

# Exploring research priorities in chronic kidney disease

## Summary report



**“I enjoyed the opportunity to discuss CKD with other patients, carers, health professionals and being able to have input into research from a patient’s perspective. I certainly felt involved, and I was treated as an equal.”**

**“The value of any such day, is to learn from each other. With this gathering, all the perspectives can be built up to create a more complete picture.”**

**- Prof. Chris Baggoley CMO**  
Australian Government



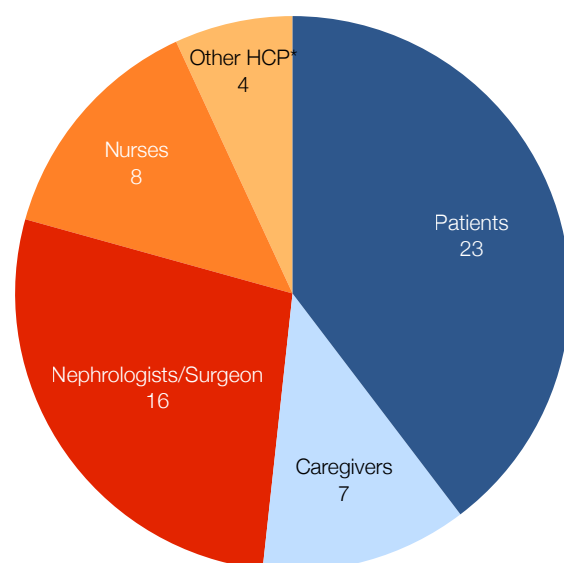
## PREAMBLE

A national workshop was convened on the 7th February 2014 at the Mercure Sydney Hotel to explore research priorities in chronic kidney disease. This report provides an overview of the participants, the process, and the preliminary results of the workshop.

## THE PARTICIPANTS

People living with chronic kidney disease, family caregivers, nephrologists, nurses, and allied health professionals participated in the workshop. Participants travelled from New South Wales, Victoria, Queensland, Northern Territory, South Australia, Western Australia and the Australian Capital Territory.

A total of 58 participants worked together to formulate, discuss and rank research questions.



\*Healthcare providers (HCP), includes allied health, researchers

# THE PROCESS

## Identifying questions

Participants were divided into groups of 8 to 10 and generated questions\* relating to:

- chronic kidney disease
- peritoneal dialysis
- haemodialysis
- transplantation

*\*Focussed on intervention*

## Choosing priority questions

Each participant had 5 votes (sticker dots). The top 10 questions with the most votes were chosen to be taken through to the next round.

## Voting by CKD stage

Each group discussed and ranked priorities for all four stages of CKD.

The top 5 ranked from each stage were chosen to be taken through to the next round.

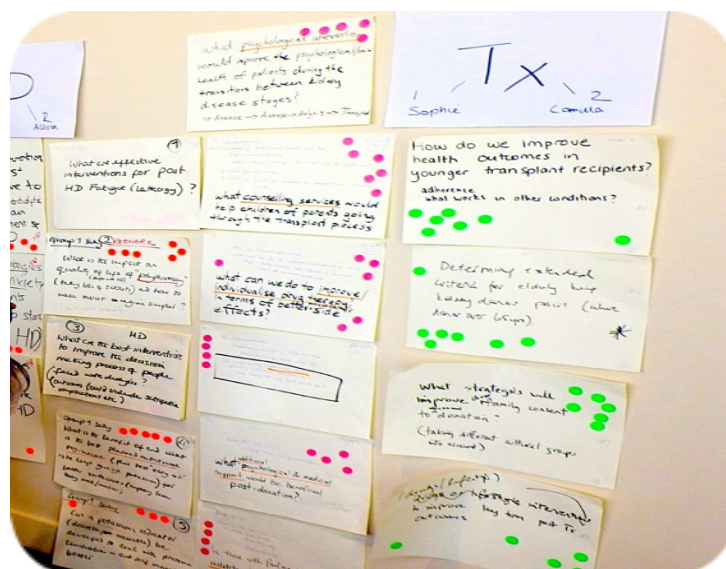
## Ranking the top 20 questions

Votes were summed and the top 5 questions from each stage of CKD were generated into a list of 20 questions.

Each participant individually ranked the top 20 questions from 1 (most important) to 20 (least important).



In total, **83** research questions were generated.





# THE TOP 10 QUESTIONS BY CKD STAGE

## 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 carers?
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 (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?

