



Kidney Health Strategic Clinical Network™

2016-2019 Transformational Roadmap

October 28, 2016

Preface

Something More that You Can Do

By Bob Stallworthy

*Patient and Family Advisor, Core Committee,
Kidney Health Strategic Clinical Network™*

*today you asked if you could help
said you could water the flowers
by the front door*

*you stood holding that hose
watered lily of the valley, the cedar tree
lawn and peony and hosta
they looked better for you having been there*

*when you were finished
your face the best flower in the garden
breaking open into bloom*

Note: This poem is the property of Bob Stallworthy. Bob's wife, Marilyn, is a patient with chronic kidney disease. This poem is a reflection on her recovery after a lengthy hospital stay post-diagnosis. Aside from this document, this poem is unpublished work and cannot be distributed without the consent of the author.

The Kidney Health Strategic Clinical Network™ is dedicated to improving the kidney health of all Albertans. This transformational roadmap is a bold vision for the kidney care community and is intended to be a dynamic and integrated plan. We have looked critically at the present and recent past to understand the burden of kidney disease and determine where there are opportunities to improve outcomes for Albertans in the future. With a focus on innovation and the application of existing knowledge, the roadmap contains goals and strategies committing us to developing and implementing change over the next three years that will achieve results that are relevant to our patients, families and partners.

The network also supports the sustainability of the health care system by careful examination of our current practices, the practices of other kidney care programs in Canada, and the use of research and innovation to achieve excellence in care and good value for investment. In partnership with providers, patients and families, administrators, policy makers, researchers and community partners, we strive to offer quality care across all ages and stages of kidney disease. By including patients and families in all aspects of our work and in the development of this transformational roadmap, we will help ensure a focus on the patient experience and on obtaining the best outcomes possible. This roadmap also highlights the necessity of our network to be integrated and aligned with Alberta Health Services' vision and health plan to meet the needs of all our stakeholders.

Thank you to our incredibly engaged Core Committee, who actively and enthusiastically participated in the development of this transformational roadmap. We would also like to thank our patient advisors, operational and academic partners, clinicians and researchers, and our community partners who shared their hope for an improved future of kidney care in Alberta.

We invite all of you to use this transformational roadmap as a gateway to engage with the Kidney Health Strategic Clinical Network™ and to guide your own quality improvement efforts. Tell us how we can work with you collaboratively to improve the kidney health of Albertans.

Many thanks,

Dr. Nairne Scott-Douglas
Senior Medical Director
Kidney Health Strategic Clinical Network™
Alberta Health Services

Louise Morrin
Senior Provincial Director
Kidney Health Strategic Clinical Network™
Alberta Health Services

Executive Summary

Chronic kidney disease affects approximately 450,000 Albertans and patients with chronic kidney disease cost the Alberta health care system close to \$5 billion each year. The Kidney Health Strategic Clinical Network™ was launched in January 2016 to address key gaps in care and outcomes related to kidney health across Alberta. Strategic Clinical Networks™ are province wide teams bringing together the experiences and expertise of health care professionals, researchers, government, communities, non-governmental organizations, and patients and their families to improve our health care system. Strategic Clinical Networks™ are the mechanism through which Alberta Health Services empowers and supports physician and clinical leaders both within Alberta Health Services and the community to work with patients and their families to develop and implement evidence-informed, clinician-led, team-delivered health improvement strategies across Alberta.

This transformational roadmap was developed through the collaborative effort of a broad network of stakeholders with an interest in improving kidney health across Alberta. Building on substantial existing work eliciting the priorities of patients and policy makers, and subsequently through collaborative Core Committee meetings and surveys, Core Committee members and a broader network of stakeholders provided valuable guidance and input into the direction and actions for the Kidney Health Strategic Clinical Network™ over the next three years.

The vision of the Kidney Health Strategic Clinical Network™ is:
“Optimal kidney health for all Albertans.”

The mission statement, or how we will achieve this vision, is:
“The Kidney Health Strategic Clinical Network™ partners with Albertans to achieve excellence in sustainable quality kidney care and outcomes. Through innovation and use of best evidence, we will optimize prevention, early identification and appropriate management across all ages and stages of kidney health.”

To reach this vision and mission, the Kidney Health Strategic Clinical Network™ has identified three strategic goals to achieve over the next three years. These strategic goals are to:

- 1) Reduce the risk of acute kidney injury and chronic kidney disease through early identification and appropriate management.

- 2) Integrate care and improve management and outcomes of patients with kidney disease.
- 3) Optimize the use of home dialytic therapies, transplantation, and conservative kidney management in appropriate patients of all ages with kidney failure.

The Kidney Health Strategic Clinical Network™ has identified ten priorities under these strategic goals in order to focus the work.

Strategic Goal #1 Priorities: Early identification of kidney disease

- 1) Increase early identification of chronic kidney disease and its risk factors in high risk populations (e.g., Indigenous Peoples and those with diabetes), appropriate risk stratification, and timely referral to the appropriate health care provider.
- 2) Identify those at high risk of acute kidney injury and develop strategies to reduce the risk.
- 3) Collaborate with other Strategic Clinical Networks™ to prevent chronic kidney disease and address underlying common modifiable risk factors for many chronic diseases.

Strategic Goal #2 Priorities: Improve management and outcomes in kidney disease

- 1) Increase use of appropriate therapies that delay progression of kidney and vascular disease.
- 2) Reduce variability in identification and management of glomerulonephritis.
- 3) Implement routine measurement of patient-reported outcome and experience measures, including the use of clinical pathways designed to improve symptoms and patient quality of life.

Strategic Goal #3 Priorities: Optimize treatment in advanced kidney failure

- 1) Increase uptake of home dialysis.
- 2) Increase access to and improve patients' experiences with pre- and post-transplant care; and increase the rate of kidney transplantation.
- 3) Improve access to and reduce variation in management for patients choosing non-dialysis kidney care (conservative kidney management).
- 4) Reduce variation and improve appropriateness of timing of dialysis initiation.



The Kidney Health Strategic Clinical Network™ has developed six Principles that provide the foundation for the Network and will serve as the basis for establishing and successfully implementing our strategic goals. These principles include:

- Patient and family-centred care
- Engagement
- Culture of quality
- Standardized, evidence-informed approaches
- Sustainability
- Research, innovation, and evaluation

Seven Key Enablers have also been identified that are essential to the success of the Kidney Health Strategic Clinical Network™. These Enablers include:

- Performance measurement
- Patient reported outcome measures & patient reported experience measures
- Sustainable funding
- Provider and patient education
- Clinical pathways
- Communication
- Pan-Strategic Clinical Network™ approaches

By following these principles, addressing these key enablers, developing a research and innovation plan as well as a communication and engagement plan for the network, the Kidney Health Strategic Clinical Network™ will be well on our way to achieving our three strategic goals and ultimately our vision of optimal kidney health for all Albertans.

