers were selected through Kidney Health Australia (KHA) and recruiting clinicians using purposive and snowballing (ie, participants were asked to nominate other participants) strategies to achieve a range of sociodemographic (age, sex, employment status, education, culturally and linguistically diverse populations, and location of residence) and clinical (CKD stage/modality and duration of diagnosis) characteristics. KHA and recruiting clinicians were advised of these criteria.

Health professionals and researchers were purposively selected to capture diversity across years of clinical experience, age, sex, practice locations, and affiliations with the following stakeholder organizations: Australian Kidney Trials Network (AKTN), Australian Institute of Health and Welfare (AIHW), Australian Government Department of Health, National Health and Medical Research Council, Australian and New Zealand Society of Nephrology (ANZSN), The Transplantation Society of Australia and New Zealand (TSANZ), Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), Agency for Clinical Innovation (ACI), and State Renal Health Clinical Networks. The workshop was convened in hotel meeting rooms in central Sydney.

Participants received reimbursement for travel and accommodations. Recruitment continued until the maximum of 60 participants was confirmed to attend, with at least half being patients/caregivers. Workshop capacity was determined by resource availability (approximate budget of A$20,000 for direct workshop costs excluding personnel salaries), group manageability, and feasibility. All participants were asked to complete a declaration of interests and disclosure form. The University of Sydney ethics committee approved the study.

Of the 60 individuals confirmed to attend the workshop, there were 58 (97%) participants, comprising 23 patients, 16 nephrologists and surgeons, 8 nurses, 7 caregivers, and 4 allied health professionals and researchers. The number of patients/caregivers who declined participation or those whom we excluded to

Table 1. Characteristics of Participating Patients and Caregivers

Characteristic	No. (%)
Participant type	
Patient	23 (77)
Caregiver	7 (23)
Female sex	14 (47)
Age category	
20-29 y	2 (7)
30-39 y	6 (20)
40-49 y	6 (20)
50-59 y	2 (7)
60-69 y	11 (37)
70-79 y	3 (10)
Employment status	
Full time	9 (31)
Part time	8 (28)
Casual	1 (3)
Retired	7 (24)
Not working	2 (7)
Student	2 (7)
Marital status	
Married/defacto	22 (73)
Divorced or separated	1 (3)
Single (living with parents, never married)	6 (20)
Highest level of education	
Grade 10	4 (14)
Grade 12	4 (14)
Nonuniversity qualification (certificate, diploma)	8 (28)
University degree (bachelor, master's, doctoral degree)	13 (45)
Location of residence, by state	
New South Wales	13 (43)
Victoria	6 (20)
Queensland	4 (13)
South Australia	6 (20)
Australian Capital Territory	1 (3)
Area of residence	
Metropolitan/urban	25 (83)
Regional	5 (17)
Current mode of RRT[a]	
None	6 (20)
Hemodialysis	10 (33)
Peritoneal dialysis	4 (13)
Kidney transplantation	9 (30)
Ethnic background	
White	21 (70)
Greek	2 (7)
Chinese	1 (3)
Lebanese	1 (3)
Jewish	1 (3)
Italian	1 (3)
Portuguese	1 (3)
Mixed ethnicity	1 (3)

Note: n = 30.
Abbreviation: RRT, renal replacement therapy.
[a]Of patients; includes RRT of patients whose caregivers attended the workshop.

Table 2. Characteristics of Participating Health Care Professionals

Characteristic	No. (%)
Female sex	10 (36)
Age category	
30-39 y	4 (14)
40-49 y	12 (43)
50-59 y	10 (36)
60-69 y	2 (7)
Role	
Nephrologist	14 (50)
Surgeon	1 (4)
Researcher	1 (4)
Dietician	1 (4)
Nurse or nurse coordinator	8 (29)
Psychologist	1 (4)
Social worker	1 (4)
Location of practice, by state	
New South Wales	13 (46)
Queensland	5 (18)
Victoria	3 (11)
South Australia	3 (11)
Western Australia	2 (7)
Australia Capital Territory	1 (4)
Northern Territory	1 (4)
Experience in caring for patients with CKD	
≤10 y	7 (25)
11-20 y	7 (25)
21-30 y	11 (39)
>30 y	3 (11)
Ethnic background	
Anglo-Saxon	19 (68)
Chinese	4 (14)
Indian	2 (7)
Russian	2 (7)
Mixed ethnicity	1 (4)

Note: n = 28.
Abbreviation: CKD, chronic kidney disease.

avoid over-recruitment of demographic/clinical characteristics could not be tracked because we used multiple recruitment strategies. Eight health professionals declined participation due to prior commitments. Participants were aged 23 to 77 years (overall mean age, 49.7 ± 12.0 [SD] years; patients/caregivers, 52 ± 14.7 years; and health care providers, 46 ± 11.9 years) and 34 (58.6%) were men. Participant characteristics are provided in Tables 1 and 2.

Prioritization Process

The prioritization process was adapted from the James Lind Alliance Priority Setting Partnership methodology for the consensus workshop,[20-24] and the framework for health research priority setting, from Viergever et al.[25] The process is detailed in Fig 1, and the facilitator's Interview Guide is provided in Table S1 (available as online supplementary material).

