

DETERMINING THE RESEARCH PRIORITIES FOR ADULT PATIENTS WITH CHRONIC KIDNEY DISEASE (CKD) NOT ON DIALYSIS

Patients, caregivers, providers, and policy makers helped us identify the most important unanswered research questions about the management of patients with chronic kidney disease (not yet on dialysis)

BACKGROUND

From December 2014 to February 2015 a national survey of patients with non-dialysis CKD, caregivers, and the clinicians and policy-makers involved in their care, was conducted to determine the research priorities for adult patients with CKD not on dialysis.

In total, 439 individuals from across Canada responded to the survey and identified 1,811 uncertainties.

Two groups participated; an **in-person group workshop** (25 people) was held on June 11, 2015 to finalize the top 10 uncertainties that were of greatest importance to patients with CKD. A second group of 26 people also reviewed the top 30 uncertainties and undertook a similar, independent ranking exercise using an **online Wiki-like tool**.

RESULTS

Both groups ranked the same item as the top research priority – “What are the most effective interventions and treatments to prevent the development and progression of kidney disease?”

Of the top 10 research priorities ranked by the Wiki Group, 5 research priorities were also ranked within the top 10 identified in the in-person group workshop. These priorities address dietary measures to slow CKD progression, CKD symptoms, and the impact of lifestyle factors and medications on kidney disease.

The infographic and table (on page 2) provide a summary of the 2 different priority setting exercises. For more information please go to the CANN-NET website www.cann-net.ca



WHAT'S NEXT?

We will continue to work with stakeholders and policy makers to ensure that the identified research priorities are addressed.

In-person workshop group ranking	Wiki rank	Online wiki-based group ranking	Workshop rank
1. What are the most effective new interventions and treatments to prevent the development and progression of kidney disease?	1	1. What are the most effective new interventions and treatments to prevent the development and progression of kidney disease?	1
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?	6	2. 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)?	7
3. What are the causes of symptoms in patients with CKD, including fatigue, low energy, sleeping problems, depression, anxiety and sexual dysfunction, and how can these best be treated to improve quality of life?	8	3. What are the best signs or markers (i.e. blood tests, urine tests or other tests) to identify and diagnose kidney disease early?	14
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?	-	4. What are the benefits and risks associated with use of vitamins, supplements and alternative/complementary therapies (i.e. herbal, naturopathic, marijuana etc.) in terms of kidney disease progression and quality of life?	11
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?	9	5. How can we predict how fast kidney function will get worse, and when kidneys will fail?	13
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?	-	6. 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?	2
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)?	2	7. What are the optimal medications (e.g. ACE inhibitors, ARBs, phosphate binders, sodium bicarbonate, etc.) to slow progression of kidney disease?	19
8. What are the optimal approaches for the prevention and treatment of cardiovascular disease in patients with CKD?	-	8. What are the causes of symptoms in patients with CKD, including fatigue, low energy, sleeping problems, depression, anxiety and sexual dysfunction, and how can these best be treated to improve quality of life?	3
9. What is the best strategy (e.g. screening, programs targeting high risk groups, programs to increase public awareness) to identify kidney disease early?	-	9. What is the impact of lifestyle factors (i.e. exercise, stress) on risk of developing kidney disease, kidney disease progression, and quality of life?	5
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 socio-economic status?	-	10. How can communication regarding patient care be improved and/or streamlined across all disciplines (primary care, nephrology, allied health) to improve outcomes and the patient experience?	12