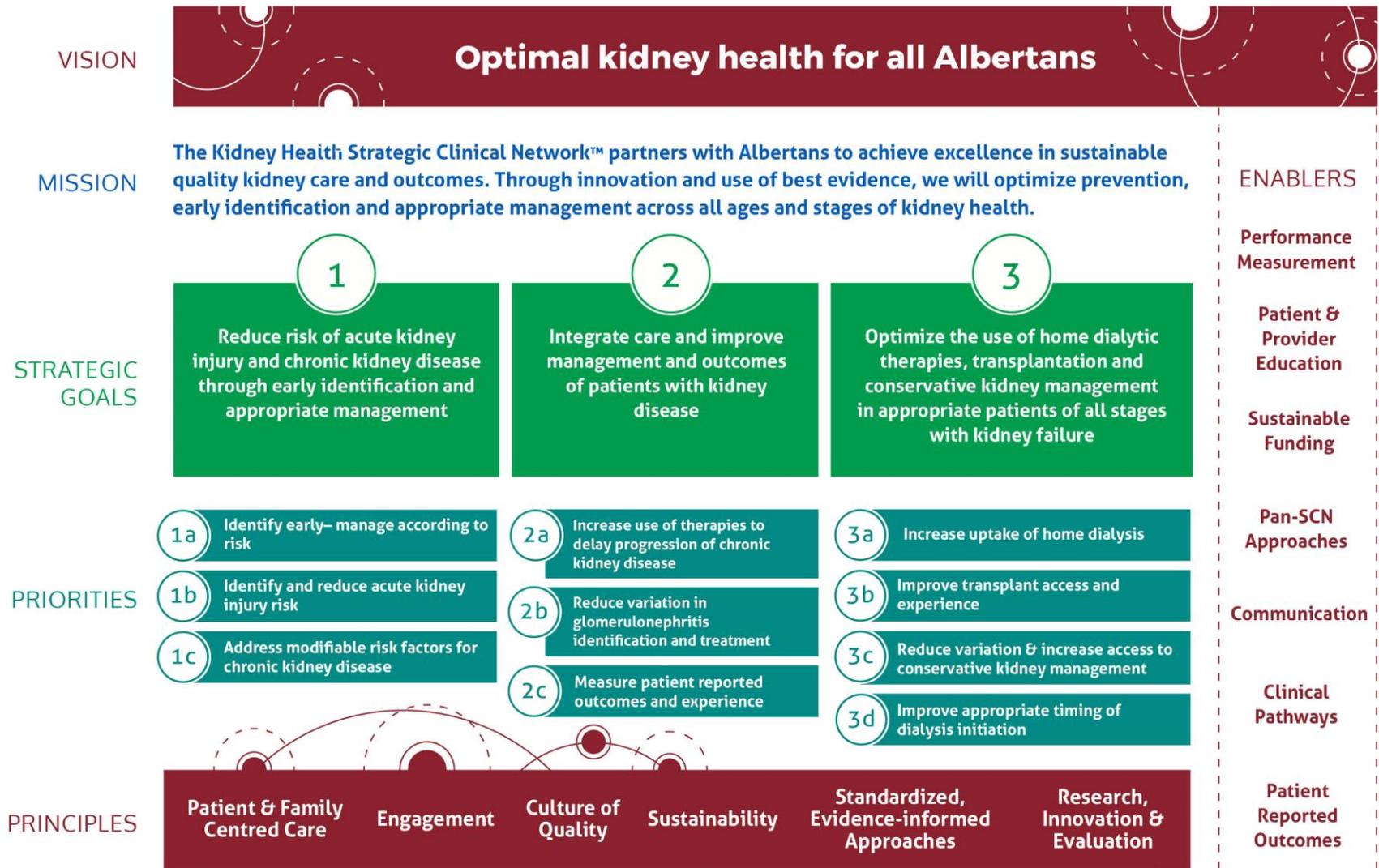


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Introduction

Alberta Health Services' mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans. One of Alberta Health Services four foundational strategies is for Clinical Health Research, Innovation and Analytics. Strategic Clinical Networks™ are a key vehicle to allow Alberta Health Services to focus on research and innovation and achieve this strategy. However, Strategic Clinical Networks™ are much broader than Alberta Health Services. Strategic Clinical Networks™ are province wide teams bringing together the experiences and expertise of health care professionals, researchers, government, communities, non-governmental organizations, and patients and their families to improve our health care system. Strategic Clinical Networks™ are the mechanism through which Alberta Health Services empowers and supports physician and clinical leaders both within Alberta Health Services and the community to work with patients and their families to develop and implement evidence-informed, clinician-led, team-delivered health improvement strategies across Alberta.



"The AHS Strategic Clinical Networks™ are a great example of organizational learning. The system has become aware of the fact that it needs to better understand how patients are experiencing it. And the SCNs™ are designed to help translate this learning into action. And it's working! AHS is doing it right."

*Mike Simoens, Patient and Family Advisor,
Core Committee, Kidney Health Strategic Clinical Network™*

Transformational Roadmaps are an important early deliverable for all Strategic Clinical Networks™. These Roadmaps serve as the strategic plan for each Strategic Clinical Network™ and will guide future work. They are aligned with the Alberta Health Services Health Plan and Business Plan strategic directions and represent the outcome of significant work that has been undertaken to understand the current state of services, understand health needs and key platforms and infrastructures in place at present, identify best and promising practices and outline key goals and priorities to move services forward over the next three years.

About the Kidney Health Strategic Clinical Network™

The Kidney Health Strategic Clinical Network™ was officially launched on January 8, 2016. It is comprised of a Leadership Team and a Core Committee, which has representation from a wide-range of multi-disciplinary stakeholders across the province with a keen interest in kidney health. A number of project teams and working groups will be formed to align with the Kidney Health Strategic Clinical Networks™ strategic goals and priority projects.

The delivery of kidney care in Alberta is coordinated through a unified body, Alberta Kidney Care, which is comprised of the Northern and Southern Alberta operational renal programs. The success of the Kidney Health Strategic Clinical Network™ requires close collaboration and alignment with Alberta Kidney Care, and as such, the two groups work closely together to achieve goals and priorities for the benefit of Albertans with kidney disease. For a detailed chart outlining the integration between these two organizations, see Appendix A.

Kidney Health Strategic Clinical Network™ **Vision:**

Optimal kidney health for all Albertans

Development of the Transformational Roadmap

This transformational roadmap was developed through the collaborative effort of a broad network of stakeholders with an interest in improving kidney health across Alberta. Building on substantial existing work eliciting the priorities of patients and policy makers, and subsequently through collaborative Core Committee meetings and two additional surveys, Core Committee members and a broader network of stakeholders provided valuable guidance and input into the direction and actions for the Kidney Health Strategic Clinical Network™ over the next three years. Feedback from these stakeholders helped outline the focused strategic goals and priorities that the Kidney Health Strategic Clinical Network™ will undertake to transform kidney care across Alberta. These strategic goals are intended to improve kidney health and system outcomes and align with the Alberta Health Services Health and Business Plan and the Alberta Quality Matrix for Health. In total, approximately 363 individuals from across the province have participated in the development of this Transformational Roadmap for the Kidney Health Strategic Clinical Network™.

It is important to the Kidney Health Strategic Clinical Network™ that the patient voice is embedded within our Transformational Roadmap and in all the work we do. Significant patient input was provided in the development of this document. The initial work of the Kidney Health Strategic Clinical Network™ was informed by two national patient-driven priority setting processes in early and advanced kidney disease^{1,2}. With five patient and family advisors sitting on our Core Committee, additional patients being a part of our working groups, and 24 more patient representatives completing the survey to our broader network, we are confident that the goals and priorities outlined throughout this document are reflective of patients' input and their needs.

Kidney Health Strategic Clinical Network™ Mission:

The Kidney Health Strategic Clinical Network™ partners with Albertans to achieve excellence in sustainable quality kidney care and outcomes. Through innovation and use of best evidence, we will optimize prevention, early identification and appropriate management across all ages and stages of kidney health.



Context

Kidney disease is the overarching term for a variety of diseases and disorders that affect the kidneys, and impair their ability to eliminate waste and excess fluids³. Chronic kidney disease, defined as the presence of kidney damage, or a decreased level of kidney function, for a period of at least three months, affects 12.5% of Canadian adults⁴. Kidney disease can range from mild to severe and in some cases, lead to kidney failure. Chronic kidney disease is defined by estimated glomerular filtration rate, an estimate of

Did you know?

Kidney Disease affects nearly 450,000 Albertans

kidney function that is similar to percent kidney function, of $<60 \text{ mL/min/1.73m}^2$ (about 60% kidney function), or by markers of kidney damage including having increased levels of the protein albumin in the urine (albuminuria). Kidney failure is defined as an estimated glomerular filtration rate $<15 \text{ mL/min/1.73m}^2$. The top two causes of kidney disease are high blood pressure and diabetes⁵ and the disease is particularly prevalent in vulnerable populations such as Indigenous Peoples and the elderly⁶. Kidney disease usually starts slowly and develops without

symptoms over a number of years, so chronic kidney disease may not be detected until kidney function is quite low. Fortunately, most people do not progress to end-stage kidney disease, especially if they are diagnosed early and are able to take steps to preserve their remaining kidney function. When patients have end-stage kidney disease, and they develop symptoms of kidney failure (typically when the estimated glomerular filtration rate falls below $10 \text{ mL/min/1.73m}^2$), including nausea, vomiting, poor energy, itching, or fluid overload, then they require treatment with kidney transplantation (for appropriate candidates), dialysis (either in-center or home-based hemodialysis, or peritoneal dialysis), or non-dialysis supportive care (use of medications to delay progression and treat symptoms, also known as Conservative Kidney Management).

Ninety-five percent of adults with kidney failure under age 60 begin treatment with dialysis rather than undergoing a pre-emptive transplant, despite the fact that kidney transplantation is considered the optimal therapy for eligible patients, as it improves both survival and quality of life^{7, 8, 9}. Transplantation is also the most cost-effective treatment for kidney failure in appropriate patients. While the cost of caring for patients receiving a kidney transplant is approximately \$100,000 in the first year, it is approximately \$20,000 in the second year with costs typically declining annually thereafter¹⁰.

Patients selecting dialysis have three choices of treatment: in-centre hemodialysis, home-based hemodialysis, or peritoneal dialysis. Hemodialysis treatment involves the blood passing through an artificial kidney, which filters out the waste and extra fluids¹¹, and also normalizes salts and acids in the body. This is usually done for four hours three times per week in a hospital or clinic setting, but patients can also be trained to do this treatment themselves at home¹¹. Peritoneal dialysis is a treatment done at home. In peritoneal dialysis, blood is cleaned as it circulates near the abdominal cavity. Clean dialysis fluid is inserted into the abdomen (each procedure is called an “exchange”) through a soft tube which is surgically placed in the lower abdominal cavity or pelvis. This clean fluid that dwells within the abdominal cavity uptakes toxins and removes extra fluid volume, which are removed when it is drained back out the same tube. Exchanges are either done four times per day, or are done at night while people sleep using a machine which does the exchanges¹¹. Despite the fact that both peritoneal dialysis and home hemodialysis are substantially less costly (annual costs of \$56,000 or \$71,000-\$90,000 respectively^a) compared to the \$95,000-\$107,000^a annual costs for patients receiving in-centre hemodialysis^{12,13}, four out of every five Albertans currently on dialysis are on in-center hemodialysis^{14, 15}.

Sometimes kidney failure occurs rapidly - referred to as acute kidney injury. This may be a result of severe infection occurring anywhere in the body, toxins including some medications, diseases that specifically attack the kidney filters, dehydration or other causes. People with acute kidney injury may require urgent dialysis treatment for a period of time, but kidney function often recovers³.

Chronic kidney disease is a common and significant public health burden across the province, affecting approximately 12.5% of Albertan adults. Approximately 450,000 people in Alberta currently have chronic kidney disease and this number continues to grow. Of these individuals, about 4,500 have end stage kidney failure¹⁶. Approximately 55% of patients living with end-stage kidney disease receive dialysis, and 45% have undergone a kidney transplant. Chronic kidney disease is also a significant financial burden on patients and their families as well as on the health care system, with an estimated cost of \$12,000 per person, or almost \$5 billion dollars each year in Alberta¹⁷. In-centre dialysis alone costs approximately \$100,000 per patient each year¹⁷. The Kidney Health Strategic Clinical Network™ hopes to improve the quality of life and outcomes for people with chronic kidney disease while promoting health care sustainability.