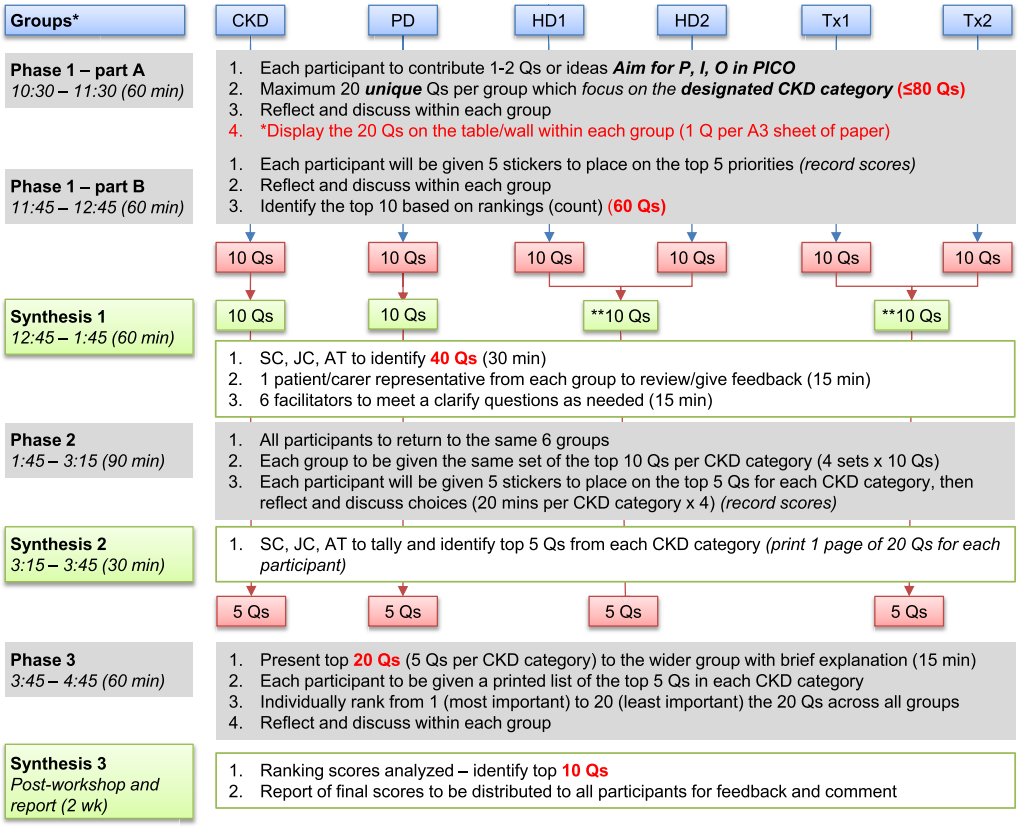

Figure 1. Flowchart of the workshop process. Chronic kidney disease (CKD) categories are non–dialysis-dependent CKD, peritoneal dialysis (PD), hemodialysis (HD), and transplantation (Tx). Abbreviations: PICO, population, intervention; comparator, outcome; Q, question. *n = 10 maximum per group. **Based on removing duplication and selecting the top-ranked 10 across both lists.

Facilitators were required to have a background in health (public health, medicine, health economics, psychology, or epidemiology) and prior experience in moderating focus groups. They were known to the investigator team to have the skills required for the task. All facilitators completed a training session that covered the workshop objectives, the role and skills of a facilitator, and how to ensure effective dialogue and manage difficult behavior.

Workshop Methods

The 1-day workshop had 3 phases.

Phase 1

Participants were divided into 6 facilitated groups of 8 to 10 members. The group composition was mixed (patients, caregivers, and health professionals) and at least half of each group comprised patients/caregivers. One group focused on non–dialysis-dependent stages 1 to 5 CKD, and another group, on peritoneal dialysis (PD). Two groups each were assigned to the topics of hemodialysis (HD) and transplantation; the emphasis on these 2 treatment types was based on participant preferences submitted prior to the workshop and group facilitation manageability. The group allocations also reflect the higher proportion of prevalent patients in Australia who are treated by HD or have received a kidney transplant.[26] One trained facilitator (S.C., A.T., G.W., K.H., A.R., and S.H.) and 1 co-facilitator (S.C., J.C.C., D.T., C.S.H., A.J., and M.L.) were assigned to each group. Participants were asked to formulate questions about interventions and to try to generate questions following the PICO (population, intervention, comparator, outcomes) framework. Generated questions were displayed on a board or wall. To vote, each participant was given 5 stickers to place adjacent to the research questions she or he thought most important; choices then were discussed as a group. If needed, additional stickers were distributed for tiebreaking.

The top 10 questions for each CKD treatment category were identified by tallying votes. For the categories HD and transplantation, which were covered by 2 groups, the top 5 questions from each group were combined to form a top 10 for the category. Thus, altogether, 4 sets of 10 questions were produced. A patient representative from each group reviewed the questions for clarity.

Phase 2

A copy of the top 10 questions for each CKD category was provided to each group. All groups discussed and ranked each question within its respective category. The top 5–ranked questions in each category progressed onto the next phase.

