



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

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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.

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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

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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

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