^a These costs are inclusive of costs associated with outpatient medical, inpatient medical, physicians, medication, patient training and dialysis procedures



Key gaps in care: prevention and early-stage kidney disease

With earlier detection of chronic kidney disease, and appropriate risk stratification, patients at high risk are able to initiate therapy sooner and slow the progression of the disease⁶. For patients with earlier stages of chronic kidney disease who have not progressed to end-stage kidney disease, treatment goals usually include reducing kidney and cardiovascular risk through appropriate lifestyle management, blood pressure control, and use of medication, as recommended by evidence supported guidelines. However there are still gaps and variability in care of patients with early stages of chronic kidney disease across the province¹⁸. Medications called Angiotensin-

Did you know?

Guidelines recommend screening for kidney disease by measuring albumin to creatinine annually in people with diabetes, but only 42% of Albertans with diabetes currently receive such testing

Converting Enzyme inhibitors and Angiotensin Receptor Blockers have been shown to delay disease progression in people with chronic kidney disease, and reduce mortality in people with chronic kidney disease and diabetes; however, the use of these medications is currently suboptimal across Alberta, with only 55-60% of patients who are at very high risk of progression to end-stage kidney disease using them. As well, a class of drugs called statins, that decrease cholesterol, have been proven to decrease cardiovascular and kidney risk; nonetheless, only 35% of high risk non-diabetic individuals with chronic kidney disease over the age of 50 use these drugs. In patients with diabetes, who are at high risk of chronic kidney disease and its complications, patient outcomes are improved by

screening for diabetic complications, including testing urine albumin-to-creatinine ratio. This evidence-supported measurement varies considerably across Alberta's former health regions, ranging from 26.8%-50.7% among diabetic adults in 2012-13⁶.

Key gaps in care: end-stage kidney disease

There are also a number of gaps in the current care of end-stage kidney disease across Alberta that the Kidney Health Strategic Clinical Network™ will seek to address. There are at least 4,500 Albertans who have kidney failure but do not yet need renal replacement therapy (transplant or dialysis), but this number far exceeds the number currently being treated in multidisciplinary chronic kidney disease clinics across the province, and is continuing to grow. Nearly 30% of these patients with non-dialysis kidney failure (estimated glomerular filtration rate of $<15\text{mL}/\text{min}/1.73\text{m}^2$) have not been seen by a Nephrologist and may not be receiving optimal care¹⁶.

The number of people receiving kidney transplants in Alberta is currently much lower than ideal. In 2015-2016, Alberta had 161 kidney transplants^{14,15}, which equates to 38.37 per million population¹⁹. By comparison, in the most recent available data, national-leading British Columbia performed 271 kidney transplants in 2015 (excluding pancreas/kidney transplants)²⁰, or 57.87 per million population¹⁹. Recent surveys have identified a number of barriers to living donation, including a lengthy and complex workup for donors and recipients, difficulty knowing how to approach potential donors, and financial barriers for donors. All barriers greatly impact both donors and recipients.

From 2014-2015, 1222 Albertans started dialysis^{14, 15}, and from 2009-2013, 6.4% of patients starting dialysis were First Nations, with rates significantly higher in the rural zones (9-16.3%)¹⁶. Only 21.4% of Albertans are referred to a Nephrologist within 90 days before starting dialysis, indicating suboptimal pre-dialysis care.¹⁶ As well, the use of peritoneal dialysis varies substantially across age groups and across Zones, despite peritoneal dialysis being associated with similar survival rates to in-centre hemodialysis, similar or better quality of life, and peritoneal dialysis having lower costs¹⁶.

In addition, for patients who choose Conservative Kidney Management, care varies and access to conservative kidney care varies across the province²¹. Currently, this non-dialysis supportive care often requires consultation with care providers in urban settings, which makes this less accessible to those living in rural areas²¹. As well, with healthcare professionals having varied skills, the patients' journey through this complex pathway may be suboptimal²¹.

Did you know?

Home dialysis is recommended for eligible patients requiring dialysis for end-stage kidney disease, but for Albertans aged 60-74 starting dialysis, use of home dialysis at 90 days varies from 10-26% across zones

Given the number of gaps and unwarranted clinical variation in kidney care in Alberta mentioned above, the Kidney Health Strategic Clinical Network™ has identified a number of areas to focus our work over the coming years. These key areas include, the early identification of chronic kidney disease in high risk populations, optimizing management for people with earlier chronic kidney disease with the goal of delaying the progression of chronic kidney disease and improving outcomes, and increasing access to transplantation and home dialysis therapies. By focusing on these areas, the Kidney Health Strategic Clinical Network™ will identify and reduce areas of unwarranted variation across Alberta, maximize efficiencies within the system, and achieve cost savings to help address other gaps in care. This transformational roadmap will outline how the Kidney Health Strategic Clinical Network™ intends to meet these objectives.



Strategic Goals for 2016 – 2019

The Kidney Health Strategic Clinical Network™ has identified three key strategic goals to focus on over the next three years. The strategic goals of the Kidney Health Strategic Clinical Network™ have been developed in the context of the full continuum of care and contribute to the overall goals of Strategic Clinical Networks™, which are ensuring:

- comprehensive care across the continuum,
- smooth transitions between services,
- efficiency is optimized, and
- value for money

Through these strategic goals, the Kidney Health Strategic Clinical Network™ will seek to improve care and outcomes for Albertans of all ages and across all stages of kidney health. As such, with the exception of Conservative Kidney Management, each priority area outlined below is relevant to adult and pediatric populations.

Strategic Goal 1: Reduce the risk of acute kidney injury and chronic kidney disease through early identification and appropriate management

Priorities

The Kidney Health Strategic Clinical Network™ has identified three key priorities that will enable us to successfully achieve this strategic goal. These priorities are:

- a. Increase early identification of chronic kidney disease and its risk factors in high risk populations (e.g., Indigenous Peoples and those with diabetes), appropriate risk stratification, and timely referral to appropriate service.
- b. Identify those at high risk of acute kidney injury and develop strategies to reduce the risk.
- c. Collaborate with other Strategic Clinical Networks™ to prevent chronic kidney disease and address underlying common modifiable risk factors for many chronic diseases.

Did you know?

16.3% of dialysis patients in the North Zone are First Nations people

Rationale

Indigenous Peoples and those with chronic diseases, including diabetes and high blood pressure, are at high risk for developing chronic kidney disease, but screening for chronic kidney disease and diabetes is not routinely done in Canadian Indigenous communities¹¹. Provincial data from 2009-2013 show that 6.4% of dialysis patients are First Nations¹⁶. Point-of-care testing in Manitoba recently identified early chronic kidney disease in 35% of First Nations¹¹, indicating that rates of chronic kidney disease in this population are very high. Other research suggests that progression of kidney disease occurs much more quickly in Indigenous Peoples²². First Nations dialysis patients in Alberta are also less likely to start dialysis with peritoneal dialysis, are substantially

Did you know?

The Kidney Health Strategic Clinical Network™ has 5 Patient Advisor's on our Core Committee and 2 others on our Living Donor Kidney Transplant Working Group

younger than non-First Nations patients (mean age 54.5 vs. 61.3), and have a high probability of also having diabetes (73.4%). While Calgary and Edmonton zones have a fairly low number of First Nations people on dialysis, prevalence is significantly higher in the rural zones (South, 10.1%; Central, 9.0%; North, 16.3%)¹⁶.

This strategic goal would also address the fact that of the 450,000 Albertans with chronic kidney disease, nearly 50% have not been appropriately risk stratified with a simple urine test²³. This makes early intervention for those at higher risk difficult and could also reduce over-intervention for those at low risk. Validated risk prediction

tools using routine laboratory data could also provide additional predictive information for patients with multiple chronic diseases²⁴.

The Kidney Health Strategic Clinical Network™ recognizes that in order to decrease the incidence of kidney failure, early identification and appropriate management of the disease is essential. By targeting high risk populations such as Indigenous Peoples and those with diabetes, the Kidney Health Strategic Clinical Network™ can identify those who are at risk of developing kidney disease early on, appropriately manage this risk, and ideally prevent them from developing kidney disease in the first place.

Acute kidney injury affects 7-18% of hospitalized patients, is associated with prolonged admissions, poor outcomes, high costs^{25, 26, 27}, and with an increased mortality that averages 30% during initial hospitalization²⁸. The occurrence of acute kidney injury has risen over four-fold in North America over the past two decades, currently exceeding more than 500 cases per 100,000 people each year^{29, 30}.

Research has also found that one in twelve survivors of acute kidney injury require the initiation of chronic dialysis after hospital discharge, a rate that is 200% higher than the risk observed in the general population³¹. In the United Kingdom, a detailed audit found that 40% of severe acute kidney injury cases were preventable³². As well, a delay in recognition of acute kidney injury was found in 43% of these patients, and 30% of patients were not properly managed once kidney injury was recognized³². Similar evidence practice gaps have been found in Canada^{33, 34}. While identifying individuals at risk of acute kidney injury has the potential for care improvements that would reduce length of hospital stay and improve long-term health outcomes for these patients³⁵; the translation of this knowledge into action has been limited³⁶.

Acute kidney injury is particularly prominent in the cardiac population. Approximately 1 in 10 patients who undergo cardiac catheterization in Alberta develops contrast-induced acute kidney injury after the procedure. In 2015, this resulted in 1,344 patients across the province developing contrast-induced acute kidney injury³⁷. Patients with contrast-induced acute kidney injury have a 2.5-10 day increase in length of stay, a 50% increase in risk of hospital readmission, and a 3% risk of kidney failure requiring dialysis^{37, 38, 39}. Considering the risk of these adverse outcomes, acute kidney injury is associated with considerable financial implications for the healthcare system. By decreasing the relative risk of contrast-induced acute kidney injury by 20%, annual direct health costs could be lowered by \$1.5 million dollars across Alberta^{37, 40}.

Chronic diseases have a significant impact on patients that are the focus area for a number of the Strategic Clinical Networks™. By partnering with other Strategic Clinical Networks™ to address this issue, the Kidney Health Strategic Clinical Network™ can leverage the expertise of a variety of stakeholders to address common risk factors and the social determinants of health that can lead to kidney and other chronic diseases, including but not limited to diabetes, obesity, cardiovascular disease, hypertension, unhealthy eating, and sedentary behaviour.

