

Health Policy as a Barrier to First Nations Peoples' Access to Cancer Screening

Les politiques de santé comme obstacle à l'accès des Premières Nations au dépistage du cancer



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Abstract

Background: First Nations peoples in Ontario are facing increasing rates of cancer and have been found to have poorer survival. Cancer screening is an important strategy to improve cancer outcomes; yet, Indigenous people in Canada are less likely to participate in screening. Ontario has established organized breast, cervical and colorectal cancer screening programs; this paper examines the health policy context that informs these programs for First Nations peoples in the province.

Method: This paper follows an embedded multiple-case study design, drawing upon a document review to outline the existing policy context and on key informant interviews to explore the aforementioned context from the perspective of stakeholders.

Results: Policies created by agencies operating across federal, regional and provincial levels impact First Nations peoples' access to screening. Interviews identified issues of jurisdictional ambiguity, appropriateness of program design for First Nations persons and lack of cultural competency as barriers to participation in screening.

Conclusion: Federal, provincial and regional policy makers must work in collaboration with First Nations peoples to overcome barriers to cancer screening created and sustained by existing policies.

Résumé

Contexte : Les membres des Premières Nations de l'Ontario sont confrontés à des taux de cancer croissants et leur survie est moins bonne. Le dépistage du cancer est une stratégie importante pour améliorer les résultats, pourtant, les Autochtones au Canada sont moins susceptibles de participer au dépistage. L'Ontario a établi des programmes organisés de dépistage du cancer du sein, du col utérin et colorectal. Cet article examine le contexte des politiques de santé qui sous-tendent ces programmes pour les membres des Premières Nations de la province.

Méthode : Cet article emploie une conception intégrée d'études de cas multiples, s'appuyant sur un examen de la documentation pour décrire le contexte politique en place et s'appuyant sur des entretiens avec des informateurs clés pour explorer le contexte susmentionné du point de vue des parties prenantes.

Résultats : Les politiques élaborées par les organismes fédéraux, régionaux et provinciaux ont une incidence sur l'accès des Premières Nations au dépistage. Les entrevues ont permis de révéler des problèmes liés à une ambiguïté territoriale, à la pertinence de la conception des programmes pour les Premières Nations et au manque de compétences culturelles comme obstacles à la participation au dépistage.

Conclusion : Les décideurs fédéraux, provinciaux et régionaux doivent travailler en collaboration avec les Premières Nations pour surmonter les obstacles au dépistage du cancer créés et maintenus par les politiques en vigueur.

Introduction: Cancer in Ontario's First Nations Population

Indigenous peoples throughout Canada (Table 1) continue to face pressing health inequities, including persistent disparities in health outcomes (Cunningham 2011; Health Council of Canada 2013; King et al. 2009; Marrett and Chaudhry 2003; Nishri et al. 2014; Tjepkema et al. 2009). In 2015, the Truth and Reconciliation Commission of Canada (TRC) called upon the federal government and all Canadians to take action to mitigate these health challenges (TRC 2015). This and other recent socio-political shifts have contributed to what Kingdon (2011) coined as a changing health policy system climate, which he defined as an increased capacity to develop policies targeting the system's capability to address long-standing issues. The increasing burden of several cancers among Indigenous peoples in Ontario is an example of a health challenge that needs to be addressed, as described in the calls to action put forward by the TRC. Our paper aims to explore the ways in which the current health policy shapes access to and participation in cancer screening among First Nations communities in Ontario and to highlight opportunities for policy change. Although cancers affect all Indigenous peoples throughout Canada (First Nations, Inuit and Métis), the scope of this paper is limited to exploring cancer policies as these apply to First Nations in Ontario.

In Canada, the provision of healthcare for First Nations and Inuit is a fiduciary responsibility of the federal government. This responsibility resulted from the 1867 *British North America Act*, which made First Nations and their lands an exclusive federal jurisdiction (Waldram et al. 2006). As such, several programs and services typically coordinated and delivered by provincial and municipal levels of government for non-Indigenous Canadians are federally provided on First Nations reserves. This programming entails the creation and oversight of health services in the community as well as the subsidizing of the cost of medical transportation to access provincial health services not available locally (Hurley 2000). This policy structure is highly contested and has often been criticized as being a patchwork approach, characterized by shifting responsibilities between federal and provincial governments as well as a lack of accountability and clarification around responsibilities (Dwyer et al. 2013; Lavoie 2013; National Collaborating Centre for Aboriginal Health 2011; Snyder et al. 2015). As policy and jurisdiction are often found to be discordant (Jordan's Principle Working Group 2015) for the delivery of healthcare to First Nations, it is critical to understand the impact that existing health policies have on participation in cancer screening if these services are to be improved.

