



The foundation of kidney care.

horizons
2022

ENHANCING EXCELLENCE
AND CAPACITY
IN KIDNEY RESEARCH



2017 Workshop Report

In partnership with:



CIHR IRSC
Canadian Institutes of Health Research
Institut de recherche en santé du Canada



Canadian Society of Nephrology/
Société canadienne de néphrologie
CSN/SCN

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IN 2016, THE KIDNEY FOUNDATION PROVIDED FUNDING TO:

68

Principal Applicants

60

Co-Applicants

147

Collaborators

32

Research Institutions

6

Provinces

2

Alport Syndrome Awards

20

Biomedical Grants

20

KRESCENT Awards

5

Allied Health Awards

The Kidney Foundation funds research across the spectrum of kidney disease. The areas of research funded in 2016 include:

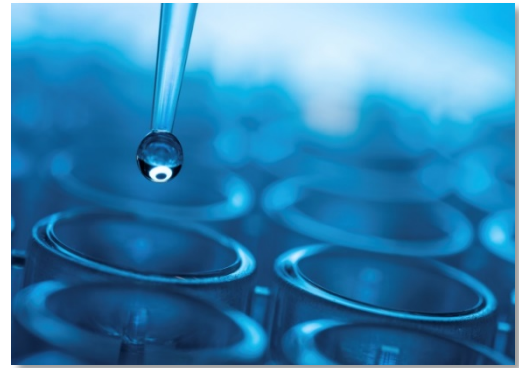
- Patient-Oriented Research
- Renal Failure
- Diabetes
- Kidney Biology
- Transplantation
- Genetics
- Kidney Development
- Glomerulonephritis
- Quality of Life
- Hypertension

Background

The goal of the **HORIZONS 2022** workshop was to bring together members of the kidney community to discuss, strategize and brainstorm about the future of kidney research in Canada.

Specific Objectives:

- To identify shared research goals based on the most critical Canadian health needs and research questions;
- To identify shared strengths and barriers to achieving those goals; and
- To identify innovative models of partnerships and funding to support those goals, including the Kidney Foundation of Canada's role.



On May 11-12, 2017, over 50 participants gathered to discuss the future of the kidney research community in Canada. Participants included patients, care-givers, researchers from all four pillars, health care providers, decision makers and funders. (*Please see **Appendix 1** for a full list of participants*).

Pre-workshop Survey

Prior to the workshop, a survey was sent to a broad group of stakeholders (*please see **Appendix 2***) to gather opinions and views regarding what they consider to be the most important issues for kidney research now and in the near future. A total of 222 respondents completed the survey, with the largest groups of respondents being patients, researchers and health care providers.

The main themes identified by the respondents included:

- Prevention/Detection: to prevent or slow the development and progress of kidney disease, and early detection and education);
- Treatment: including a better dialysis experience, management of kidney disease, eliminating (or fewer) side effects of anti-rejection drugs post-transplant;
- Technology: making better use of technology to improve kidney health, including artificial kidneys, 3D printers, portable dialysis machines, stem cells.
- Health system approaches: shorter/elimination of wait lists for transplantation, increase donors for transplantation, and patient-centered health care.

These priorities were taken into account by participants during the deliberations, as were the priorities identified by patients and providers during the two iterations of the James Lind Alliance¹ experiences that had been completed by kidney patients in the past.

Keynote Speaker

The evening prior to the workshop, a networking event was held and keynote speaker Dr. David Naylor provided a presentation titled "*Looking to the Future: Key Research Funding Priorities, Options and Strategies*". In his presentation, Dr. Naylor provided an overview of the results of the recently completed Fundamental Science Review², as well as his thoughts on research and health systems in Canada, highlighting areas where Canada is doing well, and also areas where we can improve. Canada is falling behind in overall ranking of health care compared to similar countries; similarly, we are falling behind in health research funding. Dr. Naylor also discussed the fact that Canadian patients have very little electronic access to the health system, which presents both a significant challenge and an opportunity. This high-level discussion helped set the stage for discussions during the workshop the following day.

¹ <https://www.kidney.ca/cann-net/research-priorities> and <https://www.kidney.ca/determining-ckd-research-priorities>

² <http://www.sciencereview.ca/eic/site/059.nsf/eng/home>



The workshop was structured to allow for a maximum amount of time to be spent in deliberations and discussion by participants. As such, presentations were limited to two panels: one that provided an overview of current kidney initiatives, highlighting impacts and lessons learned, and one in the afternoon that discussed innovative funding models and opportunities for the future. The purpose of the panel presentations and group discussions were to identify how the community can collectively continue to pursue excellence in kidney research, and improve lives for Canadians living with and affected by kidney disease.

