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# End-Stage Renal Disease Among Aboriginal Peoples in Canada: Treatment and Outcomes

## Summary

The burden of end-stage renal disease (ESRD) is high among Aboriginal populations in Canada, as well as globally, due to the rising rates of obesity and diabetes. ESRD is the final stage of chronic kidney disease, for which dialysis and transplantation are the main treatment options.

Using data from the Canadian Organ Replacement Register (CORR), this report examines differences between Aboriginal and non-Aboriginal ESRD patients on a number of factors, such as socio-demographic context, distance to receive treatment, co-existing health conditions, treatments received and treatment-related outcomes. The analyses revealed that Aboriginal peoples are more likely to receive treatment for ESRD compared with others in Canada. Further, when compared with other patients, Aboriginal ESRD patients

- Are younger and are more likely to have diabetes and to be obese;
- Are more likely to live in remote areas and travel much further to receive treatment;
- Are less likely to receive kidney transplantation, even after controlling for factors such as age, sex and diabetes (however, graft survival rates are similar among those that do receive a transplant); and
- Tend to have lower patient survival rates in the period following initial dialysis treatment, even after adjusting for age, sex, diabetes and distance to treatment.

To inform potential next steps, the report also provides examples of initiatives that demonstrate effective or promising approaches to health service organization and delivery that support Aboriginal populations with ESRD. Some successful approaches focus on providing culturally appropriate services, overcoming geographic barriers to accessing care, and involving community action to improve local health services and care for chronic health conditions.

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## Analysis in Brief

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## Introduction

Chronic kidney disease and end-stage renal disease (ESRD) have been recognized as a growing public health problem for populations across the globe, with higher rates in Aboriginal populations, given the associations with diabetes and obesity.<sup>1–5</sup> ESRD is the final stage of chronic kidney disease, with less than 2% of chronic kidney disease patients progressing to ESRD.<sup>6</sup> As there is no cure for ESRD, dialysis and transplantation are the main treatment options, and these are not without challenges. For example, dialysis requires dedication on the part of patients, who must adhere to treatment protocols and regular procedures, while transplantation is dependent on the availability of donor organs and patient suitability.

Limited information is available on patient characteristics and treatment-related factors for ESRD among Aboriginal peoples living in Canada. Some research has shown that compared with others in Canada, Aboriginal populations have higher prevalence of ESRD, higher death rates from chronic kidney disease<sup>2, 7–9</sup> and higher rates of chronic disease risk factors, especially obesity and diabetes.<sup>10, 11</sup> This higher prevalence of diabetes and obesity places Aboriginal populations in Canada at an increased risk of developing ESRD,<sup>12</sup> likely due to the combination of younger age at onset of diabetes and poorer glycemic and blood pressure control.<sup>2</sup> Further, diabetes affects suitability for specific treatments, such as kidney transplants, and diagnoses and/or family history of diabetes can make it difficult for ESRD patients to receive live kidney donations, since diabetes can increase the risk of post-operative complications for both donor and recipient.<sup>13, 14</sup> However, a range of other factors can also affect suitability and uptake of treatment therapies for ESRD, such as patient history of health problems (particularly heart disease, obesity, blood circulation problems and cancer), compliance with treatment, and emotional and psychological factors, as well as environmental, geographical and socio-economic contexts.<sup>15–18</sup>

This report attempts to fill an important gap in our knowledge of treatment experiences and outcomes of ESRD among Aboriginal peoples in Canada by exploring such factors as socio-demographic context, distance to receive treatment, co-existing health conditions, treatments received and treatment-related outcomes. By examining differences between Aboriginal and non-Aboriginal patients, this report assesses whether disparities exist between these two groups and contributes to identifying ways to address the gaps. Further, this report also highlights and synthesizes examples of promising approaches, initiatives and strategies aimed at supporting Aboriginal patients with ESRD. By providing this pan-Canadian information, our goal is to contribute to enhanced treatment, research and patient care for Aboriginal ESRD patients. As such, the information is intended to be valuable to policy-makers and health system managers, as well as primary and specialized care practitioners across Canada who strive to ensure that high-quality nephrology care is available and accessible to this at-risk population.

## Methods

#### **Data Source and Populations**

Data from the Canadian Organ Replacement Register (CORR) at the Canadian Institute for Health Information (CIHI) was used to examine differences between Aboriginal and non-Aboriginal ESRD patients on a number of factors relating to their treatment experiences and outcomes. CORR is a national information system, collecting data from across Canada on organ failure, transplantation and donation, and renal dialysis. Its mandate is to record and analyze the level of activity and outcomes of solid organ transplantation and renal dialysis.

CORR is one of the few pan-Canadian information systems that includes an ethnic identifier with "Aboriginal" listed as a reporting option. This identifier was used in this study to compare Aboriginal and non-Aboriginal ESRD patients. "Non-Aboriginal" is defined as all other ethnic groups combined. It should be noted that the ethnic identifier in CORR does not allow for the identification of First Nations, Inuit and Métis patients.

Presenting information on this broad Aboriginal category does not distinguish the clinical and treatment differences between these Aboriginal groups (for instance, the prevalence of diabetes is much lower among Inuit<sup>10</sup> and hence the burden of ESRD among Inuit may not be as great as for First Nations or Métis). The ethnic identifier is also subject to under-reporting by the health care professionals who record this information, as there is no standard approach to collecting information on patients' ethnic background. See Appendix A for further details.

The results of this study are based on the patient population age 20 and older, and include both incident and prevalent cases of ESRD, given that our interest is both in those initiating treatment (incident cases) and those receiving treatment (prevalent cases). Incident patients are those who began renal replacement therapy for the first time within a given calendar year; cases between January 1, 2002, and December 31, 2011, were included in this study as the incident patient cohort. The prevalent cohort included patients who were on hemodialysis or peritoneal dialysis or who had been transplanted as of December 31, 2011. Not all incident cases may be represented in prevalent counts, due to incident patient deaths and loss to follow-up before the end of a given calendar year. Aboriginal patients account for almost 1 in 20 incident and prevalent cases overall.

Prevalent cases were used to explore differences between Aboriginal and non-Aboriginal patients who were receiving ongoing treatment, on factors such as age, sex, diabetes diagnoses, distance travelled to treatment and treatment therapies received. Dialysis and graft survival outcomes are based on incident cases as they relate to initiation of treatment.