Historically, First Nations in Canada have had much lower rates of cancer incidence and mortality than non-First Nations Canadians (Gillis et al. 1991; Morgan and Laing 1981; Young and Frank 1983). However, cancer has recently emerged as a significant health challenge. Although there is a paucity of detailed data on both the prevalence and incidence of cancer among all Indigenous populations in Ontario (Chiefs of Ontario and Cancer Care Ontario 2016), there are some data to suggest that the incidence of several cancers has risen quickly among First Nations in the province, and the survival rate is poorer than before (Marrett and Chaudry 2003; Nishri et al. 2014; Withrow et al. 2017).

Health Policy as a Barrier to First Nations Peoples' Access to Cancer Screening

TABLE 1. Key terms used

Key term	Definition
Aboriginal	Aboriginal Peoples of Canada is the term used within Section 35 of the 1982 <i>Constitution Act</i> . It includes Indian (First Nations), Inuit and Métis.
First Nations	First Nations are the largest Indigenous population in Canada, south of the Arctic. First Nations peoples throughout Canada are further classified as "status" and "non-status". Status entails formal recognition of First Nations identity by the federal government and subsequently guarantees access to federal treaty rights and programs (i.e., Non-Insured Health Benefits; see also: Hurley 2000).
First Nations reserves	First Nations reserves are tracts of land that have been set apart by the Crown for the use and benefit of a First Nations band and its status members.
Indigenous	Indigenous communities, peoples and nations have a historical continuity with pre-invasion and pre-colonial societies that developed on their territories and consider themselves distinct from other sectors of society that now prevail on those territories. In Canada, Indigenous populations comprise First Nations, Inuit and Métis peoples (see also: Indigenous and Northern Affairs Canada 2017; Kenrick and Lewis 2004; The United Nations 2007).
Inuit	The Inuit are the Indigenous peoples of Inuit Nunangat (Inuit Homeland), which spans the Arctic regions of Canada. There is a growing Inuit community in Ontario, with the majority living in Ottawa and Toronto.
Métis	The Métis are descendants of people born out of relations between Indian women and European men. They are a distinct aboriginal people with a unique history, culture, language and territory (Métis Nation of Ontario 2017).
Political territorial organization (PTO)	A PTO is a governing body representing the political aspirations of its First Nations communities to all levels of government. There are four PTOs operating in Ontario: The Association of Iroquois and Allied Indians (representing seven communities), Grand Council Treaty #3 (representing 28 communities in Ontario and Manitoba), Nishnawbe Aski Nation (representing 49 communities) and The Anishinabek Nation (representing 40 communities). There are also 13 independent First Nations communities who are not affiliated with any PTO.
Residential school system	The residential school system was a federal government assimilationist policy that operated from 1870 to 1996. Indigenous children were removed from their families and forced to attend government-funded institutions. The physical and mental impacts of residential school continue to manifest among survivors and their families (Kirmayer et al. 2003).
Truth and Reconciliation Commission of Canada (TRC)	The TRC was established in 2008 with a mandate to learn the truth about what happened in residential schools and inform Canadians about this history. Upon closing in 2015, the TRC released a document identifying 94 calls to action aimed at redressing the legacy of residential schools and advancing the process of reconciliation (TRC 2015).

Screening is a key strategy to reduce the burden of cancer. Through screening, persons without cancer symptoms are tested to identify risks; if needed, further diagnostic testing is offered. Screening cannot reduce the impact for all cancer types. Large randomized controlled trials have demonstrated the benefits of mammography to screen for breast cancer and fecal occult blood testing and flexible sigmoidoscopy for colorectal cancer (Canadian Task Force on Preventive Health Care 2011, 2016; Lauby-Secretan et al. 2015; Nelson et al. 2016; Tinmouth et al. 2016). For cervical cancer, well-designed ecological studies support the use of cervical cytology (Pap smears) for screening (Canadian Task Force on Preventive Health Care 2013; Cancer Care Ontario 2012b). In Ontario, Cancer Care Ontario (CCO) is the provincial agency responsible for advising the Ministry of Health and Long-Term Care (MOHLTC) on the cancer system, including access to cancer screening. CCO currently operates three organized screening programs: Ontario Breast Screening Program, Ontario Cervical Cancer Screening Program and ColonCancerCheck. Within each program,