Outcomes / Discussion

The discussions were wide-ranging, inclusive and energetic. Participants concluded that while outcomes for people living with kidney disease have improved over the last five decades, the basic approaches to manage and treat kidney disease have not changed significantly. By and large, the focus is on management, control, and incremental enhancements. It is time, the group unequivocally agreed, to say - and to *believe* - that we can do much more. The group agreed to be transformational, creative, culture-changing and paradigm-shifting. We will change *how* we work, so that we can start imagining **a future without kidney disease**.

The most critical conclusion of the day was that the kidney community did not need a new specific targeted investment. The kidney community already has the key elements that are needed for success. Topmost among these are the three strong, successful, critical kidney research platforms inspired by previous HORIZONS meetings: KRESCENT, Can-SOLVE CKD and CNRTP, supported by the network built through CANN-NET. However, these cores of excellence exist in a sea of fragmentation. The HORIZONS participants were therefore unanimous that instead of a new targeted initiative, we need 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 three successful kidney research platforms already in place.

Connectivity (“CAN-Connect”):

Connectivity was a major theme that emerged frequently throughout the day and covered a variety of issues. For example:

- **Connectivity of patients and the community:** Integrate patients, family and caregivers into everything researchers and care teams do, within and across primary and specialist care teams, and between these and research teams
- **Cross-provincial-border connectivity:** How can we make it easier for patients and donors living in different provinces to cross provincial borders? Work-up for transplantation when the patient and donor are in different provinces must go more quickly, more smoothly.
- **Data connectivity:** How can researchers and physicians access health data from different provinces in a more streamlined manner? Can we capture the Canadian strength of collaboration by defining common data sets, and through connecting data sets? Can we enhance privacy, ethics and other policy to better meet patient needs? Is there a way to create a connected biorepository? Policies that support “biopsy for all”?
- **Connectivity to health care providers:** How can we use new technologies to create an on-line system that will allow patients to make and engage in appointments with their physicians via electronic means. All patients would have equal access to high-quality care, timely regardless of where they live. Providers could share data and learn from each other. In addition, having a system where disparate health providers can access patient information would be enormously beneficial and would reduce duplication of tests and save time and costs for the patient and providers. Participant Quote: “It would be wonderful if providers work as a coherent team, providing seamless care for the patient across primary and specialized care.”

“This disease impacts your life in so many ways, so having an easy way to make appointments would be a game changer.”

- Connectivity to other data providers and partners: For example, how can we work more closely with the Canadian Institute of Health Information (CIHI)? It was suggested that CIHI could be the spine that connects us, a ‘common backbone’ to support a national data strategy.
- Connectivity through non-traditional data gathering: Most Canadians have a cellular phone or wear a Fitbit (or other movement tracker) and these devices gather huge amounts of health data. Can we lead efforts in patient-centered/ patient-led data collection, control, sharing and use, and harness the power of these approaches for research?
- Connectivity of researchers across disciplines: How can we bridge the gap between researchers working in Pillars 1,2,3 and 4? How can we bridge the gap between researchers working within other disciplines within and beyond health? (Such as engineering, mathematics, psychosocial sciences, etc.)
- Connectivity to other funders and other sectors: Increase the number of partnerships with other funding agencies, charities, government, industry, etc. to grow impact, explore alternative funding models for both research and health care.

“We have the key pieces, including three strong, successful critical platforms – but they exist in a sea of fragmentation. We need to bridge the silos, connect the disparate pieces, integrate incoherent data systems, in order to create much greater access to, and impact from, our key platforms.”

“CAN-MARKET” and “Saving Kidneys” or “End Dialysis”

The HORIZONS group believes 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: such change doesn’t happen easily, quickly, or cheaply. Major new resources will be required, not just to support the expanded research effort, but to drive the necessary systems changes. The group thus agreed that our goal is to **double funding for kidney research**. The group laid out a practical approach to achieve this vision: we called it “Can-Market”.

Can-Market aims to:

- Change our culture: a shift is needed in the culture of kidney disease. The community must stop being so quiet and “shy” about expressing the need and our desire to find a cure. We need to ignite people’s imaginations and start “Saving Kidneys”.
- Use new technologies: so many advances in technologies have taken place over the past few years and there is a need to harness these advances. Stem cells and advances in genomics and 3-D printing show great promise and will ignite imagination of patients and donors.
- Be the go-to info source: The current KFOC website has limited practical information for patients needing to navigate through the health system, nor does it adequately promote advances in research. The KFOC website can be the “face” that starts the culture change.
- Inclusiveness: Greater consultation and outreach to non-traditional partners and stakeholders is recommended. Ensuring that the full renal community is engaged and on-board with the “Can-MARKET” idea is important.
- Build on success: The renal community has shown enormous success through the creation of numerous initiatives and Networks (KRESCENT, Can-SOLVE CKD, CNTRP, CANN-NET). We have delivered on promises and shown results. This can be enormously powerful when creating our next set of goals and deliverables and when building our case for support.
- Double research funding in five years: this is a bold and transformative goal that could be achieved through the “Can-MARKET” initiative.