#### **Statistical Analysis**

Descriptive analysis was undertaken to compare patient characteristics (age, sex, urban/rural location, adjusted household income and distance travelled to receive treatment) and treatment therapies for Aboriginal and non-Aboriginal patients. Risk-adjusted transplantation percentages were estimated by fitting a log-binomial generalized linear model with age, sex and diabetes as covariates. Dialysis and transplant outcomes were assessed according to adjusted survival curves (dialysis outcomes adjusted for age, sex, diabetes and distance to treatment; transplant outcomes adjusted for age, sex and diabetes). Survival outcomes were further assessed using a proportional hazard (Cox) regression model, including ethnicity, age, sex, diabetes, overweight (body mass index categories), referral time, peritoneal dialysis as initial treatment (versus hemodialysis), distance to treatment, dialysis initiation year and province of treatment as covariates for transplantation and dialysis survival (see Appendix A for further details on these methodologies and classifications used).

#### **Intervention Analysis**

The scan of interventions, which focused on services related to chronic kidney disease that aim to support Aboriginal patients entering the health care system, was compiled from literature searches and web-based scanning. This scan identified 58 examples of evaluated and non-evaluated interventions from Canada and comparable international jurisdictions (mainly Australia and the United States). A web-based search using Ovid Medline, for the period 2006 to 2011, identified articles and grey literature pertaining to kidney failure, pre-existing conditions (that is, common ESRD comorbidities such as diabetes), treatments for kidney failure and ESRD management, Aboriginal health, and culturally informed or culturally safe health care.

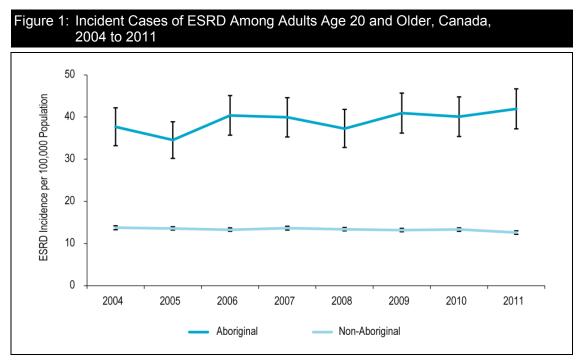
## Results

### **Patient Characteristics**

Regular access to, and use of, services to treat ESRD is influenced by socio-demographic, geographical and clinical factors, with these factors also influencing access to treatment and treatment outcomes. This section presents information on these factors relating to patient characteristics (for example, age, income and distance from health care facilities offering treatment for ESRD) and clinical profile of ESRD patients, as well as rates of ESRD among Aboriginal and non-Aboriginal patients.

#### Higher Incidence and Prevalence of ESRD Among Aboriginal Peoples

Aboriginal peoples were more than three times as likely to be new patients receiving treatment for ESRD (incident cases) as non-Aboriginals (age-standardized rate of 42 versus 13 per 100,000 in 2011). The growth in ESRD rates remained fairly steady for both Aboriginal and non-Aboriginal populations between 2004 and 2011 (see Figure 1, and Table B1 in Appendix B).



#### Note

Rates have been standardized to age distribution of 2006 Aboriginal identity population in Canada (see Appendix A for further details on methods and trend years).

#### Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

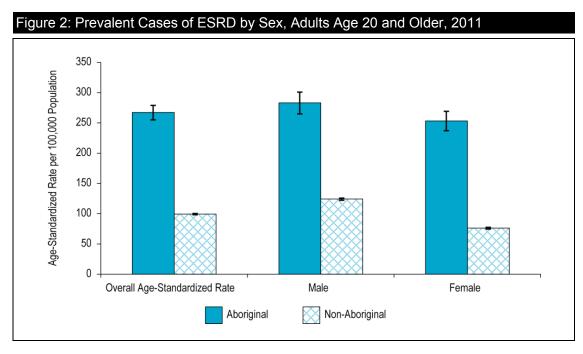
For ESRD prevalent cases (that is, patients who are alive and receiving renal replacement therapy at a point in time), Aboriginal peoples were almost three times as likely to be receiving treatment for ESRD as non-Aboriginals (age-standardized rate of 267 versus 99 per 100,000 in 2011; see Figure 2).

#### Aboriginal ESRD Patients Younger, More Likely to Have Diabetes and Be Obese

Aboriginal ESRD patients had a median age that was almost a decade younger than their non-Aboriginal counterparts (median age of 54 versus 62 for prevalent ESRD cases, p≤0.01). Rates were also higher for men than for women in both Aboriginal and non-Aboriginal groups. Non-Aboriginal men had rates almost twice

those of non-Aboriginal women (age-adjusted rate of 124 versus 76 per 100,000), while the difference in rates for Aboriginal men and women was not as great (283 versus 253 per 100,000, respectively; see Figure 2, and Table B2 in Appendix B).

Aboriginal ESRD patients were almost twice as likely to be diagnosed with diabetes as their non-Aboriginal counterparts (49% versus 27%, respectively,  $p \le 0.01$ ) and were more likely to be obese (40% versus 27%, respectively,  $p \le 0.01$ ) when they began treatment, conditions known to increase the risk of developing ESRD.



#### Notes

Error bars indicate 95% confidence intervals.

All results were significantly different between Aboriginal and non-Aboriginal patients (p<0.05).

Rates have been standardized to age distribution of 2006 Aboriginal identity population in Canada (see Appendix A for further details).

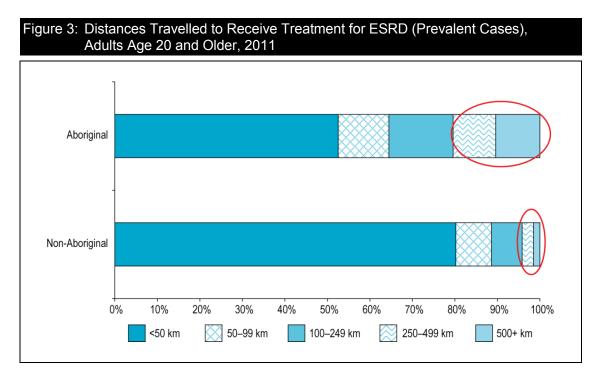
#### Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

#### Aboriginal ESRD Patients More Likely to Live in Socio-Economically Disadvantaged and Remote Areas, and Travel Further to Receive Dialysis

Aboriginal ESRD patients were twice as likely to live in lower-income neighbourhoods as non-Aboriginal ESRD patients. On initiation of treatment, 56% of Aboriginal ESRD patients lived in the least affluent neighbourhoods (lowest household income quintile, adjusted for household size) compared with 24% of non-Aboriginal ESRD patients ( $p \le 0.01$ ) (see Appendix A for further details on income classification used).

