

## Can-SOLVE CKD Network

Impact Report 2018/19





## **Our Vision**

Every Canadian with or at high risk for chronic kidney disease will receive the best recommended care, experience optimal outcomes, and have the opportunity to participate in studies with novel therapies, regardless of age, sex, gender, location, or ethnicity.



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"Over the past year, we have focused on facilitating the successful delivery of our 18 research projects while developing plans for ongoing sustainability beyond the end of current funding in 2021. The past year has also included further advancement of the network's patient engagement,

curriculum development, and knowledge translation activity in addition to the creation of several novel infrastructure initiatives that will enhance capacity for patient-oriented kidney research on a national scale.

In this report, we are pleased to highlight activities from our third year that are closing gaps in kidney disease knowledge and delivering better health outcomes for patients. Through listening to and learning from the diverse perspectives of our national community, we are leading a cultural shift from care which is disease-centred and provider-

focused to care which is patient-centred, informed by evidence, and coordinated across the health care system.

We are excited to share the progress that we have made toward our network's vision in Year 3. Our collective vision and willingness to act will impact the quality of care of those with kidney disease. To you, and everyone who was engaged in this work, thank you. We are inspired by your generosity and your commitment to ensuring better kidney health for Canadians through patient-oriented research."

Dr. Adeera Levin, Dr. Braden Manns & Dr. James Scholey Can-SOLVE CKD Network Leadership Team





#### **Patient Governance Circle**

**Patient Perspectives** 

**Indigenous Engagement** 

# Patient Governance Circle



Due to the growth in interested patient partners, the Patient Council Executive held a number of strategic planning sessions to discuss the evolution of the Patient Council. A new structure and function



emerged from these discussions, resulting in the formation of the new Patient Governance Circle.

The Patient Governance Circle brings together the existing Patient Council Executive members with a group of highly active patient partners who have taken on leadership roles across the Can-SOLVE CKD Network. The resulting 12-person Patient Governance Circle will be an agile decision-making body reflecting the significant breadth of expertise among Can-SOLVE CKD patient partners.

"Fresh faces and new ideas will add to what we've started. We were looking for ways to add sustainability as we move forward and the Patient Governance Circle is crucial as we enter the next phase of our development."

- Mary Beaucage, Co-Chair, Patient Governance Circle

# Patient Perspectives

"We bring something valuable to the table: we bring our interests and most importantly our lived experience."

Marian Reich - Patient Partner

"If you take the opportunity that you're handed by being part of this group, it can lead you to a much greater place."

Ken Litchfield - Patient Partner

"You have to advocate for yourself. Express what you want to do, because (researchers) are there to support you every step of the way." Arlene Desjarlais - Patient Partner

Ensuring better kidney health treatment for all Canadians means incorporating the personal views of kidney disease from across a wide spectrum.

By embracing the diverse perspectives of our patient partners, we are working to advance the culture of kidney research in Canada.

patient partners are involved in Can-SOLVE CKD research projects

# Indigenous Engagement

The celebration of Indigenous culture and heritage is at the heart of our efforts to ensure the best possible kidney health for all Canadians. Chronic kidney disease disproportionately affects Indigenous communities and those living in rural and remote locations. We are committed to working with partners across the country to ensure all Canadians receive the best-recommended care, regardless of location or

Our particular focus on eliminating gaps between Indigenous and non-Indigenous communities, and partnership with our Indigenous Peoples' Engagement and Research Council (IPERC), ensures the unique needs and perspectives of First Nations, Inuit, and Métis people are represented.

ethnicity.









**Research Projects** 

**Knowledge Translation** 

**Curriculum Development** 

## Research Projects

Through our 18 research projects, we are creating new knowledge about kidney health and disease shaped by patient perspectives.

Our research program is based around three themes identified in collaboration with patients, health care providers, and policy-makers. Together, our research projects will close existing gaps in kidney disease knowledge and care to deliver better health.