Phase 3

The group votes were summed and the aggregate top 5 questions from each CKD category were distilled into a list of 20 research questions. These were presented to all participants in a plenary with participants invited to comment or request clarification. Each participant received a printed copy and individually ranked the top 20 questions from 1 (most important) to 20 (least important).

Data Analysis

Descriptive statistics were calculated using SPSS (IBM; version 21). The prioritized list of the top 20 research questions for all participants was generated by combining scores from the top 20 questions that were individually ranked by participants and calculating the mean and standard deviation for each question. Histograms were generated for each question's scores and revealed that the data were not normally distributed; therefore, median and interquartile range (IQR) were calculated for each question to determine rank. Questions were then stratified by participant group (patients/caregivers vs health professionals/researchers), and Mann-Whitney U test was conducted to test for differences between groups.

A preliminary report of the research priorities workshop was sent to all invited participants so they could provide feedback and comment within a 2-week time frame. It was also uploaded on the KHA website to disseminate the findings.[27]

Research Priorities

Across all groups, a total of 83 research questions were generated (Table S2). The top 10 questions ranked by CKD treatment category are provided in Box 1. The individual top-20 ranking was completed by 55 (95%) participants. According to median scores, the 5 highest ranking questions across CKD treatment categories were: (1) How effective are lifestyle programs (diet, exercise, and smoking cessation) for preventing deteriorating kidney function in patients with early CKD? (2) What strategies will improve family consent for potential deceased donor kidney donation, taking different cultural groups into account? (3) What interventions (drugs, lifestyle) can improve long-term post-transplant outcomes? (4) What are the effective interventions for post-HD fatigue? (5) How can we improve and individualize drug therapy to provide better control of side effects in kidney transplantation?

The priority questions focused on prevention, lifestyle, quality of life, and long-term impact. Table 3 shows the differences in median scores, IQR, and rank between patients/caregivers and health care providers. The difference in median score and IQR was statistically significant for 1 question ("What interventions are most effective to reduce interdialytic weight gain?"), which had a median score of 15 (IQR, 9-18) for patients/caregivers versus 10 (IQR, 5-15) for health care professionals, $P = 0.03$).

Six questions had a difference in rank of 5 or more between patients/caregivers and health care providers. Two questions were ranked as higher priority by at least 5 rankings among patient/caregivers: What strategies will improve donor family consent to deceased donation taking different cultural groups into account? Are electronic and social media an effective modality to deliver health promotion about CKD in the general population? Four questions were ranked as higher priority among health care professionals: What are the effective interventions for post-HD fatigue? What are the best interventions to improve the decision-making process of people faced with HD and to improve their satisfaction and reduce complications? What kinds of exercise programs are safe and most effective for PD patients? What interventions are most effective to reduce interdialytic weight gain?

Of the questions ranked in the top 10 by both patients and caregivers, 8 appeared in the overall top 10 questions. Of the questions ranked in the lowest 10 by both patients and caregivers, 7 were in the overall 10 lowest ranked questions. The questions ranked in the top 7 by patients/caregivers and by health care professionals were included in the overall top 10 research priorities. Both groups ranked the research question "How can technology be used to improve patient self-monitoring in PD?" last, which was consistent with the rank of the combined group.

DISCUSSION

An Australian priority-setting partnership involving patients, caregivers, policy makers, clinicians, and researchers was convened in February 2014 to elicit shared research priorities for CKD. Priorities were focused on prevention, lifestyle, quality of life, and long-term impact of disease and treatment. For stages 1 to 5 CKD (non–dialysis dependent), the prioritized questions were centered on lifestyle interventions to prevent disease progression, education to improve self-management and access to services, health promotion in the general community, and referral and support services to improve quality of life. For PD, the

Box 1. Top 10 Ranked Research Priorities by CKD Category

Chronic Kidney Disease

1. How effective are lifestyle programs (diet, exercise and smoking cessation) for preventing deterioration in kidney function in patients with early CKD?
2. Does provision of culturally appropriate information about early CKD modify acknowledgement, medication adherence and health service uptake in patients with early CKD?
3. Does active implementation of clinical practice guidelines in general practice improve kidney health in patients with early CKD?
4. Are electronic and social media effective for delivering health promotion about CKD in the general population?
5. Do interventions that increase knowledge of support services and early referral practices increase quality of life in patients and caregivers?
6. Do interventions that enhance self-management in early CKD patients modify health services use and quality of life?
7. Do interventions that enhance shared decision making and planning impact on the quality of RRT in patients with early CKD?
8. Are interventions to enhance education about early CKD detection effective in improving early diagnosis?
9. Are complementary medicines (eg, zinc, iron, vitamin D) effective in preventing progression of kidney disease in patients with early CKD?
10. Does enhancing acknowledgement of CKD improve kidney health in patients newly diagnosed with early CKD?

Peritoneal Dialysis

1. What is the best diet or nutritional intervention to improve general outcomes of PD patients?
2. How can technology be used to improve patients' self-monitoring?
3. How can we provide better support for patients/families in transition of care from children to adults?
4. How we can be best provide support services/tools to be integrated to patients/caregivers/families to improve mental health?
5. What is the optimum staff/patient ratio in PD clinics to reduce morbidity?
6. How can we best deliver staff education services to reduce patient complications?
7. What kinds of exercise program are safe and most effective for PD patients?
8. Are there interventions or tools to improve patient cognition and slow decline?
9. How can peer support be integrated to improve patient mental health?
10. What is the best way to provide counseling to improve patient self-esteem?