One in five Aboriginal patients with ESRD (prevalent cases) was required to travel more than 250 km to a health care facility to receive treatment, compared with less than 5% of non-Aboriginal ESRD patients (Figure 3). Aboriginal patients travelled distances four times greater than their non-Aboriginal counterparts (median distance of 41 km versus 11 km, respectively). This difference is likely driven by the fact that two in five (40%) Aboriginal ESRD patients lived in remote areas (compared with 6% of non-Aboriginal ESRD patients). More than half (53%) of Aboriginal patients were within 50 km of the facility where they received treatment, compared with 80% of non-Aboriginal ESRD patients, which is consistent with the proportion of ESRD patients living in urban areas (50% of Aboriginal and 85% of non-Aboriginal ESRD patients).



#### Notes

See Appendix A for distance calculation.

Distance categories are significantly different between Aboriginal and non-Aboriginal patients (p<0.05).

Postal code information was missing for 7% of prevalent cases.

#### Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

## Box 1: Treatment Options for ESRD

**Hemodialysis** involves cleaning and filtering the blood using a machine and an artificial kidney called the dialyser or filter. Standard hemodialysis involves treatment three times per week in a hospital or community dialysis unit, with sessions lasting up to four hours. Some people are able to perform hemodialysis in their home and often do so at night when they sleep. Advantages of this treatment are expediency and efficiency. Drawbacks for standard hemodialysis are strict dietary guidelines (dialysis done at home at night does not have this limitation), a fixed treatment schedule and the travel required to get to a hospital or community unit.

**Peritoneal dialysis** uses the lining of the abdomen or stomach to filter the toxins and waste products from the blood. This involves filling the abdomen with a dialysis fluid through a permanent catheter and then draining the fluid after a certain length of time. Treatments are usually performed four times a day, with the use of a small machine at home. Advantages of this treatment include more independence, as patients are able to perform the treatment based on their own schedules. Drawbacks include a possible increased risk of infection of the abdominal cavity.

**Kidney transplantation** involves surgically implanting a kidney from a live or deceased donor in the lower abdomen. It is widely considered to be the best treatment option for suitable patients. Kidney transplantation improves both the quality and length of life. Drawbacks include taking ongoing medications to prevent rejection of the kidney, as these medications may cause complications.

**Conservative care** is another treatment choice. Some people consider dialysis to be a burden that only prolongs suffering; for these individuals, medications, diet and other therapies may be used to lessen symptoms. No information is available from CORR on this treatment option.

#### Source

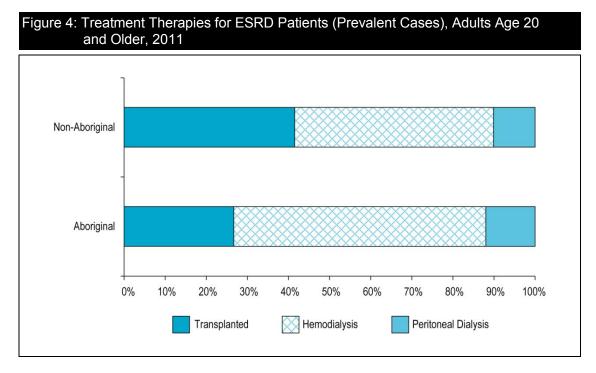
Kidney Foundation of Canada. Website. http://www.kidney.ca/. Accessed November 29, 2012.

## **Treatment Therapies for ESRD**

There are two main treatment routes for ESRD patients: dialysis, which involves the routine aid of artificial kidney machines (dialysers), and kidney transplantation, where a donor kidney is grafted on to one of the patient's failing kidneys. Strengths and limitations of these treatment modalities are presented in Box 1. This section examines disparities in these treatment therapies for Aboriginal and non-Aboriginal patients with ESRD.

#### Aboriginal ESRD Patients Less Likely to Receive Transplantation

For both Aboriginal and non-Aboriginal ESRD patients (prevalent cases), dialysis is a more common treatment therapy than transplantation, and the vast majority of both Aboriginal and non-Aboriginal patients receiving dialysis are on hemodialysis (Figure 4). Comparisons of Aboriginal and non-Aboriginal patients show that Aboriginal ESRD patients were less likely to receive kidney transplants by December 31, 2011 (27% versus 42%, respectively), with these differences persisting after controlling for age, sex and diabetes.



#### Note

Crude percentages are presented; rates have not been adjusted for age, sex, diabetes or distance to treatment. **Source** 

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

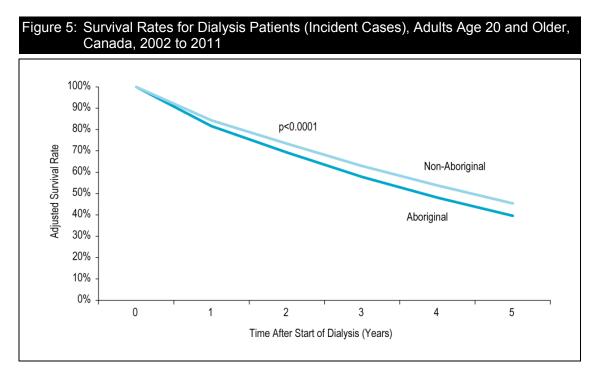
## **Outcomes for ESRD Patients**

Given the greater complexity of conditions (particularly diabetes and obesity) associated with ESRD among Aboriginal patients, the younger age of these patients and the distance barriers to treatment, it is important to know how these factors can impact treatment outcomes. This section provides information on patients' survival after dialysis initiation and kidney transplantation to inform treatment and patient care.

# Aboriginal ESRD Patients Have Lower Dialysis Survival Rates but Similar Graft Survival Rates

Aboriginal ESRD patients had lower survival rates for all five years following initial dialysis treatment than non-Aboriginal patients (rates adjusted for age, sex, diabetes and distance to treatment for the first year: 81.6% versus 84.3%; and by fifth year: 39.6% versus 45.4%, respectively; see Figure 5). These patterns are also consistent with the results of the Cox (proportional hazards) models that found an increased risk of death for Aboriginal patients compared with non-Aboriginal patients after adjusting for age, sex, diabetes and distance to treatment—hazards ratio of 1.33 after controlling for age, reducing to 1.28 after controlling for age, sex and diabetes, reducing further to 1.19 when distance to treatment is also controlled for. This suggests that controlling for diabetes and distance to treatment does narrow the gap in the risk of death between Aboriginal and non-Aboriginal patients; however, it does not fully account for the disparity between these two groups.

The graft survival rates following kidney transplantation were similar for Aboriginal and non-Aboriginal ESRD patients (age-, sex- and diabetes-adjusted rates for the first year: 94.2% versus 94.6%; and by fifth year: 83.6% versus 84.4%, respectively; see Table B3 in Appendix B). Consistent with this pattern, no significant differences in the risk of death were observed in the hazards model after adjusting for the confounding factors.



#### Note

Survival rates are adjusted for age, sex, diabetes and distance to treatment.

#### Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

## Discussion

The results presented in this report have highlighted that disparities exist in the burden of ESRD and treatment-related factors and outcomes for Aboriginal and non-Aboriginal patients. In particular, Aboriginal peoples are at increased risk of being new or existing ESRD patients, travel greater distances to receive ESRD treatment and are less likely to receive transplants. Aboriginal patients on dialysis tended to have lower survival rates than non-Aboriginal ESRD patients, but survival rates for those receiving transplants were similar for both groups.

The higher rate of ESRD among Aboriginal populations—and in this study, receiving treatment for ESRD is largely driven by the higher rates of diabetes and obesity among Aboriginal populations, a finding that is supported by many other studies.<sup>1, 2, 4, 5</sup> These two conditions increase the risk of developing chronic kidney disease and ESRD, and diabetes affects treatment options for ESRD patients, particularly kidney transplants from live donors.<sup>13</sup> Our study found that Aboriginal ESRD patients had lower rates of kidney transplantation than non-Aboriginal patients, even after controlling for age (given their younger age structure), sex and diabetes. This indicates that other factors may be influencing transplantation decisions and rates.

Lower transplantation rates are not unique to Aboriginal populations in Canada. They have been reported by Aboriginal populations elsewhere as well as by ethnic minority groups in Canada (for example, East Asians, Indo-Asians and African Canadians).<sup>18–20</sup> Some of the barriers that have been identified among these groups are also barriers for Aboriginal patients. These include a lack of language interpreters and appropriate educational resources,<sup>21–23</sup> which may adversely affect patients' understanding of treatment protocols and engagements with health care professionals.<sup>23</sup> Further, many cultures, including those of Aboriginal peoples, have adverse perceptions of organ donation,<sup>15, 24, 25</sup> which may also affect the rates of kidney transplantation found in the current study.

Distance to treatment is another potential barrier to care for patients receiving treatment for ESRD, since treatment can require patients to regularly travel to health care facilities to receive care. In the case of those receiving hemodialysis, the treatment regimen necessitates three weekly visits to a health care facility, with sessions lasting up to four hours. The results of this study show that more than one-third of Aboriginal patients live in remote areas and one in five needs to travel more than 250 km to receive treatment for ESRD, which may contribute in part to this study's findings of lower dialysis survival rates for Aboriginal patients. Prakash<sup>23</sup> suggests that limited availability of services and distances from health care facilities may relate to poorer outcomes for dialysis patients due to difficulties with early diagnosis of problems associated with treatment, including internal and external infections. Greater distances travelled for treatment can also create barriers to employment, and affect access to family/social support and participation in land-based subsistence activities during treatment.<sup>26</sup> Distance from health care facilities, however, has not been identified as a barrier associated with rates of transplantation among Aboriginal peoples in Canada.<sup>27</sup>

## Interventions Acting to Improve Chronic Care and End-Stage Renal Disease

Appropriate and effective prevention and care of ESRD requires intervention on multiple levels. To build on the results of the quantitative ESRD data analysis, a pan-Canadian scan was conducted to identify interventions that act on ESRD and its risk factors. These interventions aim to improve the experiences of Aboriginal peoples with kidney disease (and its comorbidities) who enter the health care system, and were organized using the Expanded Chronic Care Model (ECCM). The ECCM directs efforts to reduce the burden of chronic disease toward action on both the determinants of health and the delivery of high-quality health care services.<sup>28</sup> While the model is not specific to the health of Aboriginal populations or end-stage renal disease, it incorporates the various components that reflect the associations between communities (populations), health systems and individuals.<sup>28</sup> The foundation of this model, underpinning the community and health system components, focuses on population and individual-level health outcomes that result from interactions and relationships between patients and practice teams.<sup>28</sup>

Two types of interventions are showcased in this section: those that focus on activities that act directly on ESRD and those that mitigate known risk factors related to the condition prior to onset. Most of these interventions fall within three ECCM categories: Create Supportive Environments, Strengthen Community Action and Delivery System Design/Reorient Health Services. This section explores in further detail these ECCM categories and provides some examples of the promising practices that fall within these categories. For more information about how the ECCM has been used to organize interventions, please refer to Appendix A. Appendix C includes the complete list of interventions examined; some of the features of these interventions include clearly defined goals, sound methodology implementation methods, intersectoral collaboration and, in some cases, evaluation.

### **Create Supportive Environments**

Although documented inequalities in access to care for kidney disease exist among Aboriginal peoples,<sup>16, 21</sup> incorporating culturally appropriate practices may reduce some of the barriers that impede access to care.<sup>35</sup> Providing cultural safety training to health practitioners may increase their understanding of broader cultural factors, cultural safety and barriers that influence the patient–provider relationship.<sup>35, 36</sup>

Some of the interventions identified in this scan focus on improving the home community or clinical environment in order to help improve short- and long-term patient outcomes. One such example is the Six Nations Satellite Dialysis Unit, located in the Grand River Territory of Ontario. This dialysis clinic was established to provide local hemodialysis treatment that allows patients to remain in their home community, close to their social and family support networks.<sup>29</sup> This program is the product of grassroots community action that identified the need for local care; they "[made] their voices heard by governing bodies."<sup>29</sup>

### **Strengthen Community Action**

Making treatment more accessible may improve the experiences of Aboriginal patients with kidney disease, especially those who require hemodialysis treatment several times a week. With the goal of reducing overall onset of renal disease, communities have secured funding for local services, developed educational toolkits and contributed to implementing preventive screening programs.<sup>30, 31, 33, 34</sup> Communities have successfully identified local needs and implemented programs that improve access to screening and treatment and that foster patient empowerment.<sup>30, 31, 33</sup> Collaboration between communities and various levels of government has led to innovative treatment programs that can reduce or eliminate travel time for necessary treatments.<sup>32</sup> Liaison programs aim to enhance the comfort of Aboriginal patients by facilitating access to health services, improving care experiences and building trust between patients and providers.<sup>37–39</sup>

An ESRD toolkit developed by the Elsipogtog Nation, in partnership with local medical practitioners, demonstrates how cultural safety and community health can be improved by integrating community-held knowledge with external research capacity.<sup>30</sup> Elsipogtog Nation, a Mi'kmaq community in New Brunswick, recognized that community members with kidney disease were experiencing difficulty adhering to care management guidelines.<sup>30</sup> Community members partnered with researchers to explore this issue by documenting the experiences of patients who travelled to urban health centres for dialysis treatment.<sup>30</sup> The toolkit was developed to provide information and support to patients with chronic kidney disease, and provided a platform for the community to share their experiences related to kidney disease.<sup>30</sup> The toolkit may also be useful to caregivers and practitioners supporting patients at home and in the clinic.<sup>30</sup>

