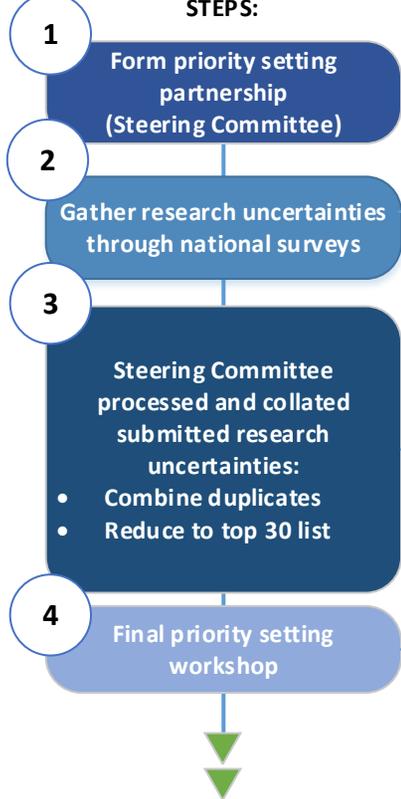


**James Lind Alliance Research
Priority Setting Methods*
STEPS:**



Process for eliciting the top 10 research priorities of patients with early and advanced CKD

CKD non-dialysis

**Steering Committee:
6 patients, 3 clinician scientists, 1 KFOC representative**

**309 patients and caregivers surveyed
2241 priorities identified**

148 unique research priorities identified

12 patients, 6 caregivers, 7 health care professionals

Top 10 Research priorities

1. What are the most effective new interventions and treatments to prevent the development and progression of kidney disease?
2. What is the best diet to slow progression of kidney disease and what are the benefits and risks of specific diets (i.e. phosphate restriction, protein restriction, low salt, etc.) in terms of kidney disease progression and quality-of-life?
3. What are the causes of symptoms in patients with chronic kidney disease, including fatigue, low energy, sleeping problems, depression, anxiety and sexual dysfunction, and how can these best be treated to improve quality of life?
4. What are the optimal strategies, such as having access to health information (e.g., lab test results), sharing of information, and/or improving communication, to help patients manage their health condition(s) themselves and to improve patient experience and outcomes.
5. What is the impact of lifestyle factors (i.e., exercise, stress) on risk of developing kidney disease, kidney disease progression and quality of life?
6. What are the optimal strategies for the management of CKD (i.e., those undertaken by the primary care physician, nephrologist, other health care professionals) to delay progression and improve outcomes?
7. What are the harmful effects of medications used in patients with CKD, and in particular the combinations of medications used to treat other diseases (such as diabetes and high blood pressure)?
8. What are the optimal approaches for the prevention and treatment of cardiovascular disease in patients with CKD?
9. What is the best strategy (e.g., screening, programs targeting high-risk groups, programs to increase public awareness) to identify kidney disease early?
10. How do we ensure that patients with CKD have equitable access to care (e.g. nephrologists, allied health clinics) irrespective of location of residence or socioeconomic status?

CKD dialysis

**Steering Committee:
5 patients, 4 clinician scientists, 1 KFOC representative**

**210 patients and caregivers surveyed
1570 priorities identified**

259 unique research priorities identified

11 patients, 5 caregivers, 18 health care professionals

Top 10 Research priorities

1. What is the best way to enhance communication between health care professionals and patients and to maximize patient participation in decision-making with regards to the advantages and disadvantages of different forms of dialysis, and access to test results to facilitate self-management?
2. How do different dialysis modalities compare in terms of their impact on quality-of-life, mortality and patient acceptability, and are there specific patient factors that make one modality better for some patients with kidney failure than others?
3. What are the causes and effective treatment(s) of, and ways to prevent, itching in dialysis patients?
4. What is the best strategy to increase kidney transplantation; including access to transplantation, increasing the efficiency of the recipient workup, and increasing the availability of donor kidneys?
5. What is the psychological and social impact of kidney failure on patients, their family, and other caregivers, and can this be reduced?
6. What are the best ways to promote heart health in dialysis patients, including management of blood pressure?
7. For people with kidney failure, what is the impact of each of the dietary restrictions (sodium, potassium, phosphate) separately, and when taken in combination, on important outcomes including quality-of-life?
8. What are the best ways to manage symptoms in people on or nearing dialysis including poor energy, nausea, cramping, and restless legs?
9. What are the causes and effective treatment(s) of depression in dialysis patients?
10. What is the best vascular access (among both new and existing types of access) for people on hemodialysis?

*(The James Lind Alliance Guidebook. Oxford, UK: James Lind Alliance, 2013.)