Hemodialysis

1. What is the impact of polypharmacy on quality of life; what is the best way to make tablet regimes simpler?
2. What are the best interventions to improve the decision making process of people faced with HD and to improve their satisfaction and reduce complications?
3. What is the benefit of and what is the best planned nutritional program (plus best 'easy aids' to help gauge potassium) for better outcomes (improving lean body mass/muscle)?
4. What are the effective interventions for post HD fatigue?
5. What strategies reduce anxiety?
6. What strategies help patients maintain work while on HD?
7. What are the best characteristics to identify which elderly patients will benefit from HD?
8. Can a potassium indicator (discrete, measurable) be developed to deal with potassium fluctuation and self-manage better?
9. What interventions are most effective to reduce inter-dialytic weight gain in patients with HD?
10. Does implementing a personalized care plan increase quality of life for patients on HD and caregivers?

Transplantation

1. What strategies will improve donor family consent to deceased donation, taking different cultural groups into account?
2. What interventions (drugs, lifestyle) can improve long term post-transplant outcomes?
3. What psychological interventions would improve the psychological health for transition between stages of kidney disease?
4. How do we improve health outcomes in young transplant recipients?
5. What can we do to improve/individualize drug therapy in terms of better management of side effects?
6. Can implementing a pharmacy clinic positively influence compliance and stop transitioning back to dialysis?
7. What additional psychological and medical support would be beneficial post donation for live donation?
8. Determining extended criteria for elderly donor recipient pairs (donors over 65 years)?
9. What counseling services would help children of parents going through the transplant process?
10. In those with a failing graft would restarting dialysis earlier improve psychological well-being and health?

Abbreviations: CKD, chronic kidney disease; HD, hemodialysis; PD, peritoneal dialysis; RRT, renal replacement therapy.

questions addressed diet and nutrition, self-monitoring technology, transition, integrated services to improve mental health, and educational interventions for staff to reduce complications. The prioritized questions for HD related to managing polypharmacy, shared decision making, nutritional management, fatigue and anxiety, and interdialytic weight gain. For transplantation, prioritized questions focused on interventions to improve posttransplantation outcomes, increasing donation rates, individualized therapy to manage side effects, and psychological interventions.

Overall, there was broad consensus between patients/caregivers and health professionals. This may be explained in part by the balanced mix of patients/

Table 3. Top 20 Research Priorities Across All CKD Categories

Rank	Question[a]	Overall[b] Median [IQR]	Patients and Caregivers[c] Median [IQR]	Rank	Health Care Professionals Median [IQR]	Rank	Mann-Whitney U *U*	*P*[d]
1	How effective are lifestyle programs (diet, exercise and smoking cessation) for preventing deterioration in kidney function in patients with early CKD?	5 [2-10]	6 [4-10]	4	4 [2-9]	1	261.5	0.1
2	What strategies will improve donor family consent to deceased donation, taking different cultural groups into account?	6 [3-13]	5 [2-11]	1	9 [6-13]	6	262.5	0.1
3	What interventions (drugs, lifestyle) can improve long term post-transplant outcomes?	7 [2-11]	5 [2-11]	1	8 [3-11]	4	314.0	0.5
4	What are the effective interventions for post HD fatigue?	7 [4-14]	10 [4-14]	8	6 [4-13]	2	300.5	0.4
5	What can we do to improve and individualize drug therapy in terms of better management of side effects in kidney transplantation?	8 [4-12]	5 [3-11]	3	10 [5-15]	7	245.0	0.01
6	What strategies help patients maintain work while on HD?	8 [4-13]	9 [6-14]	7	6 [4-9]	3	243.5	0.06
7	What psychological interventions would improve the psychological health for transition between kidney stages?	9 [5-16]	8 [5-13]	6	11 [5-17]	10	277.5	0.2
8	How do we improve health outcomes in young transplant recipients?	10 [5-15]	8 [4-14]	5	11 [5-16]	9	305.0	0.4
9	What are the best interventions to improve the decision making process of people faced with HD?	10 [6-16]	11 [7-16]	13	8 [4-15]	5	269.0	0.1
10	Does provision of culturally appropriate information about early CKD modify acknowledgement, medication adherence, and health service uptake in patients with early CKD?	11 [6-15]	12 [7-16]	15	11 [7-15]	12	324.5	0.6
11	Do interventions that increase knowledge of support services and early referral practices increase quality of life in patients and caregivers?	11 [6-16]	10 [5-14]	9	11 [8-15]	13	309.5	0.5
12	How can we best provide support services to patients, carers, and families to improve mental health in PD?	11 [7-16]	11 [5-16]	10	12 [7-15]	14	341.0	0.9
13	Does active implementation of clinical practice guidelines in general practice improve kidney health in patients with early CKD?	12 [5-15]	11 [5-17]	11	12 [7-15]	14	343.0	0.9
14	What is the best diet and nutrition to improve general health outcomes for PD patients?	12 [6-18]	12 [8-15]	17	12 [9-16]	16	334.0	0.8
15	Are electronic and social media an effective modality to deliver health promotion about CKD in the general population?	12 [9-16]	11 [6-19]	12	14 [9-17]	19	323.0	0.6
16	How can we best deliver staff education to reduce patient complications in PD?	13 [6-16]	12 [8-14]	16	14 [8-18]	18	282.0	0.2
17	What kinds of exercise programs are safe and most effective for PD patients?	13 [8-17]	15 [10-17]	19	11 [6-15]	11	247.0	0.06
18	Does implementing a personalized care plan increase quality of life of HD for patients and caregivers?	13 [9-17]	12 [6-15]	14	13 [7-16]	17	309.0	0.5
19	What interventions are most effective to reduce inter-dialytic weight gain?	13 [8-17]	15 [9-18]	18	10 [5-15]	7	230.5	0.03[e]
20	How can technology be used to improve patient self-monitoring in PD?	18 [12-20]	17 [12-20]	20	18 [13-20]	20	347.5	0.9