Health Canada's Health Transfer Policy *First Nations and Inuit Health Transfer* aims to enable accountable health governance at the local level and facilitate the implementation of services that meet the needs of First Nations and Inuit communities.<sup>31</sup> These communities perform health needs assessments to identify priorities and required resources, which are then incorporated into a Community Health Plan.<sup>40</sup> The health transfer program supports the implementation and evaluation process, which incorporates indicators such as community satisfaction, hospitalization rates and other health status data.<sup>40</sup>

#### **Delivery System Design/Reorient Health Services**

According to the ECCM, health services can be reoriented to be responsive to the social and economic needs of patients and their communities.<sup>28</sup> This reorientation may involve local capacity-building to tailor the way that local health services are delivered, or professional education that fosters culturally safe patient–provider interactions.<sup>31, 36</sup> Education and hospital liaison programs can foster confidence and improve the care experience by assisting Aboriginal patients and their families in navigating the health care system.<sup>37</sup> Some programs incorporate technology to assist patients in overcoming distance-related challenges, to facilitate access to specialized services and to provide Aboriginal-focused telehealth infrastructure.<sup>35, 41, 42</sup> Telehealth services have enabled communication between practitioners based in remote facilities and urban specialists.<sup>41</sup> These services also provide patients with video-visitation opportunities that allow them to connect with their communities while receiving treatment away from home, and to connect with families in outlying areas.<sup>35, 41</sup>

One northern Ontario program seeks to strengthen the approaches and practices used by medical professionals who work with local Aboriginal patients. Sioux Lookout's Meno Ya Win Health Centre provides an opportunity for health care provider trainees from the Northern Ontario School of Medicine to gain hands-on experience in a health care environment that incorporates traditional understandings of health into a range of preventive, chronic and acute care services.<sup>32, 43</sup>

Another Alberta-based program delivers a renal failure prevention clinic for eligible residents of the rural Siksika Nation. Local elders, the Siksika Chief and Council and the Siksika Health Committee were involved in the endorsement, design and promotion of the clinic prior to its implementation.<sup>33</sup> With the goal of improving comorbid condition management among this population, a nurse practitioner provides screening, treatment and advice on behaviour modification to clinic participants.<sup>33</sup> This intervention has led to significant improvements in treatment targets such as blood pressure, blood sugar and lipid control.<sup>33</sup>

#### **Next Steps**

The ECCM is a comprehensive framework for the organization of chronic care management in Canada. While not tailored specifically to the needs and characteristics of Aboriginal peoples in Canada, it provided a helpful structure for grouping the initial results of the intervention scan. Following the review of all of the interventions, three overarching themes emerged that are important in considering the delivery of health care services:

- Culture of the local patient population;<sup>35</sup>
- Geographic barriers to care;<sup>21, 30, 43</sup> and
- Community involvement in planning, prevention and treatment activities.<sup>30, 32, 35, 40</sup>

Collaboration among Aboriginal communities, health practitioners and planners can support improvements in health outcomes and the experiences of Aboriginal peoples living with ESRD. Services that reflect the cultural traditions of Canada's Aboriginal peoples may facilitate improved patient–provider communication<sup>36, 44</sup> and the overall comfort of patients undergoing treatment,<sup>44</sup> and lead to improved outcomes and patient satisfaction. In various locations across Canada, geographic barriers have been overcome by expanding the capacity of local facilities, implementing telehealth technologies and bringing screening services directly to patients.<sup>33, 34, 39, 41, 45</sup>

Community involvement in the planning and implementation of local health services and prevention activities can help to ensure that care is appropriate for Aboriginal communities and individuals who are being treated for ESRD.<sup>30, 32, 35, 40</sup>

## Conclusion

This study has shown that there are differences in the rates of ESRD and of treatment therapies and outcomes for Aboriginal and non-Aboriginal ESRD patients. These results suggest that further research is required to address these health disparities. Such research could explore the interrelationships between factors that may contribute to the underlying disparities in comorbidities associated with more frequent ESRD among Aboriginal peoples, as well as factors that influence treatment options, such as availability of organs for donation and under-diagnosis and late diagnosis of ESRD. Since, within a broader context, ESRD among Aboriginal peoples is not only a physical health issue but also an issue of mental, emotional and spiritual well-being,<sup>26, 30, 35</sup> it would also be valuable to explore the lived experiences of ESRD patients and how personal, family and community factors may relate to improved outcomes. A number of promising practices were also identified in this report that demonstrate ways to engage community participation in both acting on ESRD and its risk factors, and informing and organizing action to manage and treat this disease among this high-risk population. The information included in this report will be valuable to health authorities and to primary and specialized care practitioners across Canada who strive to meet the challenge of ensuring that quality nephrology care is made available and accessible to Aboriginal peoples.

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## Appendix A: Data Source, Definitions and Methods

#### **Data Source**

Data from CIHI's CORR was used to examine differences between Aboriginal and non-Aboriginal ESRD patients on a number of factors relating to their treatment experiences and outcomes. CORR is the national information system for organ failure, transplantation and donation, and renal dialysis, with a mandate to record and analyze the level of activity and outcomes of vital organ transplantation and dialysis. It is a longitudinal database that follows recipients with end-stage organ failure from their first treatment following consultation with a nephrologist to their death. CORR receives data from across Canada, from all hospital dialysis programs, regional transplant programs, organ procurement organizations and kidney dialysis services offered at independent health facilities. Coverage for dialysis treatments and transplantation is high within CORR. Patient data comes directly from all provinces; data for patients in Yukon is submitted by B.C., while Alberta submits data for patients in the Northwest Territories and Nunavut. Information is collected for incident (new) and prevalent (existing) ESRD patients.

#### **Aboriginal Identification**

Included in CORR is an ethnic identifier with an option to report Aboriginality. This variable, reported at treatment initiation, was used to create two groups: Aboriginal; and all other ethnic groups combined as non-Aboriginal. The identifier was used to compare Aboriginal and non-Aboriginal ESRD patients on socio-demographic, clinical and treatment characteristics.

#### **Study Population**

The analyses presented here are based on adult ESRD patients age 20 and older receiving renal replacement treatment (hemodialysis, peritoneal dialysis or transplant). Incident patients are those who began renal replacement therapy for the first time within a given calendar year; cases between January 1, 2002, and December 31, 2011, were included in this study as the incident patient cohort. This includes 2,658 Aboriginal and 47,402 non-Aboriginal incident patients. The prevalent cohort included patients who were on hemodialysis or peritoneal dialysis or who had been transplanted as of December 31, 2011. This includes 1,885 Aboriginal and 35,379 non-Aboriginal prevalent patients. Not all incident cases may be represented in prevalent counts, due to patient deaths and loss to follow-up among the incident cases before the end of a given calendar year. Aboriginal patients account for almost 1 in 20 incident and prevalent cases overall. There were 2,612 unknown cases for ethnicity (7%) among prevalent ESRD patients in 2011. All cases with an unknown category for ethnicity were excluded from the analyses.