Work currently underway

Enhancing Clinical Decision Support for Prevention of Contrast-Induced Acute Kidney Injury in Cardiac Catheterization: is a Partnership for Research and Innovation in the Health System grant in collaboration with the Cardiovascular Health and Stroke Strategic Clinical Network™. This project looks to identify patients at high risk of kidney injury after heart procedures and ensuring that effective interventions such as using minimal X-ray dye and optimizing use of intravenous fluids are utilized. System savings due to this initiative includes decreased length of stay, hospital readmission, and dialysis in this patient population.

Identifying diabetes and chronic kidney disease in indigenous communities: one component of the Strategy for Patient-Oriented Research funded *Can-SOLVE Chronic Kidney Disease* initiative is looking at screening, triaging, and appropriately treating Indigenous Peoples. The Kidney Health Strategic Clinical Network™ will explore the opportunity to collaborate with colleagues across the western provinces in this work, with the goal of expanding this initiative into Alberta.

Improving recognition and early management of acute kidney injury: through a Canadian Institutes of Health Research Foundation grant, this initiative is developing a real-time automated acute kidney injury alert in the electronic medical record system and augmenting this with an acute kidney injury dashboard and medication safety alerts embedded within the electronic medical record to support early recognition, appropriate provider responses, and patient safety in managing acute kidney injury on general medicine and surgery wards.

How we will know we are successful

- Decreased number of people developing acute kidney injury.
- Increased measurement of albuminuria in those at high risk of chronic kidney disease.
- Earlier diagnosis and treatment of chronic kidney disease in patients at high risk.
- Decreased number of people developing kidney disease.

Strategic Goal 2: Integrate care and improve management and outcomes of patients with kidney disease

Priorities

The Kidney Health Strategic Clinical Network™ has identified three key priorities that will enable us to successfully achieve this strategic goal. These priorities are:

- 1) Increase use of appropriate therapies that delay progression of kidney and vascular disease.
- 2) Reduce variability in identification and management of glomerulonephritis.
- 3) Routine measurement of patient-reported outcome measures, including implementing clinical pathways designed to improve symptoms and patient quality of life.

Rationale

Of the 450,000 Albertans with chronic kidney disease, 90,000 have diabetes, 54,000 have heart disease, 225,000 have hypertension¹¹, and the majority have more than one chronic disease⁴¹, which increases their risk of dying by two to eight fold¹⁸. Patients with these non-communicable chronic diseases are all at higher risk of having a heart attack, stroke, premature mortality, and kidney failure, and all benefit from preventive therapies (i.e. treating blood pressure, use of statins, lifestyle) to reduce the risk of kidney and cardiovascular risk. Given this, strategies targeting people with chronic kidney disease could improve outcomes for Albertans with a variety of chronic conditions^{42, 43, 44}.

Reduced kidney function can lead to a number of complications, including hypertension, anemia, malnutrition, bone disease, neuropathy and decreased quality of life. By identifying and treating chronic kidney disease in earlier stages, we will greatly decrease the likelihood of developing these adverse outcomes⁴⁵.

The measurement of urinary albumin excretion (albuminuria) provides a sensitive marker of chronic kidney disease. Albuminuria is a key prognostic finding in chronic kidney disease, and identifies not only a high risk group, but also a group who can benefit from therapy with angiotensin blockade, which can reduce cardiovascular and kidney risk. Early detection of kidney disease with albuminuria will enable earlier initiation of this therapy, thereby slowing the course of the disease. Of patients with chronic kidney disease and albuminuria who are at high risk, the number receiving guideline-concordant care varies considerably⁶. Furthermore, even though people with chronic kidney disease over age 65 account for the majority of those who develop kidney failure, 80% of them are not referred to a Nephrologist⁴⁶. The Kidney Health Strategic Clinical Network™ will look to delay or halt the progression of chronic kidney disease, treat co-morbid conditions, manage risks for other diseases, and increase standardization in care, including referral for those at highest risk, to address this strategic goal.

Since 95% of people with chronic kidney disease are managed by primary care physicians, when attempting to improve care and outcomes for patients with early chronic kidney disease, it is necessary to support primary care physicians⁴⁶. The Kidney Health Strategic Clinical Network™ will partner with a team that has developed the Chronic Kidney Disease Clinical Pathway to achieve this strategic goal. We will work with primary care stakeholders across Alberta to increase use of this evidence-based chronic kidney disease pathway. Since its introduction in November 2014, this online pathway has had excellent results, including:

- Enhanced communication between primary care team members, primary care teams and specialists/specialty clinics, and between healthcare providers and patients.

- 81% of healthcare providers reported increased knowledge and confidence in the care of patients with chronic kidney disease (screening, diagnosis, management, and referral).
- Providers saw the pathway as a credible tool that provided knowledge and training to help facilitate behaviour change in the care of patients, and
- 94% of healthcare providers agreed/strongly agreed that the chronic kidney disease pathway provided useful information⁴⁷.

Future enhancements include:

- Using the chronic kidney disease pathway in primary care for targeted testing of high risk patients to increase identification of chronic kidney disease.
- Implementing a validated risk prediction tool that stratifies chronic kidney disease patients to appropriate provider, investigations, and therapies.
- Enhancing self-management supports for patients with chronic kidney disease, including the development of a patient portal with educational resources aligned with abnormal laboratory results.
- Linking the chronic kidney disease pathway into primary care electronic medical records and to an electronic nephrology referral system to improve appropriate specialist referral.

Did you know?

Over 600 Albertans start dialysis each year

Although Glomerulonephritis is not as common as other kidney diseases such as diabetes-related kidney disease, it is the second most common cause of kidney failure because of its progressive nature. Management of patients with glomerulonephritis is complex, often including medications to suppress the immune system. Since these medications have many side-effects if not used carefully under close monitoring, patients with glomerulonephritis benefit from management in a multi-disciplinary clinic and use of evidence-based care pathways. At present, use of such evidence-based care pathways and multidisciplinary care is variable across Alberta.

Experiences and health outcomes of patients is a priority of not only patients and families, but also of the Kidney Health Strategic Clinical Network™. By measuring patient reported experience and outcome measures, the Kidney Health Strategic Clinical Network™ will be able to track the quality of care and patient's experience across Alberta, with the goal of improving experience and quality of life over time.



Work currently underway

Chronic Kidney Disease Pathway: this comprehensive, online care pathway provides primary care providers the tools and resources necessary to diagnose and manage patients with chronic kidney disease, and refer them to specialty care as required.

How we will know we are successful

- Decreased number of people developing kidney failure and cardiovascular disease.
- Increased use of evidence-based preventive therapies (i.e. Angiotensin-Converting Enzyme inhibitors / Angiotensin Receptor Blockers and statins).
- Decreased variability in glomerulonephritis diagnosis and optimized management.

Strategic Goal 3: Optimize the use of home dialytic therapies, transplantation, and conservative kidney management in appropriate patients of all ages with kidney failure

Priorities

In order to successfully achieve this strategic goal, the Kidney Health Strategic Clinical Network™ has identified four key priorities to focus on. These priorities are:

- a. Increase uptake of home dialysis.
- b. Increase access to and improve patients' experiences with pre- and post-transplant care; and increase the rate of kidney transplantation.
- c. Improve access to and reduce variation in management for patients choosing non-dialysis kidney care (conservative kidney management).
- d. Reduce variation and improve appropriateness of timing of dialysis initiation.



“I am fortunate that my life was saved by a living donor (kidney) transplant and the outstanding medical team at the Southern Alberta Transplant Clinic. That was five years ago, and in reflecting on my journey, it could have been a better experience, so I have volunteered as a patient advisor to work on a team dedicated to increasing the number of living donors and the quality of the experience for both donors, recipients and their families.”

*Phil Bobawsky (with Finnigan), Patient and Family Advisor
Living Donor Kidney Transplant Working Group,
Kidney Health Strategic Clinical Network™*

Rationale

Each year, over 600 Albertan adults start dialysis as a result of kidney failure. Most are treated with in-center hemodialysis, although other treatment options may be more appropriate^{14, 15}. By achieving this strategic goal, the Kidney Health Strategic Clinical Network™ will ensure patients with kidney failure are being educated on their options and are receiving the most appropriate and cost-efficient care.

As mentioned above, given that kidney transplant is associated with improved survival and quality of life, and is considered the most cost-effective treatment option for appropriate patients, increasing the rate of kidney transplantation will be a key priority for the Kidney Health Strategic Clinical Network™ for 2016-19. According to the Canadian Institute for Health Information, as of 2014, there were 487 Albertans^b waiting for a kidney transplant⁴⁸.

Did you know?

As of 2014, 487 Albertans were waiting for a kidney transplant and average wait time exceeds 8 years in parts of Alberta

^b Inclusive of both active patients (who can receive a transplant at any time) and those who are temporarily on hold (who cannot receive a transplant for a medical or other reason for a short period of time)

The Kidney Health Strategic Clinical Network™ is committed to collaborating with the Northern and Southern Alberta Transplant Programs and addressing this issue with an initial focus on increasing the rate of living kidney donor transplantation, improving equity of access across the province, and improving the experiences of both donors and recipients throughout the transplant and donation process. With the current attention for this gap in kidney care across the country, the Kidney Health Strategic Clinical Network™ will be well positioned to address this issue in Alberta.

Based on 2014 and 2015 data, only 21% of dialysis patients in Alberta are using peritoneal dialysis, with the highest rates in Calgary and North Zones, and the lowest rates in Edmonton and South Zones^{14, 15}. Demand for dialysis is increasing and is expected to continue to rise due to population growth. It is estimated that some of the Alberta Kidney Care North and South program hemodialysis facilities will be over-capacity by 2017.

