



# **The Kidney Foundation of Canada**

## **HORIZONS**

### **Strategic Research Framework 2019-2024**

## **Kidney Foundation of Canada**

### **Our Vision for Public Impact:**

The Kidney Foundation of Canada strives for excellent kidney health, optimal quality of life and a cure for kidney disease.

### **Our Organizational Vision:**

The Kidney Foundation of Canada is the key national voice and volunteer organization for kidney health. We are collaborative, passionate, and impactful.

### **Our Mission:**

The Kidney Foundation of Canada is the national volunteer organization committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality healthcare; and
- Increasing public awareness and commitment to advancing kidney health and organ donation

## INTRODUCTION

The Kidney Foundation of Canada (KFOC) has developed a strategic plan for 2018-2022. The vision is *“The Kidney Foundation of Canada strives for excellent kidney health, optimal quality of life and a cure for kidney disease”*. In addition, the specific strategic priority related to research is *“Invest strategically in research to improve patient outcomes and find a cure.”*

The objectives related to this priority are:

- The KFOC has a strategy to fund research that will have the greatest impact on patient outcomes, including a cure.
- The research strategy includes investigator-initiated and priority-driven funding across the four research pillars (biomedical, clinical, translational, and population and public health)
- Partnering on transformational and/or innovative research networks
- Impact of research on patient outcomes is better understood and leads to increased financial support
- KFOC can fund more research and leverage research partnerships that will have an impact on patient outcomes
- The KFOC is a partner in key research networks, innovative research, and clinical trials that will have a significant impact on patient outcomes and/or lead to a cure.
- Kidney and transplant research and researchers are well supported
- Patients have a role in research decisions
- Research findings are shared and improve clinical practice

This research framework responds to the first two objectives above “The KFOC has a strategy to fund research that will have the greatest impact on patient outcomes, including a cure” and “The research strategy includes investigator-initiated and priority-driven funding across the four research pillars)”. This document provides the Foundation with a research framework that will help KFOC accomplish its’ research objectives.

## BACKGROUND

In May 2017, over 50 patients, care-givers, researchers, health care providers, decision makers and funders gathered at a workshop to discuss, strategize and brainstorm about the future of kidney research in Canada.

Participants at the workshop concluded that the kidney community did not need a new specific targeted, large investment, rather the kidney community already has the key elements that are needed for success. The HORIZONS participants were unanimous in their belief that instead of a new targeted initiative, the community needs to bridge the remaining silos, connect the disparate pieces, and integrate incoherent data and systems. The goal is to expand, scale up, strengthen, connect and create much greater access to - and impact from - the successful kidney research platforms already in place. The HORIZONS participants believed that the kidney community must embrace a bold vision: the time has come to seek **a cure**, not just incremental improvement. To get there, we need to drive change not just in research, but in health care, in funding, and in policy.

While the HORIZONS workshop engendered excellent discussions, the outcomes were broad and it was clear that additional discussion was required. As a result, the HORIZONS Working Group was formed in the spring of 2018. This Working Group was comprised of 12 members of the kidney community and

met once every six weeks for approximately one year to continue the conversation that was started at the HORIZONS 2022 workshop. (Please see Appendix B for a list of Working Group members).

**The goal of the Working Group was to help the KFOC develop research priorities and a strategic research framework to best advance KFOC's mission to fund and stimulate innovative research for better treatments and a cure for kidney disease.**

Before they began their discussions, Working Group members requested information to gain a better understanding of the landscape of current kidney research funding. The group asked for the following additional information to help inform their input to the KFOC:

1. An overview of the current KFOC research competitions and funding;
2. Background on the types and themes of research funded each year by the Foundation;
3. The strategic plan developed by KFOC;
4. The results of past prioritization exercises (James Lind Alliance exercises & past KFOC surveys);
5. A review and summary of the content of Canadian and International kidney-related meetings (i.e. CSN, ASN, CST & CNTRP); and
6. The results of key informant interviews related to Gaps and Innovative Kidney Research.

Armed with this information, several discussions were held by teleconference between May 2018 and April 2019.

## RESULTS

It is recommended that KFOC continue funding research through the current suite of programs (The Biomedical Research Grant competition, the KRESCENT competition and the Allied Health Competition) as each of these competitions responds to a specific need of the community.