### **Research Themes**

#### **Earlier Diagnoses:**

Identify kidney disease earlier and support those who are at highest risk of negative outcomes.

#### **Better Treatments:**

Define the best treatments to improve outcomes and quality of life.

#### **Innovative Care:**

Define the optimal ways to deliver patient-centred care in the 21st century.

### **THEME 01: EARLIER DIAGNOSES**



AdDIT: Adolescent
Type I Diabetes
Cardio-Renal
Intervention Trial

Young people diagnosed with type I diabetes are at risk of long-term complications, including kidney and heart disease. AdDIT is measuring biological, psychosocial, and social factors in 300 youth with type I diabetes to better understand who is at risk for the development of diabetes-related kidney and heart problems.

The AdDIT team is studying biological factors in the urine that may indicate kidney injury prior to the onset of an increase in the albumin-creatinine ratio (ACR) to help identify patients at higher risk of kidney disease onset and progression in young adulthood.

An advisory council consisting of patients and their families ensures patients can take part in all aspects of the project and have a strong voice in shaping the research agenda.

The project team leveraged Can-SOLVE CKD's expertise in knowledge translation to successfully apply for a CIHR SPOR and JDRF Partnership On Innovative Clinical Trial Multi-Year Grant.



iCARE: Improving
Renal Complications
in Adolescents with
Type 2 Diabetes
through Research

Youth with type 2 diabetes are at a very high risk of experiencing kidney failure as adults, yet little is known about why this occurs. iCARE is a national study that will recruit 400 children with type 2 diabetes across Canada. The study will follow participants for two years and assess both heart and kidney outcomes. The goal is to determine the risks that contribute to kidney damage in youth living with type 2 diabetes.

3 out of 10 youth living with type 2 diabetes show early signs of kidney disease.

iCARE continued recruitment of participants across 10 national sites. The team was able to expand the study to include an additional site in Saskatoon.

The iCARE Patient Advisory Group created a workbook for youth with type 2 diabetes to help them better understand how to manage their blood sugar.



Kidney Check:
Diabetes, blood
pressure and kidney
health checks and
care in Indigenous
communities

Kidney Check is bringing kidney, diabetes and blood pressure checks to rural and remote Indigenous communities in British Columbia, Alberta, and Manitoba. Each participating community has the opportunity to design and work with the Can-SOLVE CKD team to develop a locally acceptable program, which helps to identify healthy kidneys as well as those with mild, moderate or severe kidney problems. The results will be shared with participants in real time.

Ten BC First Nations communities have been chosen through a transparent process to be part of phase I of the screening program, which is launching this fall.

A toolkit has been developed for regional teams to use in their local Kidney Check screening initiatives. The toolkit includes a risk-prediction app, standard operating procedures, and front-line care scripts for providers and patients.

Several animated videos explaining how to care for your kidneys have been created and translated into Ojibway and Cree.



Defining risk and personalizing treatment of patients with ADPKD

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the most common hereditary kidney disease and one of the leading causes of kidney failure. This project aims to transform clinical care for ADPKD by creating a national clinical trial network that will evaluate the use of next generation sequencing for genetic testing and 3D ultrasound for kidney volume measurement.

120 patients have been studied for the 3D ultrasound project, which is nearing completion.

Around 100 patients have been enrolled in the clinical trial network.

A web-based ADPKD questionnaire has been created to support the enrolment of clinical trial candidates.



Canadian Glomerulonephritis Registry It is difficult to provide effective care for glomerulonephritis (GN). GN treatments have many side effects and we need better methods to determine who is at highest risk and which treatments are best for individual patients. This project will create a network to develop personalized treatments and identify new ways of detecting high-risk GN.

The study officially launched in September 2018 with nine active Canadian sites activated and recruiting. A 10th site will be added in 2019.