Abbreviations: CKD, chronic kidney disease; HD, hemodialysis; IQR, interquartile range; PD, peritoneal dialysis.
[a]Total n = 55; 2 participants did not disclose their identity but their rankings are included in the median calculation.
[b]n = 27.
[c]n = 26.
[d]*P* = Asymptotic significance (*P*) value.
[e]Significant at $P < 0.05$.

caregiver and health professionals in each breakout discussion group. Also, the nominal group technique allows all participants to contribute ideas (research questions) individually and to discuss these ideas as a group. We sought a process of hearing views equally and all groups were moderated by a trained facilitator who encouraged open and collaborative dialogue among all participants.

Some questions were noticeable by their absence. There was a lack of discussion about mortality, although it may have been implicit in some of the generic outcomes identified. Most researchers would regard mortality as an important outcome and challenge in CKD and many clinical studies are focused on mortality, especially in dialysis. The apparent absence of mortality in research priorities has also been observed in other areas of medicine, including cancer, mental health, and pulmonary disease, for which patients/caregivers emphasize living with and managing the illness rather than dying from it.[5,28,29] We speculate that this may also reflect a perception that mortality may not be a realistic outcome, particularly in dialysis, given that mortality rates remain unacceptably high despite advances in dialysis technologies and pharmacology.[30-32]

Comparison With Other Research Priority-Setting Initiatives

Some of the research priorities generated in this workshop reflect priority areas that are consistent with findings from a recent systematic review of research priority-setting activities in kidney disease.[1] These included prevention of CKD progression, dietary management, access to transplantation, patient education, and psychosocial impact of CKD.

Recently, the US National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) commissioned the Kidney Research National Dialogue to ask practitioners, clinical and basic scientists, and members of advocacy and professional groups to identify high-priority research objectives for CKD.[16] The research objectives covered prevention, prognosis, treatment, and outcomes. Diet and nutrition and transition from pediatric to adult care were the only priorities that were similar to those identified in our study. The US Agency for Healthcare Research and Quality (AHRQ) also sought to identify topics for systematic reviews of primary research that compared the effectiveness of strategies to prevent, detect, and treat CKD or its complications.[13] Stakeholder participants were physicians and members of health professional societies, health insurance organizations, the government, and patient advocacy groups (patients and caregivers were not involved). Among the 18 highest ranked priorities for funded comparative effectiveness systematic reviews in CKD, approximately one-quarter appear to align with the top research questions in our workshop. These priorities were access to health care, patient knowledge and education, computer decision support for CKD management, and dietary strategies to slow CKD progression. The variation in priorities may be due largely to the priority-setting approach used, whether categories and topics were identified a priori by the investigator team, and whether patients and caregivers were excluded.

Recently Manns et al[18] conducted a national survey and consensus workshop with patients, caregivers, and health professionals to identify research priorities for patients receiving dialysis or nearing dialysis-dependent CKD. Among the top 10 research priorities they identified, a number were similar to those identified in our workshop; these questions concerned improving self-management in patients with CKD, shared decision making, quality of life, increasing access to kidney transplantation, reducing the psychosocial impact of CKD, dietary strategies, depression and anxiety, and caregiver support.

Strengths and Potential Limitations

This national priority-setting partnership workshop followed a systematic and transparent process of engaging patients, caregivers, clinicians, researchers, and policy makers in generating and prioritizing research questions across the spectrum of CKD. This was a large-scale priority-setting workshop, which has contributed to innovative methodological development through use of concurrent facilitated discussion groups and a 3-phase process with real-time data analysis to distill the number of questions to be ranked in each subsequent phase. We have demonstrated that this approach is effective in allowing participants to identify and prioritize research questions.

However, there are several potential limitations. While the purposive sampling strategy captured a range of demographic and clinical characteristics, culturally and linguistically diverse patients/caregivers were relatively under-represented (n = 8/30 [27%]). Additionally, no participants identified as indigenous Australian (although some participants advocated for specific indigenous issues) or resided in remote areas. Also, 45% of patients/caregivers were university graduates, which may not be reflective of the CKD population. The extent to which the priorities address all relevant Australian stakeholders may be limited. Differences in research priorities by demographics could not be determined because the workshop was designed to develop consensus and not powered to detect differences attributed to demographic characteristics.