“Kidney disease has a marketing problem.”

“We need to be transformative, creative, imaginative, and build excitement!”

Next Steps

The following next steps were suggested:

1. The group agreed to send a letter to Government (Ministers Kirsty Duncan, Jane Philpott, Bill Morneau, and Prime Minister Justin Trudeau) expressing support for the *Fundamental Science Review* (David Naylor) report and the specific recommendation for a significant increase in funding for health research over the next five years.
2. Create a task force or working group to continue the conversation that began at the HORIZONS 2022 workshop. This working group will be tasked with:
 - a. Continuing the consultation process, bringing forward the themes identified at the workshop and gaining further input and buy-in from the wider renal community, and other communities. Investigate what other jurisdictions have done and learn from them (I.e. Dr. Robert Starr recently engaged in a similar exercise in the US.)
 - b. Identify the resources needed to develop the business plan, and specific next steps with leads

“We cannot cure kidney disease in five years. But we can look ahead to what it will take, identify the key changes we need to make in the way we work, set milestones in patient care, and measure our progress in the right direction.”

Future Work for this working group includes:

- **Business plan:** Create a business plan to convey our compelling value proposition: connecting, scaling up and sustaining three incredibly successful and proven platforms. Identify key roadblocks to systemic change, and how will we address them. Identify clear, measurable goals, milestones and deliverables (tangible metrics) for the short, medium and long term. This will allow KFOC to measure progress and to understand when the goal has been achieved. This will also allow clear understanding of the cost of achieving the goals.
- **Champions:** Identify champions to lead the change.
- **Marketing:** Investigate the possibility of hiring a marketing firm to help change the way in which Canadians view kidney disease, to bring it out of the shadows and create excitement for finding a cure.
- **Pilot projects:** Investigate the possibilities of funding high-risk pilots in areas that strengthen and prove the business case.
- **Research investments:** Solicit views across Canada - what are our must-do, high-risk basic science areas? How do we expand and connect trainees?

*“This community has a unique value proposition. “We are people who get stuff done”
Now here is this new set of problems we have identified, and here is how we get there,
and how much it is going to cost.”*

HORIZONS 2022

Steering Committee Members:

Dr. William (Bill) Clark (Chair), London Health Sciences Centre, Ontario

Dr. David Cherney, Toronto General Research Institute, Ontario

Elisabeth Fowler, The Kidney Foundation of Canada

Dr. Amit Garg, President, Canadian Society of Nephrology

David Hartell, Canadian National Transplant Research Program

Gwen Herrington, Patient partner, BC

Barb LeGay, Patient partner, Nova Scotia

Mary-Jo Makarchuk, CIHR Institute of Nutrition, Metabolism & Diabetes

Linda Pellas, Kidney Foundation of Canada

Dr. Lisa Robinson, Hospital for Sick Children, Ontario

Dr. Rita Suri, Centre de Recherche du CHUM, Quebec

Dr. Tomoko Takano, McGill University Health Centre Research Institute, Quebec

Dr. Navdeep Tangri, Seven Oaks General Hospital, Manitoba

Dr. Michael Zappitelli, Montreal Children's Hospital, Quebec

*This report is dedicated to **Barb LeGay** – a wonderful and dedicated member of the kidney community and HORIZONS 2022 Steering Committee member who passed away in July 2017. Barb was an incredible voice for patients who reminded us of the resilience of the human spirit, and the power of positivity.*

Barb will be truly missed.



With thanks to our partners for their generous support:



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www.kidney.ca

Contact: Elisabeth Fowler, National Director of Research
613-793-1299 | elisabeth.fowler@kidney.ca



The foundation of kidney care.