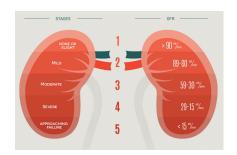
The team has created webbased tools for following up with GN patients from across Canada. Currently, 54 patients have been enrolled from coast to coast.

Kidney disease is common, but not all patients will reach kidney failure. The team has

developed an equation that uses routine lab tests to accurately predict the risk of kidney failure in patients with kidney disease. This information reduces anxiety and

empowers patients to better control their disease and its risk factors. The project will test this equation via interactive tools in family medicine clinics across Canada.

Through patient engagement, the team has refined its research priorities to place more value on studying the patient experience.



Integrating riskbased care for patients with CKD in the community Clinic recruitment has been completed, with 32 primary care clinics (16 each in Manitoba and Alberta) agreeing to participate in the study.

The team has created a website (kidneyfailurerisk.com) featuring patient stories, infographics, and important information about kidney failure risk.

The equation will be tested via interactive tools in family medicine clinics across Canada. The interactive tools will help patients and their doctors gain a better understanding of their kidney health and will help guide their care.



APPROACH: Risk prediction to support shared decision-making for managing heart disease

Heart disease is common in people with chronic kidney disease and can lead to hospitalization and shorter life expectancy. The APPROACH project aims to develop tools that can help doctors share personalized information on the benefits and risks of having a heart procedure.

Patient and physician interviews have been conducted to determine the attributes that are most important to treatment decisions for acute coronary syndrome.

A "discrete choice experiment" has been launched in two Calgary clinics to determine patient preference for either invasive or conservative treatment of acute coronary syndrome. The design of the study was tested with patient partners and their feedback was incorporated into the final design.

As the project moves into its third phase, the team will be incorporating risk information and strategies to identify patient preferences within a decisionaid.

## **THEME 02: BETTER TREATMENTS**



Precision medicine in diabetic kidney disease

Diabetic kidney disease is the most common form of end-stage kidney disease in Canada. Current treatments have been largely ineffective with little change in the rate of progression to end-stage kidney disease over the past 20 years. This project will take advantage of new techniques in molecular analysis to develop a personalized medicine approach to diagnosis and treatment of diabetic kidney disease.

Research ethics board approval has been obtained in two of four sites.

Proof-of-feasibility studies have been conducted.

Three patient partners have made key contributions to protocol review, knowledge translation, and engagement with Indigenous communities.



Clinical trials of promising repurposed drugs for ADPKD

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the most common inherited kidney disease. There is currently no cure; however, several drugs approved for other diseases show promise in treating ADPKD. This project will conduct a pilot clinical trial on a promising repurposed drug (Salsalate) to study its effectiveness and safety as a treatment for ADPKD.

Pre-clinical animal studies have been completed to support the use of Salsalate in treating ADPKD; the research team has submitted a manuscript for publication summarizing these findings.

Research ethics board approval has been obtained for a pilot study of Salsalate's safety and tolerability in patients.



ACHIEVE:
Aldosterone
inhibition and
enhanced toxin
removal in
hemodialysis
patients

Forty percent of patients that require dialysis die within three years, mostly due to heart disease. Effective treatments for heart disease in dialysis are lacking. A drug called Spironolactone is effective at reducing scarring of the heart. Spironolactone might help prevent heart-related deaths in patients with kidney failure. This project will determine if spironolactone reduces heart related deaths and hospitalizations due to heart failure.

Recruitment in Canada has been successful and new centres have been added.

The project has received additional funding of over \$2.8 million.

Brazil, the Philippines along with other countries will begin conducting trials in the spring of 2019.



DISCO: Dialysis
Symptom Control

To assess the safety and efficacy of low fixed dose medications (ropinirole and gabapentin) for the treatment of Restless Leg Syndrome (RLS) in patients with end stage kidney disease requiring hemodialysis.

CNTN is a valuable setting to refine a protocol and get feedback from multiple stakeholders.

Screening for RLS can be successfully performed using preexisting patient outcome reporting measures e.g. ESAS, IRLS.