Research has also found that from 2009-2013, approximately 17% of Albertans who had kidney failure and were followed by a Nephrologist for at least 90 days started dialysis earlier than recommended by recent Canadian Society of Nephrology clinical practice guidelines¹⁶. Randomized trial data shows that starting dialysis early, defined as initiating dialysis with an estimated glomerular filtration rate >10.5 ml/min/1.73m² in the absence of symptoms of kidney failure, has no benefit for patients, compared to waiting and initiating dialysis when symptoms occur⁴⁹. In addition, it has been found that starting dialysis early unnecessarily costs the healthcare system over \$2 million per year⁵⁰.

The Kidney Health Strategic Clinical Network™ will look to increase the uptake of home dialysis therapies, particularly of peritoneal dialysis use, and delay dialysis initiation until symptoms of kidney failure develop. This will allow for increased capacity within the Alberta Kidney Care North and South programs to meet current and future dialysis demands, reduce the per patient cost of dialysis, reduce the annual program deficits, and provide patients choices to give them with more flexibility and better quality of life¹⁶.

Evidence suggests that conservative care would be chosen by many elderly chronic kidney disease patients (age ≥ 75) or other patients for whom dialysis might not improve quality of life. A 20% utilization rate is achievable in the elderly population with chronic kidney disease⁵¹. It is estimated that if better education and support was provided, the use of Conservative Kidney Management could be increased to 20% from the current 6-10% in northern and central Alberta. In addition to respecting patients' choices regarding their care, potential cost savings may be gained by avoiding unwanted dialysis treatment. It is estimated that an increase in Conservative Kidney Management could result in up to \$3.9 million of cost savings over a three year period²¹.



By further examining use of Conservative Kidney Management across the province and standardizing care and patient support, the Kidney Health Strategic Clinical Network™ will seek to ensure that Conservative Kidney Management is offered and provided to all appropriate patients who select it.

Work currently underway

Conservative Kidney Management Pathway: Through a Partnership for Research and Innovation in the Health System grant, this project is developing a pathway to identify and better manage Albertans with end stage kidney failure who are unlikely to benefit from dialysis and who choose to not start dialysis. In addition, this care pathway can be used to guide care of patients undergoing dialysis therapy who choose to discontinue dialysis. The care pathway, which focuses on the process of care and symptom management, is being implemented and evaluated in the Northern Alberta Renal Program's Renal Insufficiency Clinics.

Appropriate Modality Selection and Timing of Initiation for Dialysis: This initiative will improve outcomes and reduce costs associated with dialysis therapy by implementing a multifaceted intervention to increase the safe and effective use of peritoneal dialysis as well as a knowledge translation based intervention to reduce the inappropriate early initiation of dialysis in patients with kidney failure. The project will include a structured assessment of all patients to determine eligibility for home dialysis, particularly peritoneal dialysis, as well as patient education about treatment options. Modifiable barriers to peritoneal dialysis will be identified and addressed through tailored strategies developed and implemented by teams at the eight chronic kidney disease clinics in the province. Implementation will be supported by a process of audit and feedback, multi-disciplinary team participation in an Innovation Collaborative, and expert consultation through site visits and webinars to help troubleshoot problem areas. Data collected will include process variables, reasons for dialysis decisions, rigorous accounting of co-morbidities, indications for procedures, reasons for and classification of hospitalizations, timing of initiation, and rationale for timing. We will also monitor adverse events to ensure maximizing peritoneal dialysis use has no adverse impact on patient outcomes. The Dialysis, Measurement and Reporting system will be the system for data recording and reporting.

Living Donor Kidney Transplant Working Group: The Living Donor Kidney Transplant Working Group has already been launched, and is charged with addressing barriers to living donor kidney transplantation and increasing the rate of living donor kidney transplantation across Alberta. Three sub-groups have been formed and will:

- develop and implement enhanced education for donors, recipients, and care providers.

- focus on process improvements intended to streamline the donor and recipient work up.
- explore and implement approaches to overcome financial barriers to living donation.

While the specific strategies within each of these groups are still to be determined, the Living Donor Kidney Transplant Working Group will draft a comprehensive plan to be implemented in collaboration with Alberta Kidney Care and Alberta's transplant programs.

How we will know we are successful

- Increased number of living donor kidney transplants.
- Increased number of patients on peritoneal dialysis within 180 days of starting renal replacement therapy.
- Increased number of patients on conservative kidney management.
- Decreased number of patients starting dialysis earlier than Canadian guidelines.



“I am honoured to be part of the group of dedicated health professionals, administrators and advisors who are the Kidney Health Strategic Clinical Network™. We come to the network from varied backgrounds, experiences, and perspectives and with different reasons for being passionate about kidney health. Together we are working to improve living kidney donor numbers in Alberta. An increased donor rate will not only benefit our public health system, it will give those waiting for a transplant reason to hope.”

***Tania Woodlock, Patient and Family Advisor**
Living Donor Kidney Transplant Working Group,
Kidney Health Strategic Clinical Network™*

Principles

The Kidney Health Strategic Clinical Network™ has identified six Principles that provide the foundation for the Network and will serve as the basis for establishing and successfully implementing our strategic goals. These principles include:

- Patient and family-centred care
- Engagement
- Culture of quality
- Standardized, evidence-informed approaches
- Sustainability
- Research, innovation, and evaluation

Patient and family-centred care

We will assess patient-reported outcome measures and patient experience to identify opportunities for improvement in kidney care. We will engage patients, families and support networks in the design and evaluation of improvement strategies, including the integration of patient advisors on our Core Committee and working groups.

Engagement

We will engage the broader kidney health community across the continuum of care, including primary health care and continuing care, and spectrum of age (including children and the elderly) and seek input in all stages of an initiative's cycle – from planning to implementation to sustainability. This includes input from providers, patients and families, administrators, policy makers, researchers and community partners.



“We are involved with the Kidney Health Strategic Clinical Network™ because we want to give back to the health care professionals who gave us consistently good care during a very difficult time. And, to pay it forward for the benefit of patients now and in the future. We chose Kidney Health Strategic Clinical Network™ because of our intimate experience both as a caregiver and as a patient who has compromised kidneys. It is amazing to be a part of a group of doctors, nurses, administrators, managers, patient/family advisors, who are all working for the same thing – optimum care for kidney patients across Alberta.”

*Bob & Marilyn Stallworthy, Patient and Family Advisor
Core Committee, Kidney Health Strategic Clinical Network™*

Culture of quality

We will foster a culture of quality improvement, based on the six dimensions of quality (as defined by the Health Quality Council of Alberta), to achieve safe, effective, patient-centred, timely, efficient and equitable kidney care.

Standardized, evidence-informed approaches

We will endeavour to minimize unwarranted variations in practice across the province; ensuring practice is based on current scientific knowledge and best available evidence, while taking into account local context and the needs and preferences of patients and families. Building a robust measurement system, including audit and feedback for clinicians, sites, zones and the province, we can better manage health outcomes for Albertans with Kidney Disease.

Sustainability

The Kidney Health Strategic Clinical Network™ is committed to optimal use of limited health care resources to drive a sustainable system of kidney care based on quality.

Research, innovation, and evaluation

We will foster and support research and innovation in kidney health to improve outcomes, where innovation is any new evidence-informed, value-added device, technology, system or service. We will evaluate our initiatives for impact on our patients and the health system.

Key Enablers

We have identified seven Key Enablers that are essential to the success of the Kidney Health Strategic Clinical Network™. These Enablers include:

- Performance measurement
- Patient reported outcome measures & patient reported experience measures
- Sustainable funding
- Provider and patient education
- Clinical pathways
- Communication
- Pan-Strategic Clinical Network™ approaches

Performance Measurement

The lack of a consistent and reliable renal data across the province has been found to be a significant gap in understanding and measuring kidney health and care in Alberta. Performance measurement, based on reliable provincially consistent data, is required to improve the quality of decisions made regarding priorities for kidney care improvement, the evaluation of improvement initiatives, and the sustainability of positive outcomes. The Kidney Health Strategic Clinical Network™ is committed to performance measurement and the transparent reporting of these measures to stakeholders, and has formed a Quality Indicators and Measurement Working Group. The primary objective of this working group will be to establish a quality indicators and reporting framework that aligns with the strategic priorities identified by the Kidney Health Strategic Clinical Network™ Core Committee. In addition, we will integrate performance measurement into all projects undertaken by the Kidney Health Strategic Clinical Network™, ensuring that metrics are identified and monitored to assess if we are meeting our objectives.

Patient Reported Outcome Measures & Patient Reported Experience Measures (PROMS & PREMS)

In addition to the current gap in Performance Measurement, the Kidney Health Strategic Clinical Network™ has also identified gaps in patient outcome and experience measures as related to kidney care. Specifically, patient reported outcomes measures and experience measures are not routinely measured in any group of chronic kidney disease patients across Alberta. The Kidney Health Strategic Clinical Network™ is committed to identifying, validating and implementing both PROMs and PREMs in patients with kidney failure, as part of the measures for success for each of our strategic goals.

The Kidney Health Strategic Clinical Network™ will ensure that measurement is linked to clinical pathways to improve patient symptoms and outcomes. This enabler will also be addressed by the above mentioned Quality Indicators and Measurement Working Group, will align with work currently underway through the Strategy for Patient-Oriented Research funded *Can-SOLVE Chronic Kidney Disease* initiative addressing chronic kidney disease, and will be conducted in collaboration with Alberta Kidney Care North and South.

Sustainable Funding

Kidney Health Strategic Clinical Network™ initiatives will consider value for money and health system sustainability. In partnership with Alberta Kidney Care, the Kidney Health Strategic Clinical Network™ will explore quality improvement initiatives that support sustainable funding and optimal patient outcomes.



