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

CANADIAN JOURNAL OF
KIDNEY HEALTH AND DISEASE
Journal canadien de la santé et de la maladie rénale

Program Report

Canadian Journal of Kidney Health and Disease
Volume 8: 1–9
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DOI: 10.1177/20543581211003744
journals.sagepub.com/home/cjk

Kidney Check Point-of-Care Testing—Furthering Patient Engagement and Patient-Centered Care in Canada's Rural and Remote Indigenous Communities: Program Report

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Abstract

Purpose of program: Access to health care services remains a significant barrier for many Indigenous people's living in rural and remote regions of Canada. Driven by geographical isolation and compounded by socioeconomic and environmental disparities, individuals living under these circumstances face disproportionately poor health outcomes. Kidney Check is a comprehensive screening, triage, and treatment initiative working to bring culturally safe preventive care to rural and remote Indigenous communities across Manitoba, Ontario, BC, Alberta, and Saskatchewan. The project's patient-oriented approach addresses concerns raised by kidney patients and their caregivers using culturally safe practices. Using the various expertise of their multidisciplinary team, Kidney Check seeks to further collaborative efforts to improve access to preventive health care for these groups. Meaningful engagement with patients, communities, and local health care stakeholders ensures Indigenous voices are heard and incorporated into the project in a way that promotes shared decision-making and sustainability.
Sources of information: As an affiliate program of the Can-SOLVE CKD Network, Kidney Check's guiding priorities were developed over 3 years of patient consultation and finalized during 2 workshops held with more than 30 patients, caregivers, Indigenous peoples, researchers, and policy makers using a modified Delphi process. Today, patients continue to participate in project development via 2 governing bodies: The Patient Governance Circle and the Indigenous Peoples Engagement and Research Council (IPERC).
Methods: Modeled after the Indigenous-led 2015 FINISHED project in Manitoba, Kidney Check employs point-of-care testing to identify diabetes, hypertension, and chronic kidney disease (CKD) in individuals, ages 10 and above, regardless of pre-existing risk factors. The Kidney Check team consists of 4 working groups: project leadership, provincial management, local community partners, and patient partners. By using and building on existing relationships between local and provincial health care stakeholders and various Indigenous communities, the program furthers collaborative efforts to bridge gaps in health equity.
Key findings: The Kidney Check program has established an infrastructure that integrates patient engagement at all stages of the program from priority setting to deployment and dissemination strategies.
Limitations: While we encourage and offer screening services to all, many still choose not to attend for a variety of reasons which may introduce selection bias. Kidney Check uses patient engagement as a foundational component of the program; however, there is currently a limited amount of research documenting the benefits of patient engagement in health care settings. More formal qualitative evaluations of these activities are needed. In addition, as the COVID-19 pandemic has halted screening procedures in most communities, we currently do not have quantitative data to support the efficacy of the Kidney Check program.
Implications: For many Indigenous people, lack of accessibility to health care services is compounded by sociopolitical barriers that disrupt relationships between patients and providers. Meaningful engagement presents one opportunity to ensure the voices and perspectives of Indigenous patients and communities are incorporated into health services. In addition, this screening paradigm has shown to be cost effective as shown by analyses done on the FINISHED screening program.

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Abrégé

Objectifs du Programme: L'accès aux services de santé demeure un obstacle important pour de nombreuses populations autochtones vivant dans les régions rurales et éloignées du Canada. En raison de l'isolement géographique et de disparités environnementales et socio-économiques, les personnes vivant dans ces situations sont confrontées à de pauvres conditions de santé. Kidney Check est une initiative complète de dépistage, de triage et de traitement qui vise à offrir des soins préventifs et respectueux de leurs valeurs culturelles aux communautés autochtones rurales et éloignées du Manitoba, de l'Ontario, de la Colombie-Britannique, de l'Alberta et de la Saskatchewan. L'approche axée sur le patient répond aux préoccupations soulevées par les patients atteints de néphropathies et leurs soignants grâce à des pratiques adaptées à leur culture. En exploitant les compétences d'une équipe multidisciplinaire, Kidney Check s'efforce de poursuivre les efforts de collaboration visant l'amélioration de l'accès à des soins de santé préventifs pour ces groupes. Un engagement significatif des patients, des communautés et des acteurs locaux du secteur de la santé garantit que les voix autochtones sont entendues et intégrées dans le projet d'une manière qui favorise la pérennité et la prise de décision partagée.