Patient partners can effectively be utilized at every stage of a clinical trial to enhance its quality and feasibility.



Evaluation of sodium deposition in soft tissues of patients with kidney disease

Salt increases the amount of fluid intake requiring high ultrafiltration rates during dialysis and causes hypertension and inflammation. This study measures body sodium storage with Magnetic Resonance Imaging (MRI) in chronic kidney disease and hemodialysis patients to explore the relationship between sodium storage and associated symptoms (itching, fatigue, restless legs).

The current study compares sodium in body tissues of children and adults.

Launched patient engagement initiative and recruited patients for the study.

Examined the causes of shortness of breath in the hemodialysis population by measuring lung structure and function.



EMPATHY: Patientreported outcomes clustered RCT This study will determine the effects of routinely measuring patient-reported outcome measures (PROMs) on the experiences of patients undergoing hemodialysis in Alberta and Ontario.

Clinician training and pilot evaluation commenced in 2018.

The Ontario Renal Network study went live in 2019.

Qualitative sub-study to begin in 2019.

### **THEME 03: INNOVATIVE CARE**



Triple I:
Restructuring kidney care to meet the needs of 21st
Century patients

Priorities for Improving Information, Interaction and Individualization among patients on Hemodialysis — Patients on hemodialysis (HD) want better information, improved interactions with their healthcare team and more individualized care. The goal of this project is to identify the top priorities to improve HD care in all three of these areas.

Completion of phase 01: focus groups and interviews, identification of challenges and solutions.

Completion of phase 02: Canada-wide patient and provider survey. The project team is now working on generating ideas for interventions based on the top 10 challenges to hemodialysis care identified in the workshops, and trialing these interventions across their national sites.



STOP Med-HD: Strategic optimization of prescription medication use in Patients on hemodialysis (HD) take on average 12 medications perday. Many of these medications lack high-quality evidence to show their effectiveness and safety in HD patients. This project will develop tools to help reduce the use of medications that lack evidence for effectiveness and safety in HD patients.

Developed and validated deprescribing algorithms for 9 medication classes have been created and validated.

Developed and currently validating bulletins and videos.

Developed videos and bulletins to keep patients informed and involved about deprescribing.



Strategies to enhance patient self-management of CKD

This project takes a multi-phase approach to respond to the need for a CKD self-management support intervention that can be individualized to a patient's unique situation, priorities and preferences to manage their disease and enhance their quality of life. The project aims to create a novel, tailored CKD patient self-management web-based tool.

Working on co-developing content and features for an e-health tool.

Delivering and evaluating the ehealth tool from now until 2021. Pursuing ongoing levels of patient engagement: Inform and consult, Involve and collaborate, and lead and empower.



Improving patient knowledge about treatment options

Indigenous patients and families have unique cultural, linguistic, and community backgrounds. Currently, there are few culturally appropriate educational tools available for Indigenous people with failing kidneys. This research project aims to engage with Indigenous peoples in SK, BC and ON to co-develop culturally appropriate tools that may facilitate making decisions about treatment options for failing kidneys.

7 video modules co-developed for further review by Indigenous patients and caregivers in SK.

Interview guide and pictorial evaluation tool developed for use in BC, SK, ON.

Scoping reviews (educational tools for Indigenous people and their kidney treatment options, how can kidney health professional best engage with Indigenous communities for better self-management).



Increasing the use of living donor kidney transplantation

This project aims to improve the work-up process for living donor candidates to improve patient experiences, outcomes, and reduce healthcare costs. In addition, this research seeks to improve access to kidney transplantation and living donation.

Analyzing interim results, disseminating 2nd round of surveys and distributing survey findings.

76 active transplant ambassadors.

>200 staff attended educational webinars.

## **Knowledge Translation**

With 18 research projects across Canada, Can-SOLVE CKD is generating a significant volume of new knowledge and evidence about kidney health, treatment, and care.

