

Setting Research Priorities for Patients on or Nearing Dialysis

Manns et al. (2014)

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For which topic were research priorities identified?

patients on or nearing dialysis

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

With increasing emphasis among health care providers and funders on patient-centered care, it follows that patients and their caregivers should be included when priorities for research are being established.

What was the objective?

to identify the most important unanswered questions about the management of kidney failure

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: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting uncertainties: via survey, stakeholders asked to submit uncertainties, additionally searching most recent guidelines relevant to care of patients receiving dialysis to identify research topics, 1820 uncertainties submitted. Step 3: data processing: out-of-scope removed, duplicates combined, identifying 85 unique summary questions from survey submissions and 30 unique summary questions from guidelines, summary document then prepared with all uncertainties including number of times uncertainty was identified by patients, caregivers, and clinicians and whether it was identified from a clinical practice guideline. Step 4: interim ranking: summary document circulated to steering group, relative importance and wording of uncertainties were discussed, resulting in shortlist of 30 uncertainties to be considered at workshop. Step 5: final prioritization: workshop: with nominal group technique, small group and large group discussions and rankings

Which stakeholders took part?

Adult patients on or nearing dialysis, their caregivers, and the healthcare professionals who care for these patients. Survey: 317 participants: 173 (54.6%) patients, 37 (12%) caregivers, and 107 (34%) healthcare professionals (25 [23%] physicians and 38 [36%] nurses). Workshop: 34 participants: 11 patients, 5 caregivers, 8 physicians, 6 nurses, 1 social worker, 1 pharmacist, 1 physiotherapist, 1 dietitian.

How were stakeholders recruited?

Patients, caregivers, and clinicians were invited to complete the online survey through communications from the partner organizations (e.g., the Kidney Foundation of Canada), and emails to members of the Canadian Society of Nephrology and Canadian Association of Nephrology Nurses and Technologists. The project team also distributed paper-based surveys in 10 Canadian hemodialysis centers and three severe CKD and peritoneal dialysis clinics.

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 11 members: patients, 1 caregiver, clinicians, 1 employee of the Kidney Foundation of Canada, 1 expert in the James Lind Alliance approach. The members held biweekly conference calls to oversee the process, were involved in data processing and the interim ranking and chose the top 30 uncertainties for the workshop.