Sources: Kidney Check étant un programme affilié du réseau CAN-SOLVE CKD, ses priorités directrices ont été élaborées à partir d'une consultation de 3 ans auprès des patients et finalisées au cours de deux ateliers utilisant une version modifiée de la méthode Delphi et réunissant plus d'une trentaine de patients, soignants, membres des communautés autochtones, chercheurs et décideurs. Les patients continuent à ce jour de participer au développement du projet par l'entremise de deux organes directeurs: le Conseil des patients et le Conseil de la recherche et de l'engagement des peuples autochtones (IPICER).

Méthodologie: Inspiré du projet de dépistage FINISHED mené en 2015 auprès des Autochtones du Manitoba, Kidney Check utilise des tests au point de service pour dépister le diabète, l'hypertension et l'insuffisance rénale chronique chez les personnes âgées de 10 ans et plus, quels que soient les facteurs de risque préexistants. L'équipe de Kidney Check se compose de quatre groupes de travail: direction du projet, gestion provinciale, partenaires communautaires locaux et patients partenaires. En utilisant et en s'appuyant sur les relations existantes entre les intervenants locaux et provinciaux du secteur de la santé et les diverses communautés autochtones, le programme favorise les efforts de collaboration pour combler les écarts en matière d'équité en santé.

Principaux Résultats: Le programme Kidney Check a mis en place une infrastructure impliquant la participation des patients à toutes les étapes du programme, de l'établissement des priorités aux stratégies de déploiement et de diffusion.

Limites: Nous encourageons et offrons ces services de dépistage à tous, mais, pour diverses raisons, beaucoup choisissent de ne pas y participer, ce qui peut introduire un biais de sélection. La participation des patients est un élément fondamental du programme Kidney Check; néanmoins, les avantages d'un engagement des patients dans les établissements de soins de santé demeurent peu documentés. Davantage d'évaluations qualitatives formelles de ces activités sont donc nécessaires. De plus, la pandémie de COVID-19 ayant interrompu les procédures de dépistage dans la plupart des collectivités, nous ne disposons pas actuellement de données quantitatives pour soutenir l'efficacité du programme.

Conclusion: Pour de nombreuses populations autochtones, le manque d'accessibilité aux services de santé est aggravé par des obstacles sociopolitiques qui perturbent les relations entre les patients et les fournisseurs de soins. La participation significative des patients et des communautés autochtones permet d'assurer que leurs voix et perspectives soient intégrées dans les services de santé. En outre, ce paradigme de dépistage s'est révélé rentable, comme le montrent les analyses effectuées sur le programme de dépistage FINISHED.

Keywords

chronic kidney disease (CKD), CKD screening, patient engagement, patient-oriented research, patient-centered care

Received January 27, 2021. Accepted for publication February 15, 2021.

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Introduction

Many Indigenous people in Canada live in rural and remote communities with limited access to mainstream health care systems and preventive health services. Often compounded by complex socioeconomic and environmental disparities, individuals living under these circumstances face disproportionately poor health outcomes.[1,2] This gap in health equity is exemplified by the high prevalence of chronic disease in these communities, regularly diagnosed at a younger age, and greater severity, than non-Indigenous Canadians.[3,4] When identified early in disease progression, diabetes, hypertension, and chronic kidney disease (CKD) may be optimized by medication and lifestyle modifications. However, in a context where primary health care is generally not accessible (geographically, economically, or culturally), people often delay seeking help and lose the preventive health benefits associated with continuity of care. As a result, many of these individuals present at urgent care facilities with late-stage CKD or other serious complications associated with uncontrolled hemoglobin A1C (HbA1c) levels or hypertension.[5] Too often, this results in a suboptimal introduction to life-sustaining dialysis requiring individuals to leave behind their communities and support networks critical to their well-being in order to be closer to specialized treatment centers.[6] Innovative models for preventive health care delivery are required to address this pervasive issue in a sustainable, effective manner.[7] The intent of this article is to outline the development and deployment of the Kidney Check program, with specific focus on the project team and patient engagement strategies.