But publishing new knowledge does not guarantee that the findings will be used in practice. Studies have found it can take up to 17 years for evidence to be adopted into clinical care. That is too long – patients deserve timely care that is based on the best evidence.

That is why Can-SOLVE CKD is committed not only to creating new knowledge but also to ensuring it reaches those who can use it. Our goal is to help transform health by delivering new treatments and care supported by research.

To help our research teams translate their findings into real-world impact, we created a Knowledge Translation Community of Practice in February 2019.

average number of years for research evidence to reach clinical practice

# Knowledge Translation Community of Practice

What is it? A virtual community with diverse membership from across the Can-SOLVE CKD Network. Participants meet each month by videoconference to develop new skills in communication and knowledge sharing – for example, how to effectively communicate your research to different audiences and which communication products are most effective. The emphasis is on improving the network's ability to report on research project outcomes.

What does it do? The KT Community of Practice aims to improve knowledge translation literacy throughout the network and support project teams to develop a range of communication products and tools. Initial workshops focused on helping project teams create visual abstracts for presentation at the 2019 Can-SOLVE CKD annual meeting to highlight research project progress.









## **Curriculum Development**

Patient-oriented research is a culture change that asks all involved to push beyond what is familiar and embrace new ways of working.

To help network members advance their skills and knowledge in this area, we are creating a suite of training programs focused on Can-SOLVE CKD's core activities. Five learning nodes are currently under development, based on the findings of a 2017 survey that determined the greatest training needs in patient-oriented kidney research. These five modules are briefly explained in the tabs below.



### Practical Tools for Teams

To enable authentic conversation and strong partnerships within patient-oriented research environments



Storytelling with Impact

To help members prepare for the important role of writing, telling, and receiving health care stories for educational and research discussion purposes



**Kidney Pro** 

To understand the breadth, domains, and impact of kidney health research in Canada and to provide hope to patients



Wabishki Bizhiko Skaanj Learning Pathway

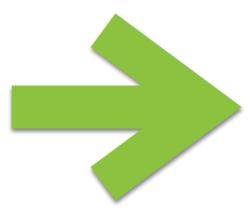
To enable respectful, culturally safe relationships with Indigenous peoples and communities in health research



Knowledge Translation

To enable our patient partners and researchers to have a practical understanding of how to apply knowledge translation in the context of kidney research





**Tools & Infrastructure** 

**Patient Leadership** 

**Supporting Reconciliation** 

## **Tools & Infrastructure**

Can-SOLVE CKD has a rare opportunity to transform not just kidney health, but the way kidney research is conducted in Canada.



In addition to our 18 research projects, we are building national infrastructure and shared resources that will benefit everyone involved in patient-oriented kidney research across the country.





These platforms will increase patients' involvement in all aspects of the research process by linking them to study opportunities and educational resources. They will also support researchers to ask and answer the questions that are most important to patients. Ultimately, we aim to make kidney research in Canada more accessible and effective for everyone.



What is it? A platform to learn about and get involved in research that responds to the needs and perspectives of patients. From a user-friendly website, patients can create an account, select topics of greatest interest, and receive up-to-date listings of kidney research opportunities across Canada.

What does it do? KidneyLink keeps patients informed about new opportunities to get involved and provides access to curated educational resources focused on nephrology research in Canada.

What is the impact? KidneyLink will increase patients' ability to participate in kidney research and will help researchers recruit greater numbers of interested patients for their studies.

#### Milestones:

- July 2018: Can-SOLVE CKD issues a request for proposals to develop a digital portal linking patients to research opportunities and education
- May 2019: The KidneyLink platform is introduced at the Can-SOLVE CKD Annual Meeting
- July 2019: A new website (kidneylink.ca) is launched to facilitate patient partner registration

What is it? A pan-Canadian bilingual network of clinical researchers established to advance multi-centre, prospective research, particularly randomized controlled trials, in kidney health. There is membership from all regions of Canada, including patient partners and Indigenous communities.