## HAEMODIALYSIS

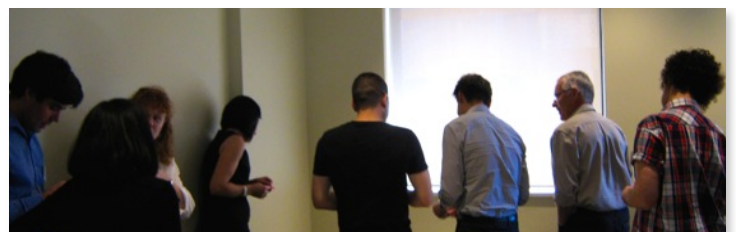
1. What is the impact of polypharmacy on quality of life; what is the best way to make tablet regimes simpler?
2. What are the best interventions to improve the decision making process of people faced with HD and to improve their satisfaction and reduce complications?
3. What is the benefit of and what 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 interdialytic weight gain in patients with HD?
10. Does implementing a personalised care plan increase QOL for patients on HD and their carers?

## 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 adult care?
4. How we can be best provide support services/tools to be integrated to patients/carers/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 programs are safe and most effective for PD patients?
8. Are there intervention 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 counselling to improve patient self-esteem?

## TRANSPLANTATION

1. What strategies will improve donor family consent to deceased donation, taking different cultural groups into account?
2. What interventions (medications, 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/individualise 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 donors?
8. Determining extended criteria for elderly donor recipient pairs (donors over 65 years)?
9. What counselling 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?



# RESEARCH PRIORITIES - YOUR TOP 20

1. How effective are lifestyle programs (diet, exercise and smoking cessation) for preventing deterioration in kidney function in patients with early CKD?
2. What interventions can improve long term post-transplant outcomes (drugs, lifestyle)?
3. What strategies will improve donor family consent to deceased donation taking different cultural groups into account?
4. What strategies help patients maintain work while on HD?
5. What can we do to improve and individualise drug therapy in terms of better management of side effects?
6. What are the effective interventions for post HD fatigue?
7. What psychological interventions would improve the psychological health for transition between kidney stages
8. How do we improve health outcomes in young transplant recipients?
9. What are the best interventions to improve the decision making process of people faced with HD?
10. Does active implementation of clinical practice guidelines in general practice improve kidney health in patients with early CKD?
11. How can we best provide support services to be integrated to patients, carers, and families to improve mental health in PD?
12. Do interventions that increase knowledge of support services and early referral practices increase quality of life in patients and carers?
13. Does implementing a personalised care plan increase quality of life for patients on HD and carers?
14. Does provision of culturally appropriate information about early CKD modify acknowledgement, medication adherence, and health service uptake in patients with early CKD?
15. What is the best diet and nutrition to improve general health outcomes for PD patients?
16. What interventions are most effective to reduce inter-dialytic weight gain?
17. Are electronic and social media an effective modality to deliver health promotion about CKD in the general population?
18. How can we best deliver staff education to reduce patient complications in PD?
19. What kinds of exercise programs are safe and most effective for PD patients?
20. How can technology be used to improve patient self-monitoring in PD?

\*Mean scores and distributions are provided in the Appendix

# IMPACT ON THE RESEARCH AGENDA

The prioritised list of research questions will be made available to researchers, policy makers, and funding agencies to help inform the development of a chronic kidney disease research agenda that is relevant to patients, caregivers, and health professionals. The full details on the methods and results of the workshop will be prepared for publication in medical journals. The workshop will also be presented at national and international conferences.

The following are some examples of how this priority setting partnership will help to drive the research agenda in chronic kidney disease:



## Kidney Health Australia (KHA)

“This priority setting exercise will prove most useful in assisting the choice of themes selected by the Australian Kidney Research Foundation for its initial focus. The views of patients in the direction of research support have been under represented in the past and this exercise helps redress that position.”

*- Tim Mathew, Medical Director*



## Australasian Kidney Trials Network (AKTN)

“The day proved very insightful. When patients and their caregivers were present in the process of assigning priorities, the outcomes of the discussion were very different compared to those arrived at by health professionals in isolation. The AKTN will be taking this into consideration in trial design: the need for attention to quality of life, symptom control, non-pharmacological interventions such as exercise, diet and nutrition, attention to cultural needs and the emphasis on psychological well-being, and psycho-social support delivery were the clearest messages on the day.”