The following strategic research priority areas were recommended for KFOC:

### Research Priority Areas:

1. Stakeholder-identified priorities: Priorities identified through all kidney-related James Lind Alliance exercises, as well as those identified through KFOC surveys & HORIZONS 2022 workshop. A list of these specific priorities is included in Appendix A and they have been grouped into 5 themes:
  - i. Communication & Connectivity
  - ii. Health System Approaches
  - iii. Promoting Health & Quality of Life
  - iv. Keeping your Kidneys Healthy
  - v. Treatment of Kidney DiseaseThese priorities also include “gap areas” identified: clinical trials; prevention, including personalized treatment and health.
2. Cutting edge/innovative/high risk research: This includes research that is revolutionary, unique and potentially unconventional.<sup>1</sup> These are ideas that have the potential for high impact, but that may be too novel, span too diverse a range of disciplines, or be at a stage

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<sup>1</sup> Adapted from <https://www.sisinternational.com/solutions/innovation/innovation-research/> SIS International Research

too early to fare well in the traditional peer review process<sup>2</sup>. Specific examples provided by the Working Group include: Innovative Organ Replacement Strategies such as research into stem cells, artificial organs, artificial intelligence and wearable technologies.

3. Highlighting Kidney Health: While 1 in 10 individuals in Canada are affected by kidney disease, it remains an under-recognized and misunderstood chronic condition. The need to bring evidence to bear on the burden and prevalence of kidney disease and the impact of the disease on the individual, the health system, and Canada, is clear. Research in this priority area will help bring kidney disease out of the shadows and will help highlight the need for increased research and funding in nephrology.

*Cross cutting themes: Indigenous & Pediatric health, gender equity*

#### **Use of Priorities:**

The strategic research priorities will be used to:

1. Inform research funding. (Researchers will be asked to explain how their research falls into one of the identified priority areas when they apply to a KFOC-led research competition. In addition to the usual evaluation parameters, grant evaluation will assess the degree to which a proposal has the potential to address need in one of these priority areas.)
2. Create yearly “priority announcements” with dedicated funding towards one of these strategic research areas; and
3. Assess future partnership opportunities.

#### **Investments in large pan-Canadian Kidney Networks & Initiatives:**

KFOC is a partner in several large research networks and kidney related initiatives (Can-SOLVE CKD, CDTRP, KRESCENT) and it is agreed that investing in and supporting these networks has been and will continue to be highly beneficial for kidney patients. KFOC must continue to be proactive in funding, promoting, and supporting initiatives that align with KFOC strategic priorities and that will have long term benefits for kidney patients.

#### **International Partnerships and Collaboration:**

As a Canadian Foundation, supported by Canadian patients, researchers, clinicians and the public, it is important that KFOC funding be provided to support the work of Canadian researchers as they are best positioned to develop and evaluate interventions relevant to Canadians living with kidney disease and in recognition that obtaining limited funding in Canada is challenging. However, international partnership and collaborations can be encouraged as they: may open up new forms of kidney research for Canadians; allow Canadian researchers access technologies and expertise that may not be available in Canada; strengthen the work conducted in Canada; validate findings from Canadian research; and help spread Canadian Kidney Research Innovations globally. These international collaborations are encouraged, as long as the funding remains with Canadian research institutions and researchers.

#### **Marketing and Fundraising:**

The Working Group agreed strongly with the outcome of the HORIZONS 2022 workshop and indicated that marketing and fundraising was another priority area for the Kidney Foundation’s research program. Even if celebrities have a transplant (i.e. Selena Gomez) the message that is translated to the public is that the individual has received a transplant and that they can now live a “normal” life. This is simply not

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<sup>2</sup>Adapted from <https://www.nap.edu/ead/11463/chapter/23> National Academies of Science, Engineering & Medicine

the reality for most Canadians living with kidney disease. Waiting lists for a kidney transplant are long, not everyone is eligible for a transplant and even after receiving a transplant, life is far from normal with medications, complications, and occasionally, rejection of the transplanted organ. In fact, end stage kidney disease has a quality of life similar to end stage cancer, and yet these harsh facts are not recognized. Kidney disease remains a mystery for the majority of Canadians. The need for more research and a greater understanding of kidney disease is evident.

KFOC must work with the community (patients, researchers, policy- and decision-makers, clinicians and the allied health professionals) to highlight the need for more research and to promote a greater understanding of kidney disease.