What does it do? CNTN promotes a culture of collaboration within the Canadian kidney community and connects investigators with interested research centres across Canada via a web-based system. The network also offers resources to help investigators develop and conduct clinical trials and overcome barriers to recruitment.



What is the impact? CNTN will increase the number of high-quality, kidney-focused randomized controlled trials in Canada.

#### Milestones:

- September 2018: Can-SOLVE CKD brought together a broad cross-section of Canada's kidney research community to develop a collaborative vision and sustainability strategy for the Canadian Nephrology Trials Network (CNTN).
- March 2019: Three new working committees (Capacity Building, Communication and Engagement, and Scientific Operations) and a governing Executive Committee were launched to execute CNTN's strategic plan.
- June 2019: The network's brand new website (cntn.ca) launched

## Patient Leadership

One of Can-SOLVE CKD's core principles is the involvement of patients as equal partners in everything we do.

Patient engagement is a spectrum, and we strive to create a broad range of roles and opportunities for patient partners based on their interests, experiences, and skills. Over the past year, we have witnessed remarkable growth in the abilities and confidence of patient partners, several of whom have taken on leadership roles throughout the network and in their communities:



- The number of research projects with a patient lead has doubled from 7 to 14
- Patients have made important contributions to the network's Research Operations Committee, which performs annual peer-review on all 18 Can-SOLVE CKD research projects. Three patient partners have stepped into this highly involved role to share their lived experience of kidney disease as well as expertise from their diverse personal and professional backgrounds.
- The growth of patient leadership is evident in the creation of the new Patient Governance Circle. Patients identified the need for a more agile governance body and drove the process of designing and implementing the new structure.
- Patient partners who have completed the "Storytelling with Impact" training module have volunteered to act as peer coaches, helping others gain the skills and confidence to share their personal kidney journeys.
- In the true spirit of patient-oriented research, our patient partners have represented Can-SOLVE CKD at regional, national, and international conferences. Some have shared their personal stories while others have presented posters and abstracts on behalf of Can-SOLVE CKD research teams and committees.

## **Supporting Reconciliation**

Through the wisdom and guidance of our patient partners and Indigenous Peoples' Engagement and Research Council (IPERC), we are committed to supporting the principles of Truth and Reconciliation across the Can-SOLVE CKD Network.



We are fostering respectful partnerships built on an understanding of the histories and cultures of Indigenous peoples. Over the past year, we have undertaken many activities that have supported researchers and patient partners to become more aware of racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health, and culturally safe health research practices.

## Financial highlights

As the network's research projects have entered active implementation, significant progress has been made in aligning actual expenditures with planned spending.

Over the reporting period, the network's total spend was 73% of planned spending (\$5,201,077 against a 2018/19 budget of \$7,147,944, not including carry-over from previous years). This represents a marked increase on the previous fiscal year (2017/18) during which actual spending was 45% of planned spending (\$4,755,117 against a budget of \$10,514,115).

The network has succeeded in increasing the proportion of budgeted funds spent during the current reporting period; however, a significant underspend from Year I and 2 remains as a result of delays in executing institutional agreements. Indeed, our total carry-over from Year I and 2 is \$11,971,335 (cash and in-kind).

Note: The terms "Year 1", "Year 2" and "Year 3" are used throughout this section to denote the years of Can-SOLVE CKD's operations. Year 1 is FY 2016/17, Year 2 is FY 2017/18 and Year 3 is FY 2018/19.