Can-SOLVE and Kidney Check

Launched in 2018, Kidney Check is 1 of 18 projects that comprise the Canadians Seeking Solutions and Innovation to Overcome Chronic Kidney Disease (Can-SOLVE CKD) network. Supported by the Canadian Institute of Health Research (CIHR) under the auspices of the national Strategy for Patient-Oriented Research (SPOR), Can-SOLVE and their affiliates are guided by research priorities set by patients managing kidney disease and their caregivers. These guiding priorities were developed over 3 years of patient consultation and finalized during 2 workshops held with more than 30 patients, caregivers, Indigenous peoples, researchers, and policy makers using a modified Delphi process. By aligning research with patient needs and implementing findings in clinical practice, Can-SOLVE aims to accelerate CKD knowledge translation (KT) and improve kidney health for future generations. Today, kidney patients are represented throughout the network via 2 governing bodies: The Patient Governance Circle and the Indigenous Peoples Engagement and Research Council (IPERC). As projects are executed, patients are included as key stakeholders in project management, contributing to the design, implementation, and KT.[8] By making patients a central component of the Can-SOLVE governance structure and project teams, patients act as vested partners in the advancement of medical knowledge.

Kidney Check addresses several of Can-SOLVEs guiding priorities, including the early identification of kidney disease, appropriate risk stratification, and timely access to therapeutic interventions within an entirely Indigenous context. Modeled after the Indigenous-led 2015 FINISHED project in Manitoba,[9] Kidney Check employs point-of-care testing to identify diabetes, hypertension, and CKD in individuals aged 10 and above regardless of pre-existing risk factors. By actively engaging with patients, communities, and local health care stakeholders, the program ensures Indigenous voices are heard and incorporated into the project in a way that promotes shared decision-making and sustainability. In addition, a well-developed cost-effectiveness model based on this screening paradigm shows excellent value for money for health care payers. The primary model drivers include adherence to prescribed treatment, treatment effectiveness, baseline CKD prevalence, and the incremental cost of managing CKD on case finding. When varied over a plausible range, the model consistently showed an incremental cost-effectiveness ratio (ICER) below or near $50 000 per quality-adjusted life-year (QALY), justifying the economic viability of the program.[10]

Kidney Check Screening Processes

Community Selection

Kidney Check communities are selected in collaboration with patient partners at the discretion of the provincial teams. Prevalence of CKD, funding for transportation to the community, geographical location, and consideration of recent kidney screening programs are a few practical considerations when selecting communities. Ideally, a blend of fly-in and drive in communities across the various health authorities of each province are included in the screening plan. Other factors include population size, accessibility to urban hubs of care, and the community's readiness to participate (Figure 1). These deciding characteristics emerged from focus groups held during the planning phase of the 2015 FINISHED program in Manitoba and were adapted as applicable to suit the need of the Kidney Check screening program. Using these predetermined criteria helps to minimize bias and ensures transparency because not all communities are able to participate in a program with limited funding. Ultimately, partnering with Kidney Check is at the discretion of each community. As of January 2021, Kidney Check will screen 13 communities in British Columbia, 3 in Alberta, and 3 in Ontario with Manitoba and Saskatchewan still to be determined. Communities that previously participated in Manitoba's FINISHED program will not be screened again through Kidney Check. This is in line with our community selection criteria, which considers how recently a screening program was held in each community.

Figure 1. Additional community selection criteria.

Screening Process

All community members are welcome to participate in the screening program, which takes place over several days and is typically conducted by 2 Kidney Check trained nurses and a health care aid. Methods of the screening process have been previously described in detail.[11] In brief, participants arrive to the site and are asked to watch a short video outlining the purposes and processes of screening before providing their consent. Consent is obtained for the screening itself and grants project team members future access to health care utilization data to aid in follow-up procedures. Blood pressure is taken according to best practices outlined by the Canadian Hypertension Education program (CHEP).[12] Finger prick droplet samples are collected and analyzed for blood chemistry on an i-STAT Alinity analyzer (Abbott Point of Care Inc., Princeton, NJ). Urinary urine albumin-to-creatinine ratio (uACR) and hemoglobin A1c levels are determined using a DCA Vantage analyzer (Siemens, Erlangen, Germany). Demographic information and clinical

Figure 2. Kidney Check screening process.

values are inputted onto an iPad application developed specifically for Kidney Check to calculate estimated glomerular filtration rate (eGFR). Clinical values, demographic information, and eGFR are used to determine each participant's risk of developing kidney failure in the next 2 to 5 years using the Kidney Failure Risk Equation (KFRE).[13] The Kidney Check application automatically calculates eGFR and KFRE, which are then used to triage patients as no risk, low, intermediate, or high risk. Pediatric ($<$18 years) patients are triaged using a separate algorithm developed in collaboration with pediatric nephrologists and endocrinologists. Immediately following screening, participants are offered risk-based counseling and additional resources regardless of their current risk (Figure 2). These discussions follow scripts developed in collaboration with Indigenous patient partners and emphasize a holistic approach to kidney health. The results of all participants are forwarded to their local primary care provider. All those determined to be at high or intermediate risk of kidney failure are immediately referred to a multidisciplinary CKD clinic to develop a long-term treatment plan.