We recognize that individuals were self-selecting and inevitably may promote a personal or institutional perspective. However, this was to some extent mitigated by achieving maximum possible variation in demographic and clinical characteristics and by recruiting health professionals from different institutions. Further, having trained facilitators moderate the discussion helped ensure that participants contributed ideas in a respectful manner and across a wide range of perspectives.

The questions formulated did not always fulfill the PICO criteria; thus, they need to be refined further for study by trials or systematic reviews. We also did not exclude questions that existing research may have already answered, and therefore the resulting priorities may not be indicative of uncertainties about CKD treatment. Previous priority-setting partnerships following the James Lind Alliance approach conducted preliminary surveys and voting exercises to identify and prioritize treatment uncertainties, removed questions that had been addressed by existing evidence, and conducted a face-to-face workshop to prioritize the remaining questions.[20,24,33,34] However, we chose to omit these initial steps to ascertain whether patients/caregivers and health professionals could identify research questions and priorities together from the outset. We have shown that it is possible to compress the research priority-setting partnership process, which has implications for cost, resources, and feasibility.

It is unknown whether a 1-day priority-setting workshop is better at generating decisions that truly reflect the interests of patients and their caregivers than a workshop preceded by a prolonged participant engagement process. Nonetheless, the 1-day workshop is a frequently used and widely accepted approach for research priority-setting partnerships and bears some similarities to the consensus development conferences outlined in the James Lind Alliance review of priority-setting approaches.[35] It is also unclear how a methodology based on quantitative analysis of the number of times questions are suggested and/or voted for compares to a qualitative analysis of research priorities based on in-depth engagement with patients and their caregivers. Gathering questions from different routes (eg, group discussions) can yield very similar questions compared to a more quantitative survey approach and may give a more nuanced result in terms of the quality of the question. However, we are not aware of a purely qualitative approach that can move from engagement to priority setting.

Implications for Future Research Priority-Setting Initiatives

The questions generated in our study were explicitly focused on interventions for the treatment and management of CKD. Nonetheless, the procedure used could be broadly applied in other research priority setting exercises. We suggest that prioritization could be conducted for other types of research questions that address etiology, diagnosis, and prognosis or even for exploring the hidden burden of living with disease. Furthermore, there are aspects of living with a serious chronic condition that are relevant regardless of condition (eg, self-managing medicines or broadly based health promotion).[36] For example, kidney disease in children, and conservative management for stage 5 CKD were beyond the scope of our study and could be considered for future prioritization initiatives. Also, it would be of interest to determine how well the 5 research priorities identified by the 2002 US NIDDK Task Force of Health Professionals (calcium and phosphorus metabolism abnormalities, neurocognitive and developmental outcomes, predictors of progression of structural kidney disease/congenital abnormalities, genetic and molecular risk factors for CKD and their effects on outcomes, and the effect of socioeconomic factors on outcomes[37]) align with those of patients and caregivers.

Different strategies or approaches to research priority setting may be required for hard-to-reach communities, including indigenous Australians, who may have understandings of health, disease, and health care that differ from the conventional vision of Western medicine.[38-41] Relevant, effective, and culturally respectful approaches require a mutually respectful partnership framework, ongoing relationships and engagement, capacity building and active involvement of indigenous staff, an understanding of communities' past and present experiences of research, recognition of the diversity of indigenous populations, and support for community ownership.[42]

The prioritized research questions generated in our study still need to be mapped against published and ongoing research to identify questions that address uncertainties in existing evidence. Also, questions may undergo further refinement and distillation according to the PICO criteria and their feasibility, after which they can be used to inform the development of a CKD research agenda that is important and relevant to key stakeholders, particularly patients and caregivers. Forums to formulate research agendas (such as this workshop) will drive clinically oriented research to answer questions of immediate relevance. Thus, a different forum may be better suited for priority setting in discovery-driven research.

Translation of Research Priorities

A key challenge after collaborative research priority setting is translating shared priorities into the agendas of funders and researchers. Therefore, evaluating the outcomes and impact of priority setting is critical. The findings of this study will be used to inform the research projects selected by the national peak consumer organization for kidney disease, KHA. The priorities also will be considered by the AKTN in planning and designing trials and by the Cochrane Renal Group in ensuring that systematic reviews address topics of concern to patients.

It has been proposed that success is achieved in research priority setting when there is improved

stakeholder understanding and confidence in the research prioritization process, a shift in priorities or reallocated resources, heightened decision-making quality in terms of the appropriate use of evidence, stakeholder acceptance and satisfaction (or "buy in"), and provision of information accessible for use or emulation by others.[43] To draw these points out further, success could be "measured" at several stages: when research proposals from the research community are aligned with (or reference) the prioritization at the time funding is being sought, when funding decisions display a resource bias to such aligned proposals, and when results from funded proposals are used as an input to subsequent prioritization refinements. Ultimately, an increase in the amount of research that reflects the shared priorities of health professionals and patients/caregivers who live with CKD would also constitute success.

CONCLUSION

Priority-setting partnerships provide an opportunity for participative democratic approaches to research question generation[44] and for wide stakeholder engagement to explore and identify research priorities. Prioritized research questions can inform patient/consumer organizations, researchers, policy makers, and funding agencies in developing a shared CKD research agenda that is relevant to all stakeholders.