# Budgeted Spending for Year 3: \$7.1M\*

\*excluding carry-forward

\$5.2M

Actual expenditures

\$1.9M

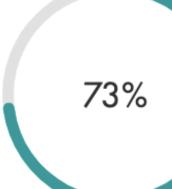
Unspent funds for carryforward to Year 4

# Year 3 Actual Expenditures vs. Planned Spending













# Year 3 Total Spending vs. Accumulated Budget\* by Research Project

\*Sum of Years 1 and 2 unspent funds and Year 3 budget



#### Theme 1: Earlier diagnosis

#### 80%

iCARE: Improving renal complications in adolescents with type 2 diabetes through research

#### 13%

AdDIT: Adolescent Type 1 Diabetes Cardio-Renal Intervention Trial

#### 46%

Kidney Check: Identifying kidney disease and diabetes in Indigenous communities

#### 31%

Defining risk and personalizing treatment of patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD) / Clinical trials of promising re-purposed drugs for ADPKD

#### 29%

Canadian Glomerulonephritis Registry

#### 10%

Integrating risk-based care for patients with CKD in the community

#### 47%

APPROACH: Risk prediction to support shared decision-making for managing heart disease



#### **Theme 2: Better treatments**

#### 10%

ACHIEVE: Aldosterone inhibition and enhanced toxin removal in hemodialysis patients

#### 3%

DISCO: Dialysis Symptom Control

#### 71%

Evaluation of sodium deposition in soft tissues of patients with kidney disease and its association with patient symptomatology

#### 46%

EMPATHY: Patient-reported outcomes clustered RCT



#### Theme 3: Innovative care

#### 61%

Restructuring kidney care to meet the needs of 21st century patients

#### 8%

Targeted de-prescribing in patients with chronic kidney disease to decrease polypharmacy

#### 19%

Strategies to enhance patient self-management of CKD

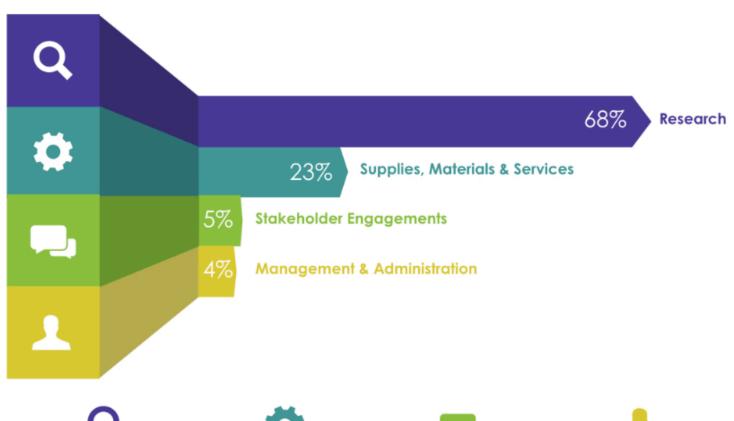
#### 5%

Improving Indigenous patient knowledge about treatment options

#### 33%

Increasing the use of living donor kidney transplantation

# Year 3 Actual Network-Wide Spending (Cash and In-Kind) by Category



Research staff, trainees, contractors, and patient partners' honoraria.



Combined costs of equipment and information technology, supplies, educational materials and services.



All costs associated with the Can-SOLVE CKD Annual Meeting, workshops, conferences, and governance.

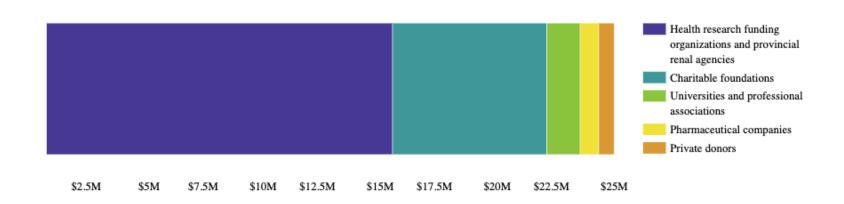


Compensation costs of administrative team supporting the projects and day-to-day activities of the network.

# Total Research Budget for 18 Projects and 5 Core Infrastructures



### **Can-SOLVE CKD Partner Funding by Category**





## Thank you!

Together we will transform kidney health for all Canadians.

Learn more www.cansolveckd.ca

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