screening guidelines have been developed based on expert reviews of available scientific evidence (Canadian Task Force on Preventive Health Care 2011; Murphy et al. 2011; Tinmouth et al. 2016; Warner et al. 2012). Table 2 provides an overview of the three organized screening programs currently operating within Ontario. Within CCO, the Indigenous Cancer Care Unit (ICCU) works to improve cancer care for Indigenous peoples throughout the province. ICCU is guided by the Joint CCO–Indigenous Cancer Committee (JOICC), which comprises members from each of the PTOs as well as other provincial Indigenous organizations.

TABLE 2. Ontario’s organized cancer screening programs (adapted from: CCO 2016)

Screening program	Recommended screening test	Screening guidelines
Ontario Breast Screening Program (OBSP)	Digital mammography provided at an OBSP screening location every two years	Women in the age range 50–74 and have: no acute symptoms no personal history of breast cancer no current breast implants not had a mammogram within the past 11 months
High-risk OBSP	Digital mammography + magnetic resonance imaging every year	Women in the age range 30–69 and: having a physician’s referral having no acute breast symptoms Fall into one of the following risk categories: known to be carriers of BRCA1 or BRCA2 gene mutation first-degree relative of a mutation carrier; has had genetic counselling and has declined genetic testing previously assessed by a genetic clinic as having >25% lifetime risk of breast cancer received radiation therapy to the chest before age 30 and at least eight years ago
Ontario Cervical Cancer Screening Program	Cytology (Pap) test performed at healthcare provider’s office every three years	Women who are 21 years old and are or have been sexually active
ColonCancerCheck (CCC)	Guaiac fecal occult blood test (FOBT) completed at home every two years. Test obtained from family physicians/ nurse practitioners or by contacting Telehealth Ontario Note: Ontario will be switching from FOBT to the fecal immunochemical test for colorectal screening in 2019.	Men and women in the age range 50–74 and have: no first-degree relative who has been diagnosed with colorectal cancer no personal history of pre-cancerous colorectal polyps requiring surveillance or inflammatory bowel disease
CCC increased risk	Colonoscopy every 5–10 years	Men and women with a family history of colorectal cancer that includes one or more first-degree relatives who have been diagnosed with colorectal cancer, but do not meet the criteria for hereditary colorectal cancer syndromes

Unfortunately, Indigenous peoples throughout Canada are often less likely to be screened (Assembly of First Nations [AFN] 2009; Cancer Quality Council of Ontario 2019; Elias et al. 2011; Sheppard et al. 2010; Withrow et al. 2014). Several factors have been shown to limit First Nations' participation in cancer screening; these include difficulties accessing screening services, including coverage for costs of transportation to screening sites (First Nations Information Governance Centre 2012); inadequate health coverage for non-status First Nations individuals (Bent et al. 2007); negative experiences with the healthcare system, including racism (Allan and Smylie 2015; Brooks-Cleator et al. 2018; Loppie et al. 2014; Wylie and McConkey 2018); impact of intergenerational trauma, including experiences of residential schools, which leads to distrust of healthcare providers and resistance to engaging with the healthcare system (Browne and Fiske 2001; Kirmayer et al. 2003; Smith et al. 2005); low levels of awareness and community-based education emphasizing the importance of screening (Loppie and Wien 2005; O'Brien et al. 2009); and limited capacity and often lack of willingness of the healthcare system to engage Indigenous populations in disease prevention, acknowledge patient symptoms, and facilitate early-detection activities (Lavoie et al. 2016; Tjepkema 2002). The presence of other salient health issues such as food insecurity (Neufeld et al. 2017) and access to safe drinking water (Patrick 2011) also competes, understandably, with First Nations peoples' engagement with screening. Therefore, it is critical to address lower participation rates and later-stage cancer diagnosis among First Nations people to improve access to and use of cancer screening services.

Approach

We followed an embedded multiple-case study design (Yin 2014), drawing upon both a document review to describe the existing policy context and key informant interviews to explore this context from the perspective of multiple stakeholders. Research ethics board approval was obtained for this study through Sunnybrook Research Institute's Research Ethics Office, the University of Toronto Research Ethics Board and Health Canada and the Public Health Agency of Canada Research Ethics Board.