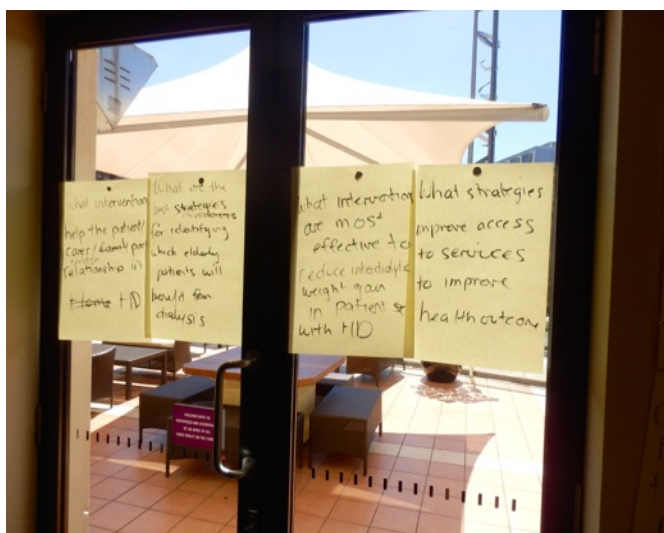
*- Carmel Hawley, Chair and Operations Secretariat*



## Cochrane Renal Group (CRG)

“The priorities developed by the workshop will help us to ensure our systematic reviews of research evidence address topics of concern to consumers, and ultimately show which areas of research should be pursued.”

*- Jonathan Craig, Coordinating Editor*



**“I’m hoping that other groups and other disease areas will learn from the experience that we’ve had here today and that more agencies will be performing priority setting exercises. I think policy makers and funding agencies will find it extremely useful.”**

**- Dr Davina Gherzi**

National Health and Medical Research Council

# ACKNOWLEDGEMENTS

We acknowledge the following people who contributed to the workshop:

## Guests

Professor Chris Baggoley, CMO, Australian Government  
Dr Davina Gherzi, National Health and Medical Research Council

## Participants

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## Facilitator

Sally Crowe

## Co-facilitators

Allison Tong, Angelique Ralph, Ann Jones, Camilla Hanson, David Tunnicliffe, Gabrielle Williams, Jonathan Craig, Kirsten Howard, Maleeka Ladhani, Shingisai Chando, Sophie Hill

## Observers

Anne Wilson, Chris Baggoley, Davina Gherzi, Luke Toy, Tim Mathew

## Collaborators

Andrew Wilson, Angela Webster, David Johnson, David Parker, Giovanni Strippoli, Jeremy Chapman, Jonathan Gillis, Kevan Polkinghorne, Peter Kerr, Vlado Perkovic

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# GLOSSARY

**Cardiovascular disease** Includes all diseases and conditions of the heart and blood vessels, such as arteries and veins. The most common disease and conditions include heart attack, heart failure, stroke, blockages in the blood vessels and vascular kidney disease.

**Chronic kidney disease (CKD)** A condition that causes reduced kidney function over a period of time. Usually, it is defined by having a glomerular filtration rate (GFR) of less than 60 mL/min/1.73 m<sup>2</sup> that is present for over 3 months.

**Dialysis** A treatment for kidney failure that removes waste products and extra water from the blood by filtering the blood through a special membrane to remove waste products.

**End-stage kidney disease (ESKD)** The stage in kidney disease when a person's kidneys have stopped working so treatment is needed to sustain life, such as dialysis or a transplant.

**Glomerular filtration rate (GFR)** The rate at which the kidneys filter wastes and extra fluid from the blood.

**Haemodialysis (HD)** A treatment for kidney failure. The patient's blood is pumped through special tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from the blood before returning it to the patient. Haemodialysis usually lasts for 4-6 hours and is done 3 or more times a week. Haemodialysis can be done in the hospital or at home.

**Interdialytic weight gain** Patients on haemodialysis have to restrict their fluid intake to prevent fluid overload. Interdialytic weight gain is usually the result of salt and water intake between two dialysis sessions. A volume overload may cause high blood pressure and heart problems.

**Intervention** In healthcare, an intervention can be any type of treatment, preventive care, test, program that a person could take or undergo to improve health or to help with a particular problem. Interventions include medications, foods, supplements, screening tests, hospital treatment, physical therapy, psychological or social support.