“As a person with a long history of kidney disease, ten years on various modalities of dialysis and recently a kidney transplant, I am able to share these personal health experiences as a patient advisor and seek to influence and guide strategies in our healthcare system to help create optimal kidney health for all Albertans. As a member of the Core Committee I participate at all meetings as a patient voice giving feedback on policies, strategic goals, patient education materials and research projects. Helping to influence improvements in the lives of patients with kidney disease and working with dedicated professionals is an exciting and rewarding challenge.”

*Bonnie Corradetti, Patient and Family Advisor
Core Committee, Kidney Health Strategic Clinical Network™*

Provider and patient education

Education for both patients and providers was identified as a major gap to kidney care in Alberta. Alberta Kidney Care and the Kidney Health Strategic Clinical Network™ have already made provider education a priority with the provincial roll-out of *Treatment Options Pathway for Kidney Failure* education (including a group-education class entitled *Planning Your Kidney Treatment: First Steps*) and will look to implement evidence-based provincially consistent patient education, knowledge translation and multi-disciplinary provider education strategies through all our initiatives. While the initial education has focused on the needs of the largest group of individuals on dialysis, work is underway to also create more culturally appropriate education for Indigenous groups. In addition, the Living Kidney Donor Transplantation Working Group will create enhanced education for donors, recipients, and providers.

Clinical pathways

The Kidney Health Strategic Clinical Network™ will utilize clinical pathways, particularly to assist with management of early chronic kidney disease, consisting of evidence-informed, patient-centred interdisciplinary care to help patients affected by kidney disease achieve optimal health outcomes. In particular, the Kidney Health Strategic Clinical Network™ will address this enabler by continuing work on the chronic kidney disease and Conservative Kidney Management pathways.

Communication

To ensure the Kidney Health Strategic Clinical Network™ achieves our mission, effective communication is essential. All Kidney Health Strategic Clinical Network™ initiatives will incorporate strategies to optimize communication between providers, and between patients and providers to ensure that information is accessible throughout the patient's journey, and thereby improve the delivery of kidney care and health outcomes. The Kidney Health Strategic Clinical Network™ Communication and Engagement plan will ensure we address this enabler.

Pan-Strategic Clinical Network™ Approaches

The Kidney Health Strategic Clinical Network™ is committed to partnering with other Strategic Clinical Networks™ to leverage existing projects, optimize resources and engage appropriate partners. Likely partners include, but are not limited to: Population Public & Indigenous Health Strategic Clinical Network™, Diabetes, Obesity and Nutrition Strategic Clinical Network™, Cardiovascular Health & Stroke Strategic Clinical Network™, Surgery Strategic Clinical Network™ and the Seniors Health Strategic Clinical Network™.

Research and Innovation Plan

The Kidney Health Strategic Clinical Network™ intends to develop a research and innovation plan in 2017. This plan will be well aligned with Alberta Health Services Strategy for Clinical Health Research, Innovation and Analytics and our strategic goals and priorities. This plan will outline our research goals and the role that the Strategic Clinical Network™ will have in research and innovation for kidney health through to 2019. It will also describe the Strategic Clinical Network™ accountabilities in relation to research and innovation underway in Alberta.

Communication and Engagement Plan

As mentioned above, the Kidney Health Strategic Clinical Network™ is in the process of developing a communication and engagement plan. This plan will outline how the Strategic Clinical Network™ intends to communicate and engage with network members and our partners over the next three years and will also align with the communication plan currently being developed for Alberta Kidney Care. The objectives of this plan are:

- To ensure that Strategic Clinical Network™ initiatives and tools are relevant and useful for patients and families as well as providers.
- To achieve effective two-way communication between the Strategic Clinical Network™ and its stakeholders – including front-line staff, patients and families, clinicians, nephrologists (including community nephrologists) and primary care providers, researchers, administrators, policy makers and community organizations to support best practice change and support for Strategic Clinical Network™ initiatives such as: dialytic therapies, transplantation, and conservative kidney management.
- To strengthen strategic partnerships in order to leverage and support connections, skills and resources of our partners including Alberta Kidney Care North & South, Alberta's Transplant Programs, the Kidney Foundation of Canada, Canadian Blood Services, other community groups and government agencies.

Conclusion

The strategies identified in this three year Transformational Roadmap will push Alberta to a leadership position within Canada in prevention, treatment and application of evidence-based practice at all levels of kidney care, and will improve outcomes – all developments fully aligned with our strategic intent and mission. We look forward to working together with our network partners to meet the challenges and opportunities ahead.



Glossary

Acute Kidney Injury

An abrupt or rapid decline in kidney function that often occurs in people with acute medical and surgical illness and those who are hospitalized. When severe patient may need to start dialysis urgently. The condition is associated with prolonged hospital admission, high costs of care, and short and long-term morbidity and mortality including chronic kidney disease.

Appropriateness

Health services are relevant to user needs and are based on accepted or evidence-based practice.

Albuminuria

Albumin is the main protein found in the blood, and small amounts of albumin appear in the urine normally. Albuminuria refers to an excess amount of albumin in the urine, and is a sensitive marker of kidney disease. People with albuminuria are at higher risk of progression to kidney failure, as well as heart attacks and stroke.

Angiotensin-Converting Enzyme inhibitors

A pharmaceutical drug used primarily for the treatment of hypertension (elevated blood pressure) and congestive heart failure.

Angiotensin Receptor Blockers

A pharmaceutical drug that helps relax your blood vessels, which lowers your blood pressure and makes it easier for your heart to pump blood.

Canadian Institute for Health Information

An independent, not-for-profit organization that provides essential information on Canada's health system and the health of Canadians.

Chronic Kidney Disease

A common, complex, chronic condition, usually occurring in conjunction with other chronic diseases (such as diabetes and cardiovascular disease), that results in the progressive loss of kidney function over a period of months or years. Chronic kidney disease is defined as abnormalities of kidney structure or function (estimated glomerular filtration rate < 60 mls/min/m² – see below) present for > 3 months.



Comorbidity	Comorbidity refers to other chronic medical conditions a patient may have. The simultaneous presence of two chronic diseases or conditions is termed multi-morbidity.
Conservative Kidney Management	Planned, comprehensive, patient-centred care for patients with end stage chronic kidney disease, which integrates palliative care principles (such as advance care planning, goals of care designation, symptom management, psychosocial and family support) with interventions to delay progression of kidney disease and minimize complications and excludes dialysis.
Dialysis	Dialysis is when we replace the function of the kidney using special equipment to clean the blood. There are two basic kinds of dialysis: hemodialysis, and peritoneal dialysis.
Early Dialysis	Initiating dialysis with an estimated glomerular filtration rate >9.5 ml/min/1.73m ² in the absence of symptoms of kidney failure.
Early chronic kidney disease	Defined as chronic kidney disease, where the eGFR is 15-60 ml/min/1.73m ² , or where there are other markers of kidney damage. Early CKD is usually managed through diet and medication.
Electronic medical record	A collection of patient health information that is stored in a digital format and can be shared across different health settings.
End-stage kidney disease	Defined as kidney failure requiring dialysis or kidney transplantation to sustain life.
Estimated Glomerular Filtration Rate (eGFR)	A measure of kidney function that is estimated from a simple blood test (serum creatinine) and other parameters (age, sex, race). In simple terms, eGFR is similar to percent kidney function – those with eGFR <60 mls/min/m ² (similar to 60% kidney function) are deemed to have chronic kidney disease, while those with eGFR <15 mls/min/m ² have kidney failure and require dialysis or kidney transplantation when symptoms of kidney failure develop.



Glomerulonephritis (glomer-u-lo-nuh-FRY-tis)	An inflammatory disease of the kidney, typically caused by an immune response, which usually causes progression to end-stage kidney disease within years.
Hemodialysis	Hemodialysis is when your blood is passed through an artificial kidney, which is called a dialyser. The dialyser filters out the waste and extra fluids. Hemodialysis is usually done for 4 hours three times per week. It is usually done in a hospital or clinic, though patients can be trained to do this at home.
Kidney	The kidneys are bean-shaped organs that remove waste products from blood.
Kidney failure	Kidney failure is defined as advanced chronic kidney disease where the estimated glomerular filtration rate is $< 30 \text{ ml/min/1.73m}^2$. Patients with kidney failure require dialysis when they develop symptoms of kidney failure such as severe fatigue, or nausea.
Living donor transplant	Type of kidney transplant in which a kidney is donated by a live donor, often a blood relative. Live donor transplants tend to last longer than transplants from deceased donors. This is usually because a live donor kidney is healthier and there is often a better genetic match. In addition, the transplant can be planned at the best time for both the donor and the recipient.
Nephrology	The study of kidneys, kidney function and the renal system.
Patient-reported experience measure (PREM)	Measurement instrument that patients complete to capture their view of what happened during their health care visit – in particular their experience.
Patient-reported outcome measure (PROM)	Measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health. The KDQOL-SF, ESAS, and Euroqol EQ-5D are all examples of PROMs.



Peritoneal Dialysis

Peritoneal dialysis is when the blood is cleaned inside the body through the peritoneum. A soft rubber tube is placed in the abdomen and clean dialysis fluid is poured in and out of the abdomen 4 times per day, or using a cyclor machine which does the dialysis at night while people sleep.

Renal Replacement Therapy

Therapy that replaces the normal blood-filtering function of the kidney, or replaces the kidney, including: hemodialysis, peritoneal dialysis or kidney transplant.

Social Determinants of Health

The social determinants of health influence the health of populations. They include income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture.

Statin

A class of lipid-lowering medications that inhibit the enzyme HMG-CoA reductase which plays a central role in the production of cholesterol.

Strategic Clinical Networks™

Networks developed by Alberta Health Services comprised of people who are passionate and knowledgeable about specific areas of health, challenging them to find new and innovative ways of delivering care that will provide better quality, better outcomes and better value for every Albertan.