Selection of cases

Three regions were selected as cases based on Ontario's regional decision-making structure for cancer care (i.e., regional cancer programs [RCPs] are aligned with health regions, also called Local Health Integration Networks [LHINs]), with embedded units of analysis within each case including community service providers (e.g., primary care providers, hospitals, public health units) and First Nations communities. We also included overarching units of analysis such as governments and agencies at the federal (e.g., Health Canada, First Nations and Inuit Health Branch [FNIHB]) and provincial levels (e.g., MOHLTC, CCO). Table 3 provides an overview of our approach.

TABLE 3. Embedded multiple case study approach

Embedded and overarching levels of analysis	Case 1	Case 2	Case 3
Federal	Health Canada – First Nations and Inuit Health Branch; Canadian Partnership Against Cancer; Assembly of First Nations		
Provincial	Ministry of Health and Long-Term Care, Cancer Care Ontario, political territorial organizations		
Regional	Regional Cancer Program A	Regional Cancer Program B	Regional Cancer Program C
Sub-regional (First Nations community)	First Nations communities (urban, rural)	First Nations communities (rural, remote)	First Nations communities (remote)
Sub-regional (health service and support)		First Nations health service provider (urban)	First Nations health service provider (remote)

Our case selection criteria aimed for diversity of communities within the region in terms of variation in location of the First Nations communities (urban, rural and remote), First Nations community population sizes and political territorial organization (PTO) affiliation. Additional case selection criteria focused on diversity of regional characteristics, including total population of all First Nations communities within the regional boundaries and geographic location within the province (north/south).

Within the selected case regions, a number of First Nations communities were approached for inclusion as embedded units of analysis. Similar to the criteria used in selecting case regions, First Nations communities were approached based on location within the region (e.g., urban, rural and remote), population size and PTO affiliation. As relationships built upon trust are key to support successful research with First Nations communities (Castleden et al. 2012; Tobias et al. 2013), we also drew on pre-existing relationships between members of the research team and First Nations communities to finalize the selection. Further embedded units of analysis at the sub-regional level – such as local health service and support providers – were also included if identified as relevant to the study by a key informant.

Key organizations operating at federal and provincial levels were also included as overarching units of analysis for the case study. These included government ministries responsible for health and/or Indigenous populations; agencies/organizations responsible for organizing, financing, delivering and/or guiding cancer services; and organizations responsible for Indigenous populations.

Selection of policy documents

The objective of the document review was to develop an understanding of health policies impacting First Nations’ access to cancer screening in Ontario. We searched publicly accessible databases (e.g., Medline, Google Scholar) and policy-related sources (e.g., Canadian Public Policy Collection) and we conducted general Web searches using a mix of key words and subject headings (e.g., MeSH) where relevant. We also conducted targeted searches of

key organizations' websites and asked key informants to identify relevant documents upon completion of their interview. Our search yielded a wide variety of documents, and we drew upon Pal (2014) to guide screening for inclusion, characterizing policy documents as those defining a course of action or inaction to be taken by an organization in addressing a given issue. Subsequently, we categorized the included policy documents under four headings: cancer screening, cancer services, general Indigenous health policy and Indigenous cancer screening policy.

Key informant interviews

Key informant interviews provided an interpretive lens on the policy context. A sampling frame was constructed based on available organizational information identified through the document review (e.g., organizational charts, Web profiles) and pre-existing contacts. Purposive sampling was used to guide recruitment of interview participants to ensure balanced representation for each case and level of analysis. Snowball sampling was also used as a secondary sampling method.

A semi-structured interview guide was developed and pilot-tested for the study. Interviews were conducted by the lead author, Joshua K. Tobias, either in person or by telephone between January 2015 and September 2016. Interviews were audio-recorded and transcribed verbatim. Thematic analysis guided exploration of the key informant interview data, drawing upon an iterative approach used to identify and refine themes. QSR International's NVivo 10 Software was used to both code and analyze data. Themes and coding framework were also reviewed and discussed through presentations given to the staff and leadership at CCO's ICCU and JOICC.

Results: Document Review

The document review identified 34 relevant documents, with nine relating to cancer screening, four to cancer services, 12 to general Indigenous health policy and nine to Indigenous cancer screening policy. Table 4 (available online at longwoods.com/content/26132) provides a summary of the policy documents included in the review.