The Kidney Check Team

Developed by a multidisciplinary team of Indigenous health care providers, adult and pediatric nephrologists, patient partners, and policy makers, the project's patient-oriented approach aims to accommodate the contexts and cultures of the communities they serve. To achieve this goal, Kidney Check seeks to establish long-term participatory partnerships with stakeholders who value, share in, and contribute to equitable health care relationships. The various expertise of the Kidney Check team is dispersed between 4 working groups whose unique functions are integral to the success of the program (Figure 3). All parties share in the development and implementation of the project in a process that upholds mutual respect, learning, and dialogue. Emphasis is placed on promoting cultural safety and shared decision-making as

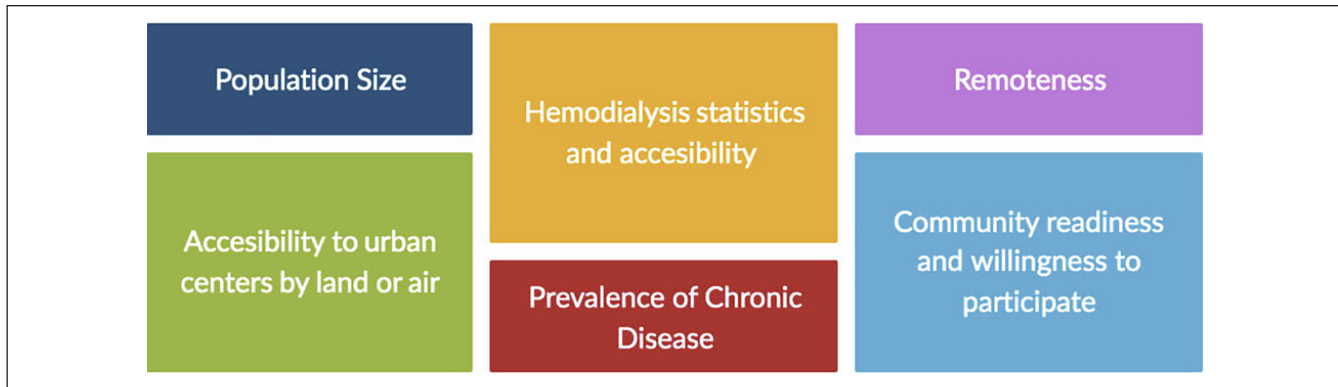

Figure 3. Kidney Check team.

a means of empowering individuals and communities to act on their knowledge and improve their health.

Project Leadership Team

Kidney Check is led by a team of Indigenous health care providers with extensive experience screening in First Nations communities, adult and pediatric clinician scientists with expertise in nephrology and epidemiology, the patient partner lead, and a communications specialist in Manitoba. Leaders are responsible for clearly articulating the programs goals as they relate to partnerships, ensuring relevant stakeholders are present at all levels of decision-making, and conducting regular meetings to support teams and provide feedback. By providing guidance and resources to the provincial teams, leadership ensures quality and regulatory standards are maintained to facilitate high functioning groups.

Provincial Management Team

Each provincial team comprises local patient partners, an adult and pediatric medical lead, the regions project coordinator, and at least one Kidney Check trained health professional to perform screening. Health care is governed provincially throughout Canada allowing provinces and regions to adapt to diverse population needs, geographical space, resources, laws, and health care delivery models. While Kidney Check screening is a standardized procedure that is accountable to a quality assurance program, provincial teams ensure the program is adapted to reflect the diverse contexts and cultures of their respective region. This is accomplished in part through partnerships with provincial health organizations dedicated to improving health care services for the Indigenous communities in their regions. In Manitoba, the First Nations Health and Social Secretariat of Manitoba (FNHSSM) aids in all aspects of the programs implementation in various First Nations communities throughout the province. An Indigenous-led organization, FNHSSM, works to deliver culturally appropriate holistic and community-based health services to all First Nations in Manitoba. Having previously partnered with the FINISHED screening initiative, their considerable understanding of screening logistics within these communities ensures Kidney Check is optimally delivered. Similar partnerships exist in Alberta and British Columbia between Kidney Check, the Kidney Health Strategic Clinical Network, and the First Nations Health Authority.[14] These groups aid in engaging other health care stakeholders within the region, diversifying the Kidney Check network and promoting the programs sustainability.