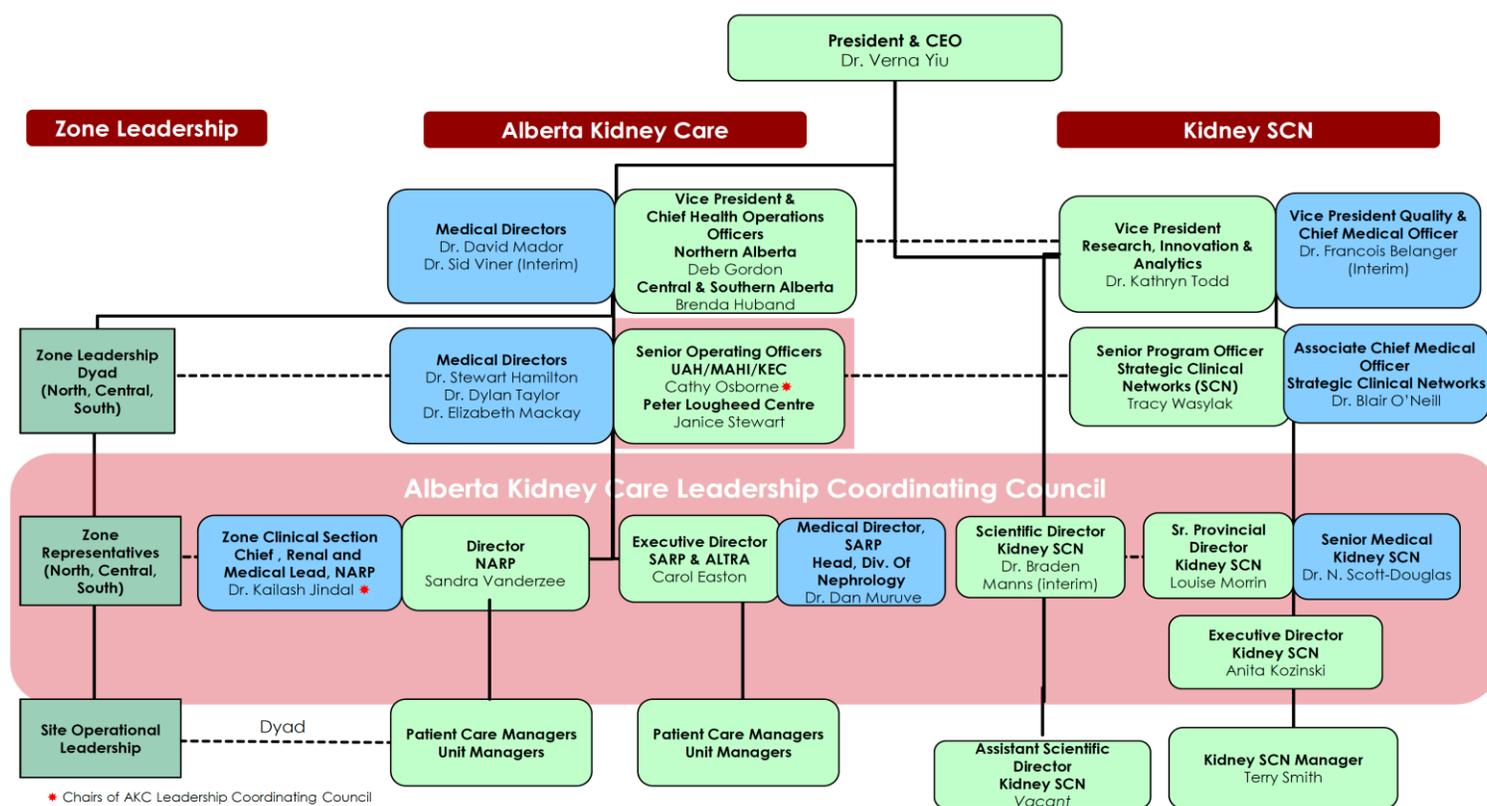


Appendix A:

Alberta Kidney Care and Kidney Health Strategic Clinical Network™ Organizational Structure



Alberta Kidney Care & Kidney SCN Integration Mechanism



Appendix B: Strategic Clinical Network™ Leadership and Core Committee Members

Leadership Team

Nairne Scott-Douglas, Dr.	<i>Senior Medical Director</i>
Louise Morrin	<i>Senior Provincial Director</i>
Anita Kozinski	<i>Executive Director</i>
Terry Smith	<i>Manager</i>
Braden Manns, Dr.	<i>Interim Scientific Director</i>
Vacant	<i>Assistant Scientific Director</i>

Core Committee

Andrew Wade, Dr.	<i>Pediatric Nephrologist, Alberta Childrens Hospital</i>
Barbara Salter	<i>Registered Nurse, Home Hemodialysis, Northern Alberta Renal Program</i>
Carol Easton	<i>Executive Director, Southern Alberta Renal Program and ALTRA</i>
Cathy Osborne	<i>Senior Operating Officer, University of Alberta Hospital, Mazankowski Alberta Heart Institute, Kaye Edmonton Clinic</i>
Crystal Browne	<i>Area Manager, Seniors Health, North Zone</i>
Dan Muruve, Dr.	<i>Medical Director, Southern Alberta Renal Program</i>
Daniel Marchand	<i>Senior Director, Strategy Implementation</i>
Denise Fillier	<i>Patient Care Manager, Southern Alberta Renal Program</i>
Donna Ouelette	<i>Director, Clinical Quality Improvement, North Zone</i>
Flavia Robles	<i>Executive Director, Kidney Foundation (Northern Alberta & The Territories)</i>
Francine Girard	<i>Associate Professor, University of Montreal</i>

Janet Stadnyk	<i>Director, Nutrition & Food Services</i>
Janice Stewart	<i>Senior Operating Officer, Peter Lougheed Centre</i>
Jenny Wichart	<i>Clinical Practice Lead, Pharmacy</i>
Joyce Van Deurzen	<i>Executive Director, Kidney Foundation (Southern Alberta)</i>
Judy MacDonald, Dr.	<i>Medical Officer of Health, Calgary Zone</i>
Julie Nhan	<i>Nurse Practitioner, Nephrology, Northern Alberta Renal Program</i>
Kailash Jindal, Dr.	<i>Medical Director, Northern Alberta Renal Program</i>
Kym Jim, Dr.	<i>Nephrologist, Central Zone</i>
Lana Chivers	<i>Senior Director Operations: Covenant Health</i>
Leasa Sulz	<i>Renal Transplant Coordinator, Northern Alberta Renal Program</i>
Lee Anne Tibbles, Dr.	<i>Associate Professor; Medical Director, Southern Alberta Transplant Program (ALTRA)</i>
Marilyn Bartoszyk	<i>Patient Care Manager, Southern Alberta Renal Program</i>
Matthew James, Dr.	<i>Assistant Professor, University of Calgary; Nephrologist</i>
Neesh Pannu, Dr.	<i>Professor of Medicine, University of Alberta; Nephrologist</i>
Neil Thompson	<i>Social Worker, Southern Alberta Renal Program</i>
Peter Campbell	<i>Acting Director, Alberta Health</i>
Robert Pauly, Dr.	<i>Associate Professor of Medicine, University of Alberta; Nephrologist</i>
Sandra Cockfield, Dr.	<i>Medical Director, Renal Transplant Program Northern Alberta</i>
Sandra Vanderzee	<i>Director, Northern Alberta Renal Program</i>
Sean Chilton	<i>Chief Zone Officer, South Zone</i>
Sherie Allen	<i>Senior Operating Officer, Central Zone</i>
Stacy Greening	<i>Senior Operating Officer, North Zone</i>
Tina Nicholson, Dr.	<i>Medical Lead – Calgary Foothills Primary Care Network (Cochrane)</i>
Tracy Schwartz	<i>Patient Care Manager, Northern Alberta Renal Program</i>



Vinay Deved, Dr. *Nephrologist, Edmonton*
Vishal Bhella, Dr. *Family Physician, Calgary*

Patient Engagement

Bonnie Corradetti *Patient Advisor (Calgary)*
Bob and Marilyn Stallworthy *Patient Advisors (Calgary)*
Mike Simoens *Patient and Community Engagement Researcher (Calgary)*
Tracey Ricard *Patient Advisor (Edmonton)*

Support Members

Alice Ndayishimiye *Health Technology Assessment Analyst*
Allan Ryan *Director, Clinical Analytics*
Christi Retson-Spalding *Senior Communication Advisor*
Colleen Shepherd *Director, Information Technology Clinical Services*
Jessica Lamb *Senior Consultant, Engagement & Patient Experience*
Linda Dziuba *Senior. Practice Lead – Social Work*
Susan Sobey *Senior Planner, Planning & Performance*

Alternates (Delegate)

Joyce Buzath *Director, System and Service Planning; Central Zone, Planning & Performance*
Yvette Dick *Quality Assurance Consultant, Clinical Quality Assurance*

References

1. Determining the research priorities for patients with chronic kidney disease not on dialysis. **Hemmelgarn, BR et al.** 2016, Nephrol. Dial. Transplant. doi:10.1093/ndt/gfw065
2. Setting Research Priorities for Patients on or Nearing Dialysis. **Manns, BJ et al.** 2014, CJASN. doi:10.2215/CJN.01610214
3. **The Kidney Foundation of Canada.** What is kidney disease. [Online] [Cited: May 16, 2016.] <http://www.kidney.ca/kidney-disease>.
4. Prevalence estimates of chronic kidney disease in Canada. **Arora P., Vasa P., Brenner D., Iglar K., & McFarlane, P.** 9, s.l. : CMAJ, 2013, Vol. 185.
5. **Mayo Clinic.** Chronic Kidney Disease Causes. [Online] Mayo Foundation for Medical Education and Research, 2016. [Cited: May 20, 2016.] <http://www.mayoclinic.org/diseases-conditions/kidney-disease/basics/causes/con-20026778>.
6. **Kidney Health Strategic Clinical Network™.** Quality of Care in Early Stage Chronic Kidney Disease 2012-2013. s.l. : Alberta Health Services, 2015.
7. **US Renal Data System.** USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States . Bethesda, MD: National Institutes of Health, 2012.
8. A study of the quality of life and cost-utility of renal transplantation. **Laupacis, A., Keown, P., Pus, N., Krueger, H., Ferguson, B., Wong, C., & Muirhead.** 1996, Kidney International, pp. 235 – 242.
9. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. **Wolfe R, Ashby V, Milford E, Ojo A, Ettenger R, Agodoa L, et al.** 1999, New England Journal of Medicine, pp. 1725-1730.
10. Cost analysis of ongoing care of patients with end-stage renal disease: the impact of dialysis modality and dialysis access . **Lee H, Manns B, Taub K, et al.** 2002, American Journal of Kidney Diseases, pp. 611-622.
11. **Levin, A.** Can-SOLVE Chronic Kidney Disease Research Proposal. 2015.