Organizational landscape of cancer screening policy making for First Nations

The review of the documents listed in Table 4 clearly demonstrates that First Nations health policy in Canada is characterized by complex relationships between multiple federal, provincial/territorial, regional, municipal governments and Indigenous authorities. Each plays a unique role in a system of healthcare delivery rooted in 19th century legislation (e.g., the *British North America Act*, *The Indian Act*) and further supported by the 1979 Federal Indian Health Policy as well as Section 35 of the 1982 *Constitution Act*. As it pertains specifically to cancer screening, the FNIHB Non-Insured Health Benefits (NIHB) Program includes medical transportation benefits detailed within the NIHB Medical Transportation

Framework (AFN, 2014; Health Canada 2005). This includes services covered by provincial health plans, including cancer screening services recommended within Ontario's organized cancer screening programs. Cost for medical travel for screening and costs incurred while travelling to participate in screening are reimbursed through the program, which includes necessary health services that are unavailable on-reserve or in the patient's community of residence. This policy predominantly impacts access to mammography and colonoscopy.

The Canadian Partnership Against Cancer (CPAC), an independent organization funded by the federal government with a mandate to shape a national strategy for cancer control, contributes to the improvement of provincial screening programs by evaluating and analyzing emerging research as well as assessing evidence for screening guidelines. CPAC has also launched the First Nations, Inuit and Métis Action Plan on Cancer Control (CPAC 2011) aimed at improving the quality of Indigenous patients' cancer care. This initiative includes specific components addressing access to cancer-related programs and services in remote and rural communities.

Provincial-level policy context

In Ontario, MOHLTC has the overall responsibility of governance of the healthcare system, including its funding arrangements and service delivery throughout the province. This entails oversight of strategic policy direction and priorities, legislation, establishment of funding models and the monitoring of and reporting on the performance of the healthcare system. In 2006, the *Local Health System Integration Act* introduced a regional health service model to the province through the creation of 14 Local Health Integration Networks (LHINs). The *Patients First: Action Plan for Healthcare* (MOHLTC 2015b) provides guidelines for healthcare delivery in Ontario. The plan is centred upon improving access to services, coordinating and integrating care closer to home, providing education and information as well as sustaining the value and quality of the healthcare system. The MOHLTC-supported Northern Health Travel Grant provides financial support to all eligible residents of Northern Ontario requiring a medical specialist or services that are not available locally but rather only at a designated health facility that is at least 100 km away.

CCO is an agency of the Ontario Government and the principal advisor to MOHLTC on cancer services and the cancer system. CCO is governed by the provisions of both the 1990 *Cancer Act* and the 2009 Memorandum of Understanding with MOHLTC (CCO 2011). CCO's key commitments are detailed within formal cancer plan documents, with the most recent, Ontario Cancer Plan IV (CCO 2015c), including implementation of provincial cancer prevention and screening programs, managing the performance of the cancer system in collaboration with 14 regional cancer programs and LHINs and ensuring health equity across the cancer system. The mandate of ICCU is currently set out in their *Aboriginal Cancer Strategy III* (CCO 2015b), which was collaboratively developed with First Nations, Inuit and Métis peoples throughout the province.

Regional-level policy context

The CSIC report (2001) addressed major concerns about Ontario's cancer system (although notably made no mention of cancer services for Indigenous peoples) and was the precursor to major restructuring of cancer services in 2004, ultimately resulting in the creation of RCPs (Sullivan et al. 2005). There are currently 14 RCPs; these are generally aligned with the LHIN structure, with the exceptions of the Toronto Central LHIN, which is supported by two RCPs, and the Mississauga-Halton and Central West LHINs, which are supported by the same RCP. The RCPs are based at regional cancer centres that are integrated with host hospitals, with the RCP Regional Vice President working under a dual-reporting relationship with the CEOs of the host hospital and CCO. Within this relationship, CCO and RCPs work together to promote high performance in the cancer system across the province, taking into account the unique needs of each region. Furthermore, the RCPs are responsible for ensuring that service providers meet the requirements and targets set out in their partnership agreements with CCO. CCO's ICCU works with RCPs, providing support to the Indigenous populations within their regions. ICCU and RCPs collaborate with Indigenous communities and organizations within the individual regions to develop Regional Indigenous Cancer Plans. These plans outline key cancer priorities and strategies for addressing those tailored to the unique needs of the Indigenous population within each region while aligning with both the time frame and strategic priorities outlined in the Aboriginal Cancer Strategies (CCO 2012a, 2015b).