Local Community Partners

Community leaders, elders, health care providers, and other community champions contribute to the success of the screening initiative by providing insight on how to best use engagement strategies and local resources. Their knowledge of the community aids in coordinating project logistics to ensure the screening teams can efficiently accommodate high throughput while maintaining quality control standards in a culturally safe and appropriate manner. Champions assist in the distribution of marketing materials at the beginning of the program and provide ongoing advocacy throughout the screening event to maximize participation. Their support and guidance foster a collaborative relationship between the Kidney Check team and local health resources that upholds culturally safe practices and the OCAP (ownership, control, access, and possession) principles. The First Nations Principles of OCAP ensures communities maintain control over all data collected during the screening events. The principles are fundamentally tied to self-determination, allowing communities' full control over how the data are stored, used, and shared.[15] At project completion, all data will be removed from the mainframe server and given to the proper Indigenous custodians in each province, as well as each community, if desired.

Patient Partners

Kidney Check works with more than 10 patient and caregiver partners throughout Canada whose diverse skill sets and lived experiences in the health care system help shape

the program. Their experiences provide a unique insight into the challenges faced by Indigenous people managing CKD, guiding the program's design, implementation, and communication strategies. This includes aiding in the development of community selection criteria, engagement procedures, screening procedures, educational materials, and KT strategies. By sharing their knowledge at community engagement events, patient partners advocate for the importance of screening, early treatment, and a holistic approach to disease management.

Pediatric Considerations

Children have been identified as a priority group for the Kidney Check program by the leadership team and community partners. Despite a significantly increased risk of chronic diseases in Indigenous children,[16] clinical screening is not currently being done by primary care practitioners. To maximize screening opportunities for children, school leadership, including the principle and teachers, as well as Child and Family Services were identified as important community partners. Youth champions and youth focused KT materials and incentives were key facilitators to engage young people and their parents. Successful tools were presentations at professional development days for teachers, videos, and role plays by youth champions.

Cultural Safety and Kidney Check

As Kidney Check works exclusively with Indigenous patients, culturally safe clinical practices play an important role in the project's design and implementation. As a principle, cultural safety focuses on the people receiving care and emphasizes the need for self-awareness, empathy, and respect on the part of health service providers.[2,17] For Kidney Check and the Can-SOLVE network, IPERC serves to guide culturally safe collaborations with Indigenous communities across Canada. Comprising Indigenous physicians, health care workers, patient partners, elders, and academics, IPERC ensures the unique needs and perspectives of Indigenous peoples are addressed and respected. These values are encompassed by the Wabishki Bizhiko Skaanj (wah-bish-kih-biish-ih-goo-skaa-nch), "white horse" cultural safety learning pathway adopted by Kidney Check and the Can-SOLVE network in 2018. Developed by a working group commissioned by IPERC, the pathway includes the Kairos blanket exercise, the renowned San'yas Indigenous Cultural Safety training, OCAP, and Tri-Council Policy Statement (TCPS-2) certification among other components. Taken together, the pathway fosters a deeper awareness of racial biases, Indigenous stories, the impact of colonization on Indigenous health, and culturally safe health research practices. By using educational strategies that foster interaction, participation, and critical analysis, co-learners build on their knowledge and experience to develop a more holistic understanding of Indigenous health. All members of the Kidney Check team are encouraged to explore the pathway and incorporate what they learned into their day-to-day lives and clinical practice.

Engagement Strategy

The ongoing support required by people living with chronic disease necessitates that patients be active and engaged in both disease management and prevention.[18] For many Indigenous people, lack of physical accessibility to health care services is compounded by sociopolitical barriers that disrupt relationships between patients and providers. As a result, many Indigenous individuals are reluctant to attend services. Meaningful engagement presents one opportunity to ensure the voices and perspectives of Indigenous patients and communities are incorporated into health services. Increasing the capacity of services to be more responsive to Indigenous people needs fosters shared decision-making, empowerment, and self-management, improving health outcomes and service utilization.[19] Kidney Check aims to engage with Indigenous patients and communities on multiple levels throughout the design, implementation, and post-screening aspects of the program. This is done on a provincial, regional, and community level by working with dedicated patient partners, local leaders, and various health care stakeholders.