**APPENDIX A**  
**Strategic Kidney Research Priorities**

<b>THEME</b>	<b>RESEARCH PRIORITIES</b>
Communication & Connectivity	Enhancing communication between health care professionals and patients for patient-centered* care
	Improving patient access to health information to enhance ability to manage their health condition(s)
	Exploring patient-centered health care to maximize patient participation, optimize self-management and improve efficiency of the health care system.
Health System Approaches	Exploring strategies to increase kidney transplantation and workup efficiency
	Developing criteria for organs to reliably predict suitability of organs for transplantation, and to predict outcomes. Developing tests to determine patient suitability for transplant.
	Ensuring equitable access to kidney health care (e.g. nephrologists, allied health clinics) for all Canadians living with CKD. Determining best methods for equitable allocation of donor kidneys
	Determining parameters to better match organs to recipients to improve overall outcomes (for example by age, nephron dosing)
Promoting Health & Quality of Life	Customizing dialysis modalities based on impact on quality of life, patient acceptability, specific patient factors and mortality.
	Preventing, determining causes, and treating itching in dialysis patients.
	Managing psychological and social impacts of kidney disease on patients, their families, and other caregivers.
	Determining the impact of dietary restrictions (sodium, potassium, phosphate) on outcomes including quality of life.
	Understanding and managing the causes and symptoms in CKD and/or dialysis patients including poor energy, nausea, cramping, depression/anxiety, sexual dysfunction, and restless legs.
	Exploring the impact of lifestyle factors (i.e. exercise, stress) on the risk of developing kidney disease, kidney disease progression and quality of life.
	Establishing treatments that work best to prolong the life of the kidney transplant & personalizing immunosuppression for patients to improve the results of transplantation

Keeping your Kidneys Healthy/Well (Previously: Prevention & slowing progress)	Promoting of heart health in kidney patients, including management of blood pressure. Exploring optimal approaches for the prevention and treatment of cardiovascular disease in patients with CKD.
	Investigating new interventions, strategies and treatments to prevent the development and slow the progression of kidney disease and improve outcomes.
	Individualizing the best diet to slow progression of kidney disease. Determining 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.
	Increasing education of kidney disease (e.g. screening, programs targeting high risk groups, programs to increase public awareness).
Treatment of Kidney Disease & side effects	Investigating the best vascular access (among both new and existing types) for people on hemodialysis.
	Identifying harmful effects of medications and polypharmacy/combinations of medications used in patients with CKD.
	Determining the best way to treat vascular or antibody mediated rejection.
	Preventing sensitisation in patients with a failing transplant, to improve their chances of another successful transplant. (e.g. removal of the transplant, withdrawal of immunosuppressive medicines or continuation of these medicines)
	Stratifying patients who are unsuitable for transplant (considering factors such as age, body mass index, history of cancer, co-morbidities?)

\*Patient-centered care is defined as: “In patient-centered care, an individual’s specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements. Patients are partners with their health care providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective.”<sup>3</sup> This term encompasses other terminology like person-centered or person-directed care. Additionally, “ the term patient is overarching and is inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.”<sup>4</sup>

<sup>3</sup> New England Journal of Medicine Catalyst, accessed at <https://catalyst.nejm.org/what-is-patient-centered-care/> April 8, 2019

<sup>4</sup> Canadian Institutes of Health Research, Strategy for Patient-Oriented Research, accessed at <http://www.cihr-irsc.gc.ca/e/45851.html>, April 11, 2019.



**APPENDIX B**  
**HORIZONS Working Group members**

**WG Members at a glance:**

Mary Beaucage, Ontario	Justin Chun, Alberta
Catherine Dunn, Ontario	Meghan Elliott Alberta
Elisabeth Fowler, Ontario	David Hartell, Ontario
Matt James, Alberta	Ana Konvalika, Ontario
Christine Marquis, Quebec	Tomoko Takano, Quebec
Karthik Tennankore, Nova Scotia	Nancy Verdin, Alberta
Cathy Woods, Manitoba	

- Mary Beaucage, kidney patient, living donor kidney transplant recipient
- Justin Chun, Clinical Assistant Professor and Nephrologist at the University of Calgary and Alberta Health Services
- Catherine Dunn, parent & care-giver
- Meghan Elliott, Clinical Assistant Professor, Department of Medicine, University of Calgary
- Elisabeth Fowler, National Director of Research, Kidney Foundation of Canada
- David Hartell, Executive Director, Canadian Donation and Transplantation Research Program
- Matthew James, Associate Professor, Community Health Sciences Department, University of Calgary
- Ana Konvalinka, Scientist, Toronto General Hospital Research Institute
- Christine Marquis, Associate, Research Programs, Kidney Foundation of Canada
- Tomoko Takano, Professor/Senior Scientist, Division of Nephrology, McGill University Health Center
- Karthik Tennankore, Associate Professor, Division of Nephrology, Department of Medicine, Department of Surgery, Dalhousie University.
- Nancy Verdin, occupational therapist, kidney patient
- Cathy Woods, Anishinaabe kidney patient.