12. Economic evaluation of dialysis therapies. **Klarenbach S, Tonelli M, Chui B, Manns BJ.** 11, 2014, Nat Rev Nephrol, Vol. 10, pp. 644-652.
13. Health care costs of peritoneal dialysis technique failure and dialysis modality switching. **Chui BK, Manns B, Pannu N, et al.** 1, s.l. : American Journal of Kidney Diseases: The official Journal of the National Kidney Foundation, 2013, Vol. 61.
14. **Southern Alberta Renal Program.** Dialysis and Transplant Data. Calgary : Alberta Health Services, 2016.
15. **Northern Alberta Renal Program.** Dialysis and Transplant Data. Edmonton : Alberta Health Services, 2016.
16. **Kidney Health Strategic Clinical Network™.** Prevalence of severe kidney disease and use of dialysis and transplantation across Alberta from 2004-2013. Alberta Health Services, 2015.
17. The economics of end-stage renal disease care in Canada: incentives and impact on delivery of care. **Manns B, Mendelsohn D, Taub K.** 7, Int J Health Care Finance Econ, 2007, pp. 149-169
18. **Kidney Disease Improving Global Outcomes.** Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. 2012.
19. **Statistics Canada.** Population by sex and age group, by province and territory. [Online] Statistics Canada, 2015. [Cited August 11, 2016.] <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo31a-eng.htm>
20. **BC Transplant.** 10 year transplant trends by organ group. [Online] BC Transplant, 2016. [Cited August 11, 2016] <http://www.transplant.bc.ca/statistics-research/transplants-bc-by-group>
21. **Davison S & Fassbender, K.** AIHS PRIHS 2 Grant Application: Development, Implementation and Evaluation of a Provincial Conservative Kidney Care Clinical Pathway. 2014.
22. Access to health care among status Aboriginal people with chronic kidney disease. **Gao S, Manns BJ, Culleton BF, et al.** 10, Nov 4, 2008, CMAJ, Vol. 179, pp. 1007-1012.
23. Mass screening for chronic kidney disease in rural and remote Canadian First Nations People: Methodology and demographic characteristics. **Lavallee B, Chartrand C, McLeod L, et al.** 9, 2015, Canadian Journal of Kidney Health and Disease, Vol. 2.

24. Knowledge translation for nephrologists: strategies for improving the identification of patients with proteinuria. **Hemmelgarn BR, Manns BJ, Straus S, et al.** 6, 2012, Journal of Nephrology, Vol. 25, pp. 933-943.
25. Hospital-acquired renal insufficiency: A prospective study. **Hou SH, Bushinsky DA, Wish JB, Cohen JJ, Harrington JT.** 1983, Am J Med, Vol. 74, pp. 243-248.
26. Long-term risk of mortality and other adverse outcomes after acute kidney injury: a systematic review and meta-analysis. **Coca SG, Yusuf B, Shlipak MG, Garg AX, Parikh CR.** 2009, Am J Kidney Dis., Vol. 53, pp. 961-973.
27. Raising awareness of acute kidney injury: a global perspective of a silent killer. **Lewington A., Cerda J, Mehta R.** 2013, Kidney Int., Vol. 84, pp. 457-467.
28. Acute kidney injury, mortality, length of stay, and costs in hospitalized patients. **Chertow GM, Burdick E, Honour M, Bonventre JV, Bates DW.** 2005, J Am Soc Nephrol, Vol. 16, pp. 3365-3370.
29. Community-based incidence of acute renal failure. **Hsu CY, McCulloch CE, Fan D, Ordonez JD, Chertow GM, Go AS.** 2007, Kidney Int, Vol. 72, pp. 208-212.
30. Incidence and mortality of acute renal failure in Medicare beneficiaries 1992 to 2001. **Xue JL, Daniels F, Star RA et al.** 2006, J Am Soc Nephrol., Vol. 17, pp. 1135-1142.
31. Chronic dialysis and death among survivors of acute kidney injury requiring dialysis. **Wald R, Quinn RR, Luo J et al.** 2009, JAMA, Vol. 302, pp. 1179-1185.
32. Adding insult to injury: a review of the care of patients who died in hospital with a primary diagnosis of acute kidney injury (acute renal failure). **Stewart J, Findlay G, Smith N, Kelly K, and Mason, M.** 2009
33. Improving Prevention, Early Recognition and Management of Acute Kidney Injury after Major Surgery: Results of a Planning Meeting with Multidisciplinary Stakeholders. **James MT, Dixon E, Roberts DJ, et al.** Can J Kidney Health Dis. 2014;1:20.
34. The impact of documentation of severe acute kidney injury on Mortality. **Wilson FP, Bansal AD, Jasti SK et al.** 2013, Clin Nephrol.
35. Development of a clinical research agenda for acute kidney injury using an international, interdisciplinary, three-step modified delphi process. **Kellum JA, Mehta RL, Levin A. et al.** 2008, Clin J Am Soc Nephrol, Vol. 3, pp. 887-894.
36. Canadian Society of Nephrology Commentary on the 2012 KDIGO Clinical Practice Guidelines for Acute Kidney Injury. **James MT, Bouchard J, Ho J, et al.** 2013, Am J Kidney Dis.

37. Associations between acute kidney injury and cardiovascular and renal outcomes after coronary angiography. **James MT, Ghali WA, Knudtson ML, Ravani P, Tonelli M, Faris P, Pannu N, Manns BJ, Klarenbach SW, Hemmelgarn BR.** 2011, *Circulation*, pp. 409-416.
38. A predictive model for progression of chronic kidney disease to kidney failure. **Tangri N, Stevens LA, Griffith J, et al.** 15, Apr 20, 2011, *JAMA*, Vol. 305, pp. 1553-1559.
39. Contrast-induced acute kidney injury and risk of adverse clinical outcomes after coronary angiography: a systemic review and meta-analysis. **James MT, Samuel SM, Manning MA, Tonelli M, Ghali WA, Faris P, Knudtson ML, Pannu N, Hemmelgarn BR.** 2013, *Circ Cardiovasc Interv*, pp. 37-43.
40. Incremental Health Care Costs of Acute Kidney Injury in Alberta. **Collister D, Pannu N, James MT, Ye P, Hemmelgarn BR, and Klarenbach SW.** s.l. : Canadian Society of Nephrology, 2014.
41. Diabetes, kidney disease and cardiovascular disease patients. Assessing care of complex patients using outpatient testing and visits: additional metrics by which to evaluate health care system functioning. **Levin A, Chaudhry MR, Djurdjev O, Beaulieu M, Komenda P.** 9, Sep 2009, *Nephrology, dialysis, transplantation: official publication of the European Dialysis and Transplant Association - European Renal Association*, Vol. 24, pp. 2714-2720.
42. Access to care for aboriginal compared to non-aboriginal people with chronic kidney disease. **Gao, S., Manns, B., Culleton, B. et al.,** 17:637A, s.l. : *J Am Soc Nephrol*, 2006.
43. Comorbidity as a driver of adverse outcomes in people with chronic kidney disease. **Tonelli M, Wiebe N, Guthrie B, James MT, Quan H, Fortin M, Klarenbach SW, Sargious P, Straus S, Lewanczuk R, Ronksley PE, Manns BJ, Hemmelgarn BR.** 2015, *Kidney International*, Vol. 88, pp. 859–866.
44. Relation between kidney function, proteinuria, and adverse outcomes. **Hemmelgarn, B.R., Manns, B.J., Lloyd, A. et al.** 303, 2010, *JAMA*, pp. 423–429.
45. National Kidney Foundation Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification. **Levey, AS et al.** 139, s.l. : *Ann Intern Med*, 2003, pp. 137-147.
46. A Cluster Randomized Trial of an Enhanced eGFR Prompt in Chronic Kidney Disease. **Manns B, Tonelli M, Culleton B, et al.** 4, 2012, *Clinical Journal of the American Society of Nephrology*, Vol. 7, pp. 565-572.

47. A Chronic Kidney Disease clinical pathway for primary care. **Hemmelgarn, B & Donald, M.** 2016.

48. **Canadian Institute for Health Information.** e-Statistics on organ transplants, waiting lists and donors. [Online]. Canadian Institute for Health Information, 2016. [Cited August 22, 2016] <https://www.cihi.ca/en/types-of-care/specialized-services/organ-replacements/e-statistics-on-organ-transplants-waiting>

49. A randomized, controlled trial of early versus late initiation of dialysis. **Cooper BA, Branley P, Bulfone L, et al.** 2010, N Engl J Med, pp. 609-619.

50. **Quinn R, Ravani P, Pannu N.** AIHS PRIHS 2 Grant Application: Improving outcomes and reducing costs associated with dialysis therapy: the impact of modality choice and optimal timing of dialysis initiation. 2014.

51. Conservative care for end-stage kidney failure in the UK: a national survey. **Okamoto I, Tonkin-Crine S, Rayner H, Murtagh FEM, Farrington K, Caskey F, Tomson C, Loud F, Greenwood R, O'Donoghue DJ, Roderick P.** 2014, CJASN.