Leadership Engagement

Kidney Check works with local partners to determine the best way to approach each community, respectful of each community's needs, cultures, and practices. Typically, a letter is sent to Chief and Council requesting a meeting between the screening team and local community representatives to discuss partnering with Kidney Check. This ensures the screening program is formally welcomed to the territory and that this welcome is acknowledged in accordance with local Indigenous protocols. These protocols vary, but often include an offering of tobacco or an honorarium, to be given to an elder or local authority figure upon Kidney Check arrival to the community. Following this exchange, Kidney Check meets with community leadership and local health care stakeholders to introduce the screening program and discuss best practices for delivery in their respective community. An emphasis is placed on the program's preventive approach to kidney health, stressing the importance of early detection and early intervention in slowing disease progression. These discussions include members from the screening team, patient partners, and a nephrologist who are able to address any questions or concerns that are raised.

Health Care Stakeholder Engagement

Local health care stakeholders include nurses, health center staff, Indigenous Diabetes Workers, and local primary care

providers. Kidney Check uses a variety of marketing tools (social media, e-newsletters, the Can-SOLVE Web site) to introduce the screening process and emphasize their role in furthering preventive health care in the region. A formal meeting is arranged to discuss the screening logistics, timelines, and any potential barriers or risk issues to develop efficient mitigation strategies. As part of the circle of care, all patients' screening results are forwarded to local providers for follow-up. In addition, a process is established for those identified as high risk to be referred to a multidisciplinary kidney health clinic where they are able to access care with a nephrologist, dietician, and pharmacist to design a treatment plan.

Community Engagement

Prior to the screening event, Kidney Check is introduced to the community at large. Planned in collaboration with local representative(s), the engagement event typically includes a shared meal alongside various presentations given by Kidney Check team members, health care workers, and patient partners. These presentations outline the screening process and emphasize the importance of preventive kidney care. Patient partners share their own experiences managing kidney disease and their role within Kidney Check and the Can-SOLVE network. Community members are encouraged to ask questions and become familiar with the screening team staff. The various perspectives encourage a holistic, 2-eyed seeing approach to health and wellness where both biomedical and Indigenous ways of knowing are recognized and respected.

Conclusions

Kidney Check is a comprehensive screening, triage, and treatment initiative working to bring culturally safe preventive care to rural and remote Indigenous communities across Manitoba, Ontario, BC, Alberta, and Saskatchewan. The project's patient-oriented approach addresses concerns raised by Kidney patients and their caregivers using culturally safe practices. Using the various expertise of their multidisciplinary team, Kidney Check seeks to further collaborative efforts to improve access to preventive health care for these groups. Meaningful engagement with patients, communities, and local health care stakeholders ensures Indigenous voices are heard and incorporated into the project in a way that promotes shared decision-making and sustainability. As a fundamental component of the program, there is a paucity of research examining the efficacy of patient engagement in health care settings. Additional research including formal qualitative studies among various patient populations is needed. Furthermore, while the screening program is offered to all, many chose not to participate for a variety of reasons, which may introduce selection bias. Currently, screening is halted in most communities due to the COVID-19 pandemic, as such we are unable to offer an examination of qualitative evidence that may elucidate the impact of these limitations.

To further promote sustainability, Kidney Check has committed to continue working with patient partners to advocate for continued screening as a government-funded program. Until then, the program intends to implement passive surveillance strategies using administrative data to identify those with hypertension, diabetes, or other risk factors and notify those patients and their providers to monitor uACR and eGFR. Patients identified as high risk for kidney disease will be offered remote nephrology counseling services in addition to suggestions for pharmacologic management. These counseling services will adhere to the same cultural safety principles and practices followed by the Kidney Check screening teams. Currently, the prevalence of CKD among adults in these communities may be as high as 30% with 20% of Indigenous children showing early signs of increased risk. By screening for disease early, many individuals can reduce their chance of progressing to end-stage kidney disease, protecting themselves and the integrity of their communities.

Ethics Approval and Consent to Participate

The Kidney Check program was reviewed and approved by the Bannatyne Health Research Ethics board at the University of Manitoba.

Consent for Publication

Not applicable.

Availability of Data and Materials

Not applicable.

Acknowledgments

The authors would like to thank our patient partner Cathy Woods for her contributions to the manuscript, as well as our other patient partners for their continued support in the project.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Canadian Institutes of Health Research and the Can-SOLVE CKD Network.

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