#### **Statistical Analysis**

#### **Examining Patient Characteristics**

Descriptive analysis was undertaken to compare the demographic, clinical and treatment experiences of Aboriginal and non-Aboriginal patients on factors such as age, sex, diabetes, distance travelled to receive treatment and treatment therapies (hemodialysis, peritoneal dialysis, kidney transplants). Baseline patient characteristics were tested using a Chi-square test, Student-t test or non-parametric Wilcoxon test as appropriate. All tests were two-sided. A test p-value of less than 0.05 was considered to be statistically significant.

#### Age-Standardization

Incident and prevalent cases of ESRD were age-standardized per 100,000 people, using the direct method of standardization. Rates were standardized to the 2006 Aboriginal identity population.<sup>46</sup> An age-standardized rate is a weighted average of the age-specific rates, where the weights are the proportion of a standard population in the corresponding age groups. This represents what the crude rates would have been in the study population if that population had the same age distribution as the standard population.

The denominator used to calculate crude rates and age-specific rates was taken from 2006 Census counts; the 2006 population was multiplied by eight to correspond to the eight years of CORR data (2004 to 2011). For this reason, the trend figure in this report has been presented for these years only, as data prior to 2004 would need to be based on counts from the 2001 Census. It is not appropriate to present rates based on both the 2001 and 2006 censuses, due to differences in identification of Aboriginal peoples in the two censuses.

It should be noted that there were 22 incompletely enumerated Indian reserves and settlements in the 2006 Census and, as a result, the denominator used to calculate rates is likely to under-count the Aboriginal population in Canada.

#### **Determining Distance to/Location of Treatment**

To classify dissemination areas into urban, rural and remote categories, Statistics Canada's Statistical Area Classification was used. **Urban areas** were defined as communities with more than 10,000 residents and that were labelled by Statistics Canada as a census metropolitan area (CMA) or a census agglomeration (CA). Areas outside urban areas and outside the territories were divided into four categories—Strong, Moderate, Weak and No Metropolitan Influenced Zones (MIZ)—according to the proportion of residents that commuted to work in an urban core. Areas in the territories outside CMAs and CAs were classified as No MIZ. For this report, Strong and Moderate MIZ areas were classified as **rural**, and Weak and No MIZ areas as **remote**.

To calculate distance to treatment, geographical location was determined for both patients and facilities by using the centre-points of the patients' and facilities' postal codes to link to Statistics Canada's Postal Code Conversion File (PCCF+). The "as the crow flies" distance was then calculated using this geographical information. (Note that the great circle distance formula was used to take into account the curvature of the Earth.)

#### **Income Classification**

In this study, income is based on neighbourhood income per person equivalent (IPPE), which is a household size–adjusted measure of household income, based on 2006 Census summary data at the dissemination area level, and using person-equivalents implied by the 2006 low income cut-offs (LICOs). Note that the 2001 single-person equivalents were 1.00 for one person, 1.25 for two persons, 1.55 for three persons, 1.95 for four or five persons and 2.44 for six or more persons sharing the same household (regardless of age).<sup>47</sup>

#### **Analyzing Outcomes**

Risk-adjusted transplantation percentages were estimated by fitting a log-binomial generalized linear model with age, sex and diabetes as covariates. The age-, sex- and diabetes-adjusted five-year graft survival curves were calculated as directly adjusted survival probabilities for Aboriginal and non-Aboriginal patients at predetermined time points, based on a stratified proportional hazard (Cox) regression model. Ethnicity, age, sex, diabetes, overweight (BMI categories), referral time, peritoneal dialysis as initial treatment (versus hemodialysis), distance to treatment, dialysis initiation year and province of treatment were covariates included in the proportional hazards models for transplantation and dialysis survival. For dialysis survival, patients were censored at first kidney transplant, loss to follow-up, leaving the country or recovered function. For transplant

graft survival, patients were censored at loss to follow-up or leaving the country. For more information on data sources, definitions and methodology, please refer to the *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2002 to 2011.* 

#### **Intervention Analysis**

Building on the results of the quantitative data analysis, a scan was conducted to identify interventions aimed at supporting Aboriginal peoples affected by ESRD and its comorbidities. The scan identified examples of evaluated and non-evaluated interventions or activities from published literature and websites from Canada and comparable international jurisdictions.

The interventions listed in Appendix C were identified out of a range of academic and grey literature sources published between 2006 and 2011. A web-based search was conducted using Ovid Medline based on preestablished terms to ensure that the most applicable Canadian sources were identified. These terms were nested within multiple search headings: keywords (including end-stage renal disease, hemodialysis, Canada, intervention), subject headings (including kidney failure + chronic, Inuit, renal dialysis) and synonyms (including First Nations and Aboriginal). The search yielded articles and grey literature pertaining to kidney failure, preexisting conditions (that is, common ESRD comorbidities such as diabetes), treatments for kidney failure and ESRD management, Aboriginal health and culturally informed or culturally safe health care.

The Expanded Chronic Care Model (ECCM), which integrates intervention strategies for chronic illness across the health system, was used as an organizing framework.<sup>28</sup> While this model is not specific to the health of Aboriginal populations or to ESRD, it allows for an analysis of different components within the health system, including relevant policy areas at community and individual levels. Intervention results are broadly applicable to patients with a range of chronic conditions, while some inclusions focus specifically on those who are receiving dialysis to treat ESRD (hemodialysis or peritoneal dialysis). The results include a selection of interventions developed for Aboriginal peoples in similar national and health system contexts, such as Australia. Selected articles and documents referred to the provision or improvement of renal care to Aboriginal peoples. This included initiatives that could be considered promising practices, as well as those that integrated an evaluation of the reported outcome(s) or the process of implementation. Sources that featured interventions or policies contributing to improving care for ESRD and its comorbidities were included.