**Kidney function** Also known as renal function. This refers to how well the kidneys are filtering the blood. Kidney function is now calculated using a blood sample and a formula to find the estimated glomerular filtration rate (eGFR).

**Kidney transplantation** When a healthy kidney is taken from one person and surgically placed into someone with kidney failure. The kidney can come from a live or deceased donor. It is important to remember that a transplant is a treatment not a cure for kidney disease.

**Nephrologist** A doctor who specialises in kidney function.

**Outcome** The end result or consequence of an intervention.



**Peritoneal dialysis (PD)** In peritoneal dialysis, a fluid called dialysis solution is put into the abdomen to remove wastes and fluid from the blood. This fluid captures the waste products from a person's blood. After a few hours when the fluid is nearly saturated with wastes, the fluid is drained through a catheter.

**Personalised care plan** Personalised care planning aims to ensure that people with long term conditions are more involved in decisions about their care through a care planning discussion.

**Phosphate** A mineral, together with calcium, that keeps your bones strong and healthy. Too much phosphate causes itching and pain in the joints, such as the knees, elbows and ankles. When the kidneys are not functioning properly, high levels of phosphate accumulate in the blood.

**Polypharmacy** The use of multiple medications.

**Potassium** An essential mineral, which helps nerve endings and muscles to work. Potassium is usually removed by healthy kidneys. If your level of potassium is too high or low, it can cause an irregular heartbeat. Very high potassium levels may cause the heart to stop.

**Psychological impact** The way in which kidney disease and dialysis affect the emotions, mood and feelings of patients, their family and friends.

**Quality of life (QOL)** A person's general well-being.

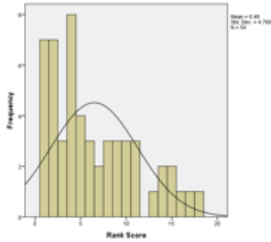
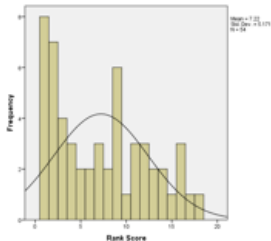
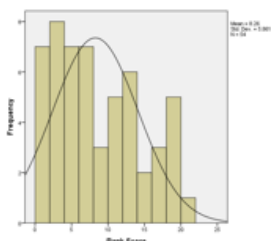
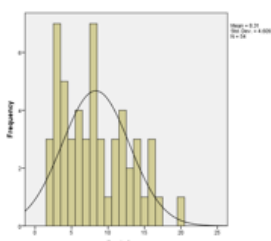
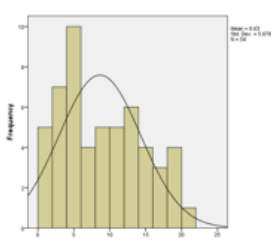
**Renal replacement therapy (RRT)** A term used to describe treatment (e.g. dialysis, kidney transplantation) for people with end-stage kidney disease.

**Social impact** The way in which kidney disease affects how patients interact with their family, friends and community.

\*Definitions adapted from Kidney Health Australia (<http://www.kidney.org.au>); National Kidney and Urologic Diseases Information Clearinghouse ([kidney.niddk.nih.gov](http://kidney.niddk.nih.gov))

# APPENDIX

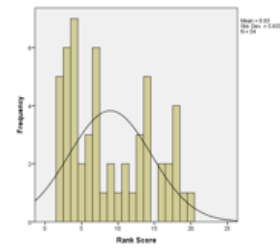
The “distribution of scores” graph shows the spread of all votes from 1 (most important) to 20 (least important).

Rank	Research question	Mean (SD) i.e average	Distribution of scores
1	How effective are lifestyle programs such as diet, exercise and smoking cessation for preventing deterioration in kidney function in patients with early CKD?	6.48 (4.77)	
2	What interventions can improve long term post-transplant outcomes (drugs, lifestyle)?	7.22 (5.17)	
3	What strategies will improve donor family consent to deceased donation taking different cultural groups into account?	8.26 (5.86)	
4	What strategies help patients maintain work while on HD?	8.31 (4.61))	
5	What can we do to improve and individualise drug therapy in terms of better management of side effects?	8.63 (5.68)	

6

What are the effective interventions  
for post HD fatigue?