ACKNOWLEDGEMENTS

A full list of those involved in the priority-setting partnership workshop follows. Guests: Prof Chris Baggoley (Chief Medical Officer, Australian Government) and Dr Davina Ghersi (National Health and Medical Research Council). Participants: Adam Martin, Alan Cass, Amber Eggersdorff, Balaji Hiremagalur, Barbara Swift, Bill Handke, Carmel Hawley, Carol Pollock, Cheryl Hyde, Cynthia Morisey, Daniel Ussher, Daniella Dickenson, Dianna Fornasier, Fabian Marsden, Filomena Diaz, Gary Goodship, Germaine Wong, Gina Challita, Jacqui Ellis, Jane Nearhos, Jane Poon, Janine Jeffries, Jenny Best, Joe Hiltz, John Podolak, Karyn Smith, Kathy Kable, Keith Brenner, Kelly Lambert, Kendal Staveley, Laraine Aw, Laurence Howes, Lawrence Staveley, Loraine Chambers, Marilyn Velonas, Martin Chambers, Martin Gallagher, Mary McMenemy, Matthew Roberts, Maureen Lonergan, Neil Boudville, Neil Moorehead, Paul Swift, Phil Clayton, Raoul Odell-Moore, Richard Allen, Richard Muirden, Ron Wittman, Rowan Walker, Sarah Taylor, Shilpa Jesudason, Stephen McDonald, Steve Chadban, Sushma Mathur, Tanya Solomonov, Tristan Brenner, Vicki Velonas, and Wai Lim. Facilitators/Co-facilitators: Sally Crowe, Allison Tong, Angelique Ralph, Ann Jones, Camilla Hanson, David Tunnicliffe, Gabrielle Williams, Jonathan Craig, Kirsten Howard, Maleeka Ladhani, Shingisai Chando, and Sophie Hill. Observers: Anne Wilson, Chris Baggoley, Davina Ghersi, Luke Toy, and Tim Mathew.

Support: The study is funded by the National Health and Medical Research Council, The University of Sydney, and Kidney Health Australia. The funding organization had no role in the design and conduct of the study; data collection; management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript.

Financial Disclosure: The authors declare that they have no relevant financial interests.

SUPPLEMENTARY MATERIAL

Table S1: Facilitator question guide.
Table S2: Generation of research questions (phase 1).
Note: The supplementary material accompanying this article (http://dx.doi.org/10.1053/j.ajkd.2015.02.341) is available at www.ajkd.org

REFERENCES

1. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. *Lancet*. 2009;374(9683):86-89.
2. Richards T. Patients' priorities. *BMJ*. 1999;318(7179):277.
3. Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. *Lancet*. 2000;355(9220):2037-2040.
4. Chalmers I, Bracken MB, Djulbegovic B, et al. How to increase value and reduce waste when research priorities are set. *Lancet*. 2014;383(9912):156-165.
5. Caron-Flinterman JF, Broerse JE, Teerling J, Bunders JF. Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. *Health Expect*. 2005;8(3):253-263.
6. Bourne AM, Whittle SL, Richards BL, Maher CG, Buchbinder R. The scope, funding and publication of musculoskeletal clinical trials performed in Australia. *Med J Aust*. 2014;200(2):88-91.
7. Cheyne H, McCourt C, Semple K. Mother knows best: developing a consumer led, evidence informed, research agenda for maternity care. *Midwifery*. 2013;29(6):705-712.
8. Stewart RJ, Caird J, Oliver K, Oliver S. Patients' and clinicians' research priorities. *Health Expect*. 2010;14(4):439-448.
9. Thornton H. Patient and public involvement in clinical trials. *BMJ*. 2008;336(7650):903-904.
10. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA*. 2012;307(15):1583-1584.
11. Petit-Zeman S, Firkins L, Scadding JW. The James Lind Alliance: tackling research mismatches. *Lancet*. 2010;376(9742):667-669.
12. American Society of Nephrology. American Society of Nephrology Renal Research Report. *J Am Soc Nephrol*. 2005;16(7):1886-1903.
13. Crews DC, Greer RC, Fadrowski JJ, et al. Setting an agenda for comparative effectiveness systematic reviews in CKD care. *BMC Nephrol*. 2012;13:74.
14. Schipper K, Abma TA. Coping, family and mastery: top priorities for social science research by patients with chronic kidney disease. *Nephrol Dial Transplant*. 2011;26(10):3189-3195.
15. Tong A, Sainsbury P, Carter SM, et al. Patients' priorities for health research: focus group study of patients with chronic kidney disease. *Nephrol Dial Transplant*. 2008;23(10):3206-3214.
16. Kaskel F, Batlle D, Beddhu S, et al. Improving CKD therapies and care: a national dialogue. *Clin J Am Soc Nephrol*. 2014;9(4):815-817.
17. Tong A, Chando S, Crowe S, et al. Research priority setting in kidney disease [published online ahead of print January 9, 2015]. *Am J Kidney Dis*. http://dx.doi.org/10.1053/j.ajkd.2014.11.011.
18. Manns BF, Hemmelgarn B, Lillie E, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol*. 2014;9(10):1813-1821.

19. Pollock A, St George B, Fenton M, Crowe S, Firkins L. Development of a new model to engage patients and clinicians in setting research priorities. *J Health Serv Res Policy*. 2014;19(1):12-18.