Appendix 1

Full List of Participants

Last Name	First Name	Location
Agharazii	Mohsen	Quebec, QC
Alexander	Todd	Edmonton, AB
Audrain	Ashley	Toronto, ON
Barbour	Sean	Vancouver, BC
Beaucage	Mary	Nipissing First Nation, ON
Boucher	Chantal	Montreal, QC
Burns	Kevin	Ottawa, ON
Campbell	Michelle	Ottawa, ON
Cherney	David	Toronto, ON
Clark	Bill	London, ON
Côté	Connie	Ottawa, ON
Dunn	Catharine	Toronto, ON
Fizzell	Michael	Toronto, ON
Flowitt	Felicia	Toronto, ON
Fowler	Elisabeth	Ottawa, ON
Garg	Amit	London, ON
Hartell	David	Ottawa, ON
Harwood	Lori	London, ON
Hébert	Marie-Josée	Montreal, QC
Herrington	Gwen	Vancouver, BC
Ho	Julie	Winnipeg, MB
James	Matthew	Calgary, AB
Kennedy	Chris	Ottawa, ON
Kidston	Paul	Toronto, ON
Kraprielian	Roger	Toronto, ON
Lafrance	Jean-Philippe	Montreal, QC
Levin	Adeera	Vancouver, BC
Liu	Brian	Toronto, ON
Makarchuk	Mary-Jo	Toronto, ON
Marquis	Christine	Montreal, QC
Munger	Martin	Montreal, QC
Myles	Elizabeth	Montreal, QC
O'Brien	Jim	Toronto, ON
Ralph	Trina	St. John's, NL
Reich	Heather	Toronto, ON
Robinson	Lisa	Toronto, ON
Robles	Flavia	Edmonton, AB
Rosenblum	Norm	Toronto, ON
Saha	Sumit	Toronto, ON
Samuel	Susan	Calgary, AB
Sapir-Pichhadze	Ruth	Montreal, QC

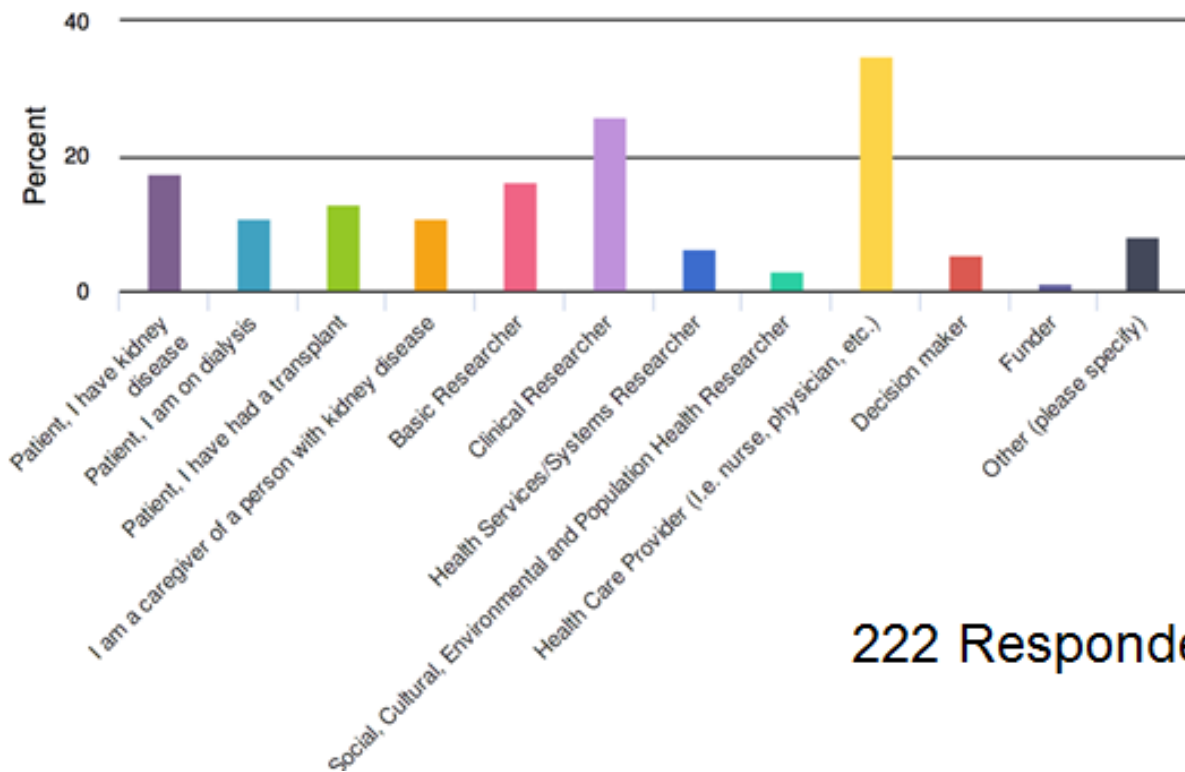
Appendix 1

(Continued)

Last Name	First Name	Location
Schindler	Pia	Vancouver, BC
Sherman	Phil	Toronto, ON
Sontrop	Jessica	London, ON
Sood	Manish	Ottawa, ON
Star	Robert	Boston, MA, USA
Suri	Rita	Montreal, QC
Takano	Tomoko	Montreal, QC
Tangri	Navdeep	Winnipeg, MB
Van Deurzen	Joyce	Calgary, AB
Walsh	Michael	Hamilton, ON
Woods	Cathy	Winnipeg, MB
Zappitelli	Michael	Montreal, QC

Pre-workshop survey

1. How do you identify yourself? Select all that apply.



222 Respondents