#### **Study Limitations**

There are several limitations to this study. A major limitation of this study is the use of a broad Aboriginal category in the analysis. The lack of specificity within the ethnic identifier in CORR does not allow for the identification of First Nations, Inuit and Métis patients. Using this broad Aboriginal category masks the differences between First Nations, Inuit and Métis on the prevalence and incidence of ESRD, related conditions, treatment experiences and outcomes. For instance, the underlying prevalence of diabetes is much lower among Inuit,<sup>10</sup> suggesting that the rate of ESRD is also likely to be lower in Inuit as a whole, given the strong association between diabetes and ESRD. The Aboriginal comparison group in these pan-Canadian analyses also likely represents largely First Nations patients, given that according to the 2006 Census, First Nations account for almost two-thirds of the Aboriginal population in Canada, compared with approximately 4% for Inuit and 35% for Métis.<sup>46</sup>

The ethnic identifier variable is also subject to under-reporting by health care professionals (for example, doctors, nurses, dietitians and social workers) who record this information. An internal CIHI review of the accuracy of the ethnic identifier variable in CIHI databases (including CORR) found that the ethnicity question was asked directly only one-quarter (28%) of the time, and inference was used to determine ethnicity almost half the time, usually based on physical appearance (18%).<sup>48</sup> Further, for 7% of prevalent dialysis patients, ethnicity was unknown.

Also, certain variables—including diabetes, weight and residence address—were documented only at the time of treatment initiation. It is therefore unknown how many prevalent patients continue to experience these health conditions as they progress through treatment, and whether there were any changes to location of residence that were used to calculate distance to treatment.

This study also does not measure the quality of care received or whether sufficient care was received according to individual needs or health care choices. In addition, while conservative care is an option for those diagnosed with ESRD, there is no available information on these individuals, or on those who are on wait lists for treatment. In addition, due to data limitations, results could not be presented by province/territory or region.

## Appendix B: Data Tables

#### Table B1: Incident Cases of ESRD Among Adults Age 20 and Older, Canada, 2004 to 2011

		Abori	ginal	Non-Aboriginal				
	Number	Rate per 100,000	95% Confidence Interval	Number	Rate per 100,000	95% Confidence Interval	Rate Difference	Rate Ratio
2004	266	37.7	33.2–42.2	4,556	13.8	13.3–14.2	23.9	2.7
2005	244	34.6	30.2–38.9	4,670	13.6	13.2–14.0	21.0	2.5
2006	285	40.4	35.7–45.1	4,635	13.3	12.9–13.7	27.1	3.0
2007	282	40.0	35.3-44.6	4,859	13.7	13.2–14.1	26.3	2.9
2008	263	37.3	32.8–41.8	4,901	13.4	13.0–13.8	23.9	2.8
2009	289	40.9	36.2–45.7	4,959	13.2	12.8–13.6	27.8	3.1
2010	283	40.1	35.4-44.8	5,098	13.3	12.9–13.7	26.8	3.0
2011	296	41.9	37.2–46.7	4,903	12.6	12.2–13.0	29.3	3.3

#### Note

Rates have been standardized to age distribution of 2006 Aboriginal identity population in Canada (see Appendix A for further details on methods and trend years).

#### Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

Table B2: Prevalent Cases of ESRD Among Adults Age 20 and Older, Canada, 2011								
	Aboriginal			Non-Aboriginal				
	Number	Rate per 100,000	95% Confidence Interval	Number	Rate per 100,000	95% Confidence Interval	Rate Difference	Rate Ratio
All ESRD Patients								
Overall	1,885	267.1	255.3–279.4	35,379	136.4	135.0–137.8	130.7	2.0
Age-Standardized Rate*		267.1	255.1–279.1		99.4	98.2–100.5	167.7	2.7
Sex								
Male								
Crude Rate	942	282.5	265.0–301.2	21,459	168.3	166.1–170.6	114.2	1.7
Age-Standardized Rate*		283.0	264.9–301.0		124.1	122.2–125.9	158.9	2.3
Female	Female							
Crude Rate	943	253.3	237.6–270.0	13,920	105.6	103.8–107.3	147.7	2.4
Age-Standardized Rate*		253.1	237.0–269.3		76.2	74.8–77.6	177.0	3.3
Age Group	Age Group							
Male								
20–34	84	69.1	55.8–85.5	1,182	33.6	31.8–35.6	35.5	2.1
35–44	166	209.6	180.0–244.0	2,022	88.8	85.1–92.8	120.8	2.4
45–54	209	309.4	270.2–354.4	3,922	148.0	143.4–152.7	161.4	2.1
55–64	264	669.7	593.6–755.6	5,023	236.9	230.5–243.6	432.8	2.8
65–74	167	910.8	782.7–1,060.0	4,931	389.9	379.2–400.9	520.9	2.3
75+	52	710.9	541.7–932.9	4,379	473.7	459.9–488.0	237.2	1.5

#### Table B2: Prevalent Cases of ESRD Among Adults Age 20 and Older, Canada, 2011 (cont'd)

		Aboriginal			Non-Aboriginal			
	Number	Rate per 100,000	95% Confidence Interval	Number	Rate per 100,000	95% Confidence Interval	Rate Difference	Rate Ratio
Female								
20–34	127	94.9	79.7–112.9	828	24.3	22.7–26.1	70.6	3.9
35–44	167	185.0	159.0–215.3	1,302	58.1	55.0–61.3	126.9	3.2
45–54	207	273.3	238.5-313.2	2,438	92.9	89.3–96.6	180.4	2.9
55–64	216	518.4	453.6–592.3	3,170	144.7	139.7–149.8	373.7	3.6
65–74	175	854.7	737.0–991.2	3,032	220.7	213.0-228.7	634.0	3.9
75+	51	493.5	375.0–649.3	3,150	232.6	224.6-240.8	260.9	2.1

#### Note

\* Age-standardized to the age distribution of 2006 Aboriginal identity population in Canada (see Appendix A for further details on methods). **Source** 

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information

# Table B3: Adjusted Graft Survival Rate (Percentage) for Adult Transplant Patients (Incident Cases) Age 20 and Older, Canada

	One Year	Two Years	Three Years	Four Years	Five Years
Aboriginal	94.2	91.8	89.2	86.6	83.6
Non-Aboriginal	94.6	92.3	89.8	87.3	84.4

Note

Rates are adjusted for age, sex and diabetes.

Source

Canadian Organ Replacement Register, 2011, Canadian Institute for Health Information.

