

# Determining the Research Priorities for Patients with Chronic Kidney Disease not on Dialysis

Hemmelgarn et al. (2017)  
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**For which topic were research priorities identified?**  
chronic kidney disease

**In which location was the research priority setting conducted?**  
North America - Canada

**Why was it conducted at all?**  
Similar to most other conditions, the chronic kidney disease (CKD) research agenda has traditionally been driven by investigators, as well as by commercial interests, resulting in studies that may not optimally inform patient care], or that fail to address the specific needs of those who are affected by the condition and make decisions about clinical care]. The importance of engaging the broader stakeholder community in determining research priorities has been recognized, with increasing emphasis on patient-centered care, defined as care that is respectful of patient preferences and in which patient values guide clinical decisions]. Involving patients and their caregivers as key stakeholders in determining research priorities has been identified as being of key importance, with the goal of building partnerships in research and health care.

**What was the objective?**  
to identify the top 10 research priorities for patients with non-dialysis chronic kidney disease, their caregivers, and the clinicians and policy-makers involved in their care

**What was the outcome?**  
a ranking list of 10 research questions

**How long did the research prioritization take?**  
No information provided.


**Which methods were used to identify research priorities?**  
JLA method

**How were the priorities for research identified exactly?**  
Step 1: collecting research uncertainties: survey to identify uncertainties about the overall management of non-dialysis CKD including diagnosis, prognosis and treatment issues, 2241 uncertainties submitted, additionally most recent clinical practice guidelines relevant to the care of patients with CKD not on dialysis searched to identify their recommendations for research, 15 uncertainties added. Step 2: data cleaning: categorizing submissions into one of 15 categories, indicative questions formulated, resulting in 1826 in-scope uncertainties. Step 3: interim ranking: summary document with 148 indicative questions circulated to steering group, members of steering group independently reviewed indicative questions and ranked their top 30, results collated and reported back to the steering group, in three conference calls steering group discussed indicative questions to achieve a consensus shortlist of 30. Step 4: final prioritization: workshop with nominal group technique: small and large group exercises to reach consensus

**Which stakeholders took part?**  
Patients with non-dialysis chronic kidney disease (CKD), their caregivers, and the clinicians and policy-makers. Survey: 439 participants: 272 (62%) patients, 37 (8%) caregivers, 112 (26%) clinicians/policymakers (28 physicians, 35 nurses, 12 policymakers). Workshop: 25 participants: 12 patients with non-dialysis CKD, 6 caregivers, 3 physicians, 2 nurses, 1 pharmacist, 1 policy-maker.

**How were stakeholders recruited?**  
The online survey was distributed through communications from the partner organizations (e.g. the Kidney Foundation of Canada), social media, and emails to members of the Canadian Society of Nephrology, the Canadian Association of Nephrology Nurses and Technologists, the Canadian Association of Dietitians and the Canadian Association of Nephrology Administrators. Paper-based surveys were distributed through CKD clinics. The Steering Group enlisted the support of nephrology networks, partner organizations and nephrologists from across Canada to identify potential participants for the workshop. Participants were required to be a member of a stakeholder group: patients with CKD; informal caregivers of persons with CKD (relatives, family members or friends who help patients manage their illness); healthcare professionals (primary care physicians, nephrologists, nurses, pharmacists, social workers or dietitians) who care for patients with CKD; or health policy-makers (nonclinicians with the ability to influence or determine policies and practices related to healthcare delivery for CKD).

**Were stakeholders actively involved or did they just participate?**  
Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 12 members: patients with dialysis CKD, 1 caregiver, clinicians (nephrologists), researchers and 1 employee of the Kidney Foundation of Canada. The steering group held bi-weekly conference calls to oversee the process, participated in data processing and the identification of research priorities. 29 participants of the study identified the highest priority research questions.

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