Results: Key Informant Interviews

A total of 44 of the 68 invitees participated in the interview (participation rate: 65%). Of these, 13 were recruited from the overarching (federal, provincial) units of analysis, with the remaining 31 individuals located within the regional cases (case 1: $n = 9$; case 2: $n = 12$; case 3: $n = 10$).

Results of key informant interviews: perspectives on the policy context for cancer screening

Three key themes emerged from key informant interviews: jurisdictional ambiguity, appropriateness of cancer screening program design for First Nations and lack of cultural competence. Although cases were selected to achieve diversity across the range of case selection criteria identified, the cross-case comparison revealed consistent thematic similarities among the selected cases. As such, the results of key informant interviews across each level of analysis are presented thematically, with regional differences highlighted where relevant. Table 5 (available online at longwoods.com/content/26132) provides representative quotes for each of the three identified themes.

Jurisdictional ambiguity

Each interview participant was asked if they could identify the key organizations responsible for developing policies that influence how and when First Nations peoples throughout the

province receive cancer screening. Across all levels of analysis, very few participants could identify multiple organizations or describe the approach that organizations would use to develop relevant policies. This pointed to a lack of awareness of jurisdictional responsibilities as well as of how various organizations collaborate. Among interviewees who were able to identify specific organizations, most identified MOHLTC, FNIHB and/or CCO as primarily responsible for setting relevant policies.

Within the three cases selected, awareness of federal responsibilities for healthcare provision was high among federal-level informants as well as community (sub-regional) key informants across all cases. Notably, awareness of the federal responsibility for First Nations healthcare was low among regional and provincial key informants. All key informants were also largely unable to speak to the process of operationalizing responsibilities across federal and provincial jurisdictions. Within case 3, key informants described challenges in obtaining medical transportation to access mammography services. Although several community members have detailed their experiences of being denied medical transportation, key informants were unable to articulate which agency would be best positioned to collaborate with FNIHB to address the issue. Among individuals within the RCPs, there was a greater level of awareness pertaining to transportation barriers in regions with higher numbers of remote communities. Some key informants, especially those working in remote areas, were able to speak in detail about policies such as FNIHB's NIHB Medical Transportation Framework or MOHLTC's Northern Health Travel Grants.

When discussing policy development, key informants operating primarily within the overarching federal or provincial organizations could often identify multiple sources that they believed informed the creation of programs and policies specific to their own organization, such as clinical guidelines presented by the Canadian Task Force on Preventive Health Care. However, these individuals were often unsure how other organizations developed policies that impact on access to screening. For example, FNIHB participants were aware of CPAC as an organization but could not speak to CPAC's First Nations, Inuit and Métis Action Plan on cancer control recommendations regarding health administrative data or how these have supported the development of First Nation, Inuit and Métis (FNIM) identifiers within cancer databases.

Appropriateness of cancer screening program design for First Nations

Key informants in each of the three cases expressed that policies are developed largely to address the needs of the non-Indigenous population and that the unique needs of First Nations peoples are only considered at later stages. Typically, when facing difficulties in policy implementation, for example, current clinical guidelines for screening were often questioned in terms of appropriateness. Given the high rates of several cancer risk factors among First Nations, many community-level key informants suggested that screening program design may require modification.

In case 1, CCO policies and pathways for providing screening results to a First Nations individual were described as requiring adaptation to the reality of First Nations' daily life in

the region. It was noted that individuals in this region may have both an on-reserve address and an urban residence. As such, delays in the receipt of mailed correspondence such as invitations to screening, results or follow-up requests may occur. This issue was believed to be compounded by an absence of primary care practitioners and an increased reliance on walk-in clinics for healthcare.

At the organizational level, discussion regarding the appropriateness of a screening program design varied among key informants. Those working in First Nations organizations believed that processes had been developed without community voice. However, this often also included a recognition that the prevailing culture was slowly changing as a result of assertions for inclusion from First Nations leadership.

Many informants suggested that the key to improving cancer screening participation among First Nations is the Indigenous representation in both processes of policy development and evaluation. Although it was articulated that inclusion of Indigenous perspectives in policy evaluation remains rare, it was noted that opportunities for Indigenous voices to be heard in policy evaluation are increasing. In case 2, a committee of representatives from the First Nations communities in the region, CCO and RCP has been created. This group meets regularly to provide guidance on the development and implementation of the Regional Aboriginal Cancer Plan.