# Appendix C: Interventions Acting to Improve Chronic Care and End-Stage Renal Disease

Intervention	Program Features and Outcomes
Self-Management/Develop	
Screening for Limb, I-Eye, Cardiovascular and	<ul> <li>In partnership with First Nations in Alberta, Health Canada and the University of Alberta</li> <li>Mobile clinics deliver one-stop screening services to 44 First Nations communities in Alberta</li> </ul>
Kidney Complications (SLICK) (Alberta) <sup>45</sup>	<ul> <li>Clinicians build awareness of personal care standards, potential complications; encourage patients to seek follow-up care</li> <li>Led to improvements in clinical exam and lab test results, weights; increased visits to physicians;</li> </ul>
Stay Healthy— Management of Diabetes (Canadian Diabetes Association) <sup>49</sup>	<ul> <li>reduced emergency department visits and hospitalizations</li> <li>Promotes knowledge and supports patients' self-management practices in areas of nutrition (tailored toward local, traditional foods and cooking practices)</li> <li>Promotes activities feasible for populations in remote settings, or for those with limited mobility</li> </ul>
Create Supportive Environ	ments
Six Nations Satellite Dialysis Unit, Grand River Territory of Ontario <sup>29</sup>	• Dialysis clinic provides local treatment, allowing patients to remain in their communities, near social and family support
Territory of Ontario	<ul> <li>Inception involved grassroots action; residents identified need, "[made] their voices heard by governing bodies"</li> </ul>
	Funding from multiple agencies, including Six Nations and Health Canada
Northern Alberta Renal Program (NARP) <sup>50</sup>	<ul> <li>Multidisciplinary approach to care that aims to prevent or delay the onset of renal failure</li> <li>A range of services provided by a multidisciplinary team of allied health workers to provide renal-specific services, both in clinic and at home; these include home dialysis, self-management techniques, diabetes-related diagnostics and rural kidney clinics</li> </ul>
Diabetes Wellness	Patients share experiences related to managing diabetes, coping with treatments
Project: Talking Circles <sup>51</sup>	<ul> <li>Patients share experiences related to managing diabetes, coping with treatments</li> <li>Patients knew the facilitator personally and were invited to participate, which encouraged participation as trust was built</li> </ul>
Decision Support	
Cultural Competence and Cultural Safety	Provides knowledge and tools to health professionals who work in Aboriginal settings to support incorporating cultural competencies into their practice
in Health Program (Canada) <sup>36</sup>	Course includes a review of the colonial history of First Nations in Canada; inclusive, respectful communications skill-building
	Offered jointly by the Aboriginal Nurses Association of Canada and the Canadian Healthcare Association
Aboriginal Health Transition Fund (Federal) <sup>52, 53</sup>	• Supports First Nations and Inuit communities and organizations to integrate existing federally funded health systems within First Nations and Inuit communities <sup>52</sup>
	<ul> <li>Includes primary care, health education, screening, engagement;<sup>52</sup> initiatives for methods/tools, training/capacity-building, program adaptation, culturally informed services<sup>53</sup></li> </ul>
Strengthen Community Ac	
Ripples in the Water: A Toolkit for Aboriginal	Documents the experiences of patients required to travel for dialysis
People on Dialysis (Elsipogtog Nation,	Identifies barriers to care, ways to achieve good health (particular focus toward individuals recently diagnosed, their families, facing unknown challenges)
New Brunswick) <sup>30</sup>	Information targeted to needs of patients, families and care providers who provide support to patients in the local community
Steps to a Healthier Anishinaabe (United	Multi-site culturally competent health promotion
States—Michigan) <sup>54</sup>	• Tribal coordinator in each community, community action plan for each tribe, adapt best practices to be culturally appropriate, ongoing technical assistance, respect tribal sovereignty
	Majority of funds disbursed to tribes who design/implement interventions for community's needs
	Focus on risk factors—obesity, diabetes, asthma, nutrition, lack of physical activity, tobacco use

Intervention	Program Features and Outcomes						
Delivery System Design/Reorient Health Services							
Aboriginal Patient Liaison	Patient liaisons coordinate post-discharge services, facilitate movement from facilities						
Program—Northern Health (British Columbia) <sup>55</sup>	<ul> <li>Promote adherence to treatment regimes, encourage traditional approaches to healing in local communities when possible</li> </ul>						
Alberta Health	Mobile dialysis unit provides dialysis services to patients who live in Lac La Biche						
Services Mobile Dialysis Bus (Alberta) <sup>56</sup>	Two nurses and one renal specialist physician oversee care, with support from social workers and dietitians using onboard telehealth equipment						
Sioux Lookout Meno Ya	Culturally sensitive services and activities						
Win Health Centre <sup>32</sup>	Medication reconciliation process involves hospital staff, retail pharmacy						
	Care involves families and addresses cultural requirements						
	Accommodates traditional medicines and foods when possible						
Southern Alberta Renal Program— Mobile Prevention	Nurse practitioners provide weekly screening clinics to members of the Siksika Nation and provide self- management counselling						
Clinic (Alberta	Provides measurement and testing for comorbidities such as diabetes, high blood pressure						
Health Services) <sup>33</sup>	Outcomes include improvements in targeted measurements and improved treatment adherence						
Aboriginal Patient Navigator Program	• Liaison workers ensure patients understand hospital processes and that health care staff understand the patients' needs						
(Vancouver Coastal Health) <sup>38</sup>	Provides a communication link between patients and health care providers, assists with discharge planning						
Alberta First Nations	Program developed out of partnership between First Nations communities and Health Canada						
TeleHealth Program (Health Canada) <sup>42</sup>	• Aims to develop technical infrastructure required to support telehealth in First Nations communities in Alberta by installing appropriate equipment, training health care workers, providing internet access to First Nations health centres						
	Administers a health portal to provide access to online health resources						
Aboriginal Health Coordinator (Alberta	<ul> <li>In partnership with Maskwacis Health Services, provides promotion and prevention programs, encourages self-reliance and self-determination</li> </ul>						
Health Services) <sup>39</sup>	<ul> <li>Provides cultural awareness education for health care staff; helps clients, families, agencies and communities access programs and services</li> </ul>						
	Assists staff to access information to better understand Aboriginal health concerns, social support networks and barriers to accessing care						
Aboriginal Liaison Program (Burntwood Health Authority) <sup>57</sup>	• Liaison workers support Aboriginal clients and health authority staff in language translation, cultural awareness, understanding and access improvement efforts						
Health and Social	Liaison workers visit every Aboriginal patient, providing emotional, spiritual and social support						
Liaison Workers (Whitehorse Hospital) <sup>58</sup>	• Provide help with communication in health care settings (hospitals and community health centres)						
(winteriorse riospital)	Advocate for Aboriginal peoples using health services						
Information Systems							
Aboriginal Health Transition Fund (First	• Coordinates funding to support First Nations and Inuit communities and organizations to improve integration between existing federal, provincial and territorial health systems						
Nations, Inuit and Aboriginal Health— Health Canada) <sup>52</sup>	<ul> <li>Streamlines adaption of existing health services to better meet the needs of First Nations, Inuit and Métis in Canada, both on- and off-reserve</li> </ul>						
First Nations and Inuit Health Transfer—Health	Enables Aboriginal communities in health program design, establishing services and     encouraging accountability						
Transfer Policy <sup>40</sup>	Guided by a Circle of Program Management, communities generate health needs assessments, develop community health plans, and implement and evaluate programs						

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