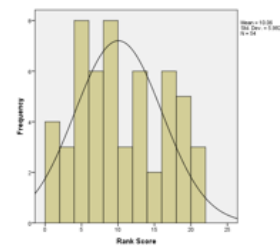
8.93 (5.63)



7

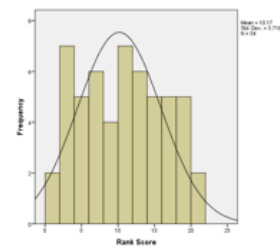
What psychological interventions  
would improve the psychological  
health for transition between kidney  
stages?

10.06 (5.98)



8

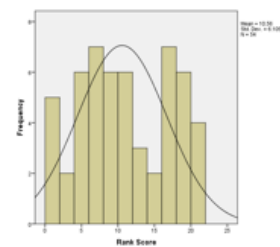
How do we improve health outcomes  
in young transplant recipients?

10.17  
( 5.72)

9

What are the best interventions to  
improve the decision making process  
of people faced with HD?

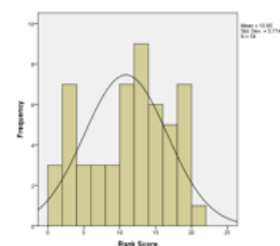
10.56 (6.11)



10

Does active implementation of clinical  
practice guidelines in general  
practice improve kidney health in  
patients with early CKD?

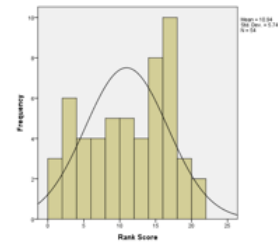
10.85 (5.77)



11

How can we best provide support services to be integrated to patients, carers, and families to improve mental health in PD?

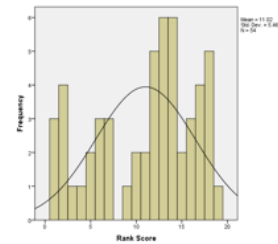
10.94 ( 5.74)



12

Does implementing a personalised care plan increase quality of life for patients on HD and carers?

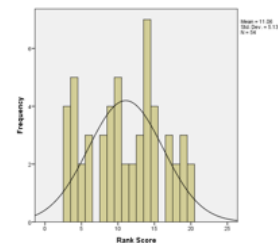
11.02 (5.46)



13

Do interventions that increase knowledge of support services and early referral practices increase quality of life in patients and carers?

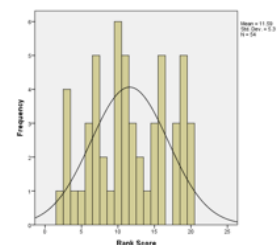
11.06 (5.13)



14

Does provision of culturally appropriate information about early CKD modify acknowledgement, medication adherence, and health service uptake in patients with early CKD?

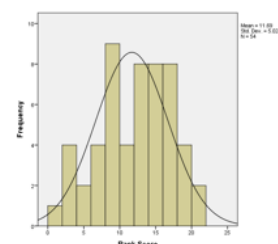
11.59 (5.3)



15

What is the best diet and nutrition to improve general health outcomes for PD patients?

11.69 (5.02)

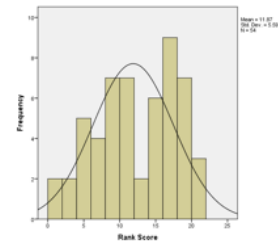




16

What interventions are most effective to reduce interdialytic weight gain?

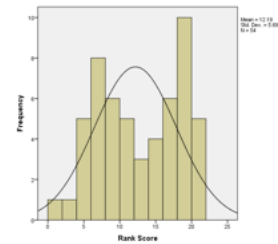
11.87 (5.59)



17

Are electronic and social media an effective modality to deliver health promotion about CKD in the general population?

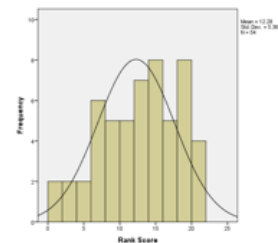
12.19 (5.70)



18

How can we best deliver staff education to reduce patient complications in PD?

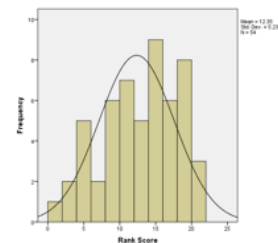
12.28 (5.36)



19

What kinds of exercise programs are safe and most effective for PD patients?

12.35 (5.24)



20

How can technology be used to improve patient self-monitoring in PD?

15.7 (4.75)