20. Pollock A, St George B, Fenton M, Firkins L. Top 10 research priorities relating to life after stroke—consensus from stroke survivors, caregivers, and health professionals. *Int J Stroke*. 2014;9(3):313-320.

21. Gadsby R, Snow R, Daly AC, et al. Setting research priorities for type 1 diabetes. *Diabet Med*. 2012;29(10):1321-1326.

22. Eleftheriadou V, Whitton ME, Gawkrodger DJ, et al. Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. *Br J Dematol*. 2011;164(3):530-536.

23. Cowan K, Oliver S. *The James Lind Alliance Guidebook*. Oxford, UK: James Lind Alliance; 2013.

24. Batchelor JM, Ridd MJ, Clarke T, et al. The Eczema Priority Setting Partnership: a collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. *Br J Dermatol*. 2013;168(3):577-582.

25. Viergever RF, Olifson S, Ghaffar A, Terry RF. A checklist for health research priority setting: nine common themes of good practice. *Health Res Policy Syst*. 2010;8:36.

26. ANZDATA. *Thirty Fifth Annual Report*. Adelaide, Australia: Australian and New Zealand Dialysis and Transplant Registry; 2012.

27. Kidney Health Australia. Exploring research priorities in chronic kidney disease. http://www.kidney.org.au/LinkClick.aspx?fileticket=zZc%2FBcOhA%2BA%3D&tabid=635&mid=1837. Accessed January 27, 2015.

28. Corner J, Wright D, Hopkinson J, Gunaratnam Y, McDonald JW, Foster C. The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *Br J Cancer*. 2007;96(6):875-881.

29. Owens C, Ley A, Aitken P. Do different stakeholder groups share mental health research priorities? A four-arm Delphi study. *Health Expect*. 2008;11(4):418-431.

30. Block GA, Klassen PS, Lazarus JM, Ofsthun N, Lowrie EG, Chertow GM. Mineral metabolism, mortality, and morbidity in maintenance hemodialysis. *J Am Soc Nephrol*. 2004;15(8):2208-2218.

31. Foley RN, Collins AJ. End-stage renal disease in the United States: an update from the United States Renal Data System. *J Am Soc Nephrol*. 2007;25(6):2644-2648.

32. Green D, Roberts PR, New DI, Kalra PA. Sudden cardiac death in hemodialysis patients: an in-depth review. *Am J Kidney Dis*. 2011;57(6):921-929.

33. Davila-Seijo P, Hernández-Martín A, Morcillo-Makow E, et al. Prioritization of therapy uncertainties in dystrophic epidermolysis bullosa: where should research direct to? An example of priority setting partnership in very rare disorders [published online ahead of print April 22, 2013]. *Orphanet J Rare Dis*. http://dx.doi.org/10.1186/1750-1172-8-61.

34. Best S, Tate T, Noble B, et al. The palliative and end of life care priority setting partnership (peolcpsp): determining evidence uncertainties from the perspective of the end user of research [abstract]. *BMJ Support Palliat Care*. 2014;(suppl 1):A42.

35. Crowe S. *Setting Priorities for Treatment Uncertainties—A Review of Methods*. Oxford, UK: James Lind Alliance; 2009. http://www.lindalliance.org/pdfs/Methods_page/JLA_Priority_Setting_approaches_V2_Nov_09.pdf. Accessed June 24, 2014.

36. Ryan R, Santesso N, Lowe D, et al. Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews. *Cochrane Database Syst Rev*. 2014;4:CD007768.

37. Chesney RW, Brewer E, Moxey-Mims M, et al. Report of an NIH task force on research priorities in chronic kidney disease in children. *Pediatr Nephrol*. 2006;21(1):14-25.

38. Cass A, Lowell A, Christie M, et al. Sharing the true stories: improving communication between Aboriginal patients and healthcare workers. *Med J Aust*. 2002;176(10):466-470.

39. Rix EF, Barclay L, Stirling J, Tong A, Wilson S. 'Beats the alternative but it messes up your life': aboriginal people's experience of haemodialysis in rural Australia. *BMJ Open*. 2014;4(9):e006945.

40. Rix EF, Barclay L, Stirling J, Tong A, Wilson S. The perspectives of aboriginal patients and their health care providers on improving the quality of hemodialysis services: a qualitative study. *Hemodial Int*. 2015;19(1):80-89.

41. Anderson K, Devitt J, Cunningham J, Preece C, Cass A. "All they said was my kidneys were dead": indigenous Australian patients' understanding of their chronic kidney disease. *Med J Aust*. 2008;189(9):499-503.

42. Jamieson LM, Paradies YC, Eades S, et al. Ten principles relevant to health research among indigenous Australian populations. *Med J Aust*. 2012;197(1):16-18.

43. Sibbald SL, Singer PA, Upshur R, Martin DK. Priority setting: what constitutes success? A conceptual framework for successful priority setting. *BMC Health Serv Res*. 2009;9:43.

44. Hills S, Draper M. A new conceptual framework for advancing evidence-informed communication and participation. In: Hills S, ed. *The Knowledgeable Patient: Communication and Participation in Health*. Oxford, UK: Wiley Blackwell; 2011:12-26.