Lack of cultural competence

Those working closely with First Nations communities, typically at the regional and community levels, identified cultural competency issues as a barrier to participation in screening. Previous experience with racism when seeking healthcare was discussed as causing apprehension and anxiety about further engagement with the healthcare system, including hesitancy to participate in screening. Community-level informants from all cases spoke about having directly experienced overtly racist treatment in healthcare settings.

Some informants at federal and provincial levels who were responsible both for policy design as well as implementation recognized the need for increased cultural training for healthcare service providers. Importantly, however, a small number of participants at this level of analysis maintained that this type of training was not a priority and argued that staff should be focused on developing other skills.

Discussion and Conclusion

Given the increasing cancer incidence and poorer cancer-related survival rate among First Nations, our study sought to explore how existing policies shape access to and participation in cancer screening among First Nations communities in Ontario. We identified three key factors impacting the policy context for cancer screening: jurisdictional ambiguity, absence of an Indigenous-specific screening program design and lack of cultural competence. While the first reflects long-standing governance arrangements (i.e., federal responsibility for First Nations health) that are challenging to change but possible to clarify, the other two reflect processes that are more amenable to change and align well with the more general shift from

a predominantly medical model of healthcare to an increasingly patient-centred orientation (MOHLTC 2015b) toward health services and policy (e.g., increased First Nations voice in policy design).

Although there were differences in the First Nations population structure (e.g., population size, percentage urban/rural/remote) across each of the three cases, the overall descriptions of challenges inherent in cancer screening were quite similar in nature for all the three cases. For instance, difficulties pertaining to access to transportation for screening due to jurisdictional ambiguity or experiencing racism when seeking screening was. The inclusion of First Nations' representation in policy design and evaluation was discussed as being somewhat easier in case 3, where the majority of individuals live in First Nations communities located in rural areas.

Despite commitments made both federally and provincially (Jordan's Principle Working Group 2015), insights from key informants reveal that barriers to effective screening policies and programs are rooted in long-standing issues of jurisdictional ambiguity. This has resulted in both the creation of policies that do not necessarily reflect First Nations' lived realities and the increase in frustration with the cancer screening system for First Nations peoples and uncertainty regarding where best to address grievances. Our results echo existing critiques of the current Indigenous health policy structure (Dwyer et al. 2013; Lavoie et al. 2010; Lavoie 2013; National Collaborating Centre for Aboriginal Health 2011; Snyder et al. 2015) and corroborate the emerging discourse from within First Nations' health literature that supports the creation of a national Indigenous policy framework (Lavoie 2013; Richmond and Cook 2016).

Inadequate Indigenous-specific screening program design results from the relatively few Indigenous persons who are involved in the process of designing a health policy. Key policy stakeholders operating at all levels should seek to increase opportunities to include Indigenous communities and organizations throughout the province in developing and carrying out evaluations. Across Canada, First Nations communities have increasingly begun asserting self-determination within health service delivery – including policy design and evaluation – with measurable improvements in health outcomes (Lavoie et al. 2015; Richmond and Cook 2016). Within our study, several community-level informants shared their frustration with the NIHB program and its ambiguities in enabling access to screening. However – as discussed by one key informant involved in the process – it is encouraging to note that this program is currently under joint review within a collaborative process, including both Health Canada and Indigenous representatives from across the country.

The three cases produced consistent findings that suggest that developing effective and appropriate cancer screening policies requires increased attention to the specific realities and needs of Indigenous populations. Currently, screening guidelines in Ontario do not make individualized recommendations for the First Nations population. There is some limited evidence suggesting that developing guidelines specific to individual ethnic groups may improve participation in screening (Williams et al. 2016). A comprehensive review of this issue at the provincial or national level, inclusive of Indigenous voices, may help clarify how a screening

program design could be modified to better serve the needs of Indigenous communities.

CCO has entered into a number of formalized relationships with First Nations PTOs and independent communities through the signing of relationship protocols. These agreements provide public recognition of the relationship and enhance accountabilities, creating greater capacity for the inclusion of First Nations' within the development, implementation and evaluation of provincial cancer initiatives and policies.

Our results are in line with those of others who have emphasized the critical importance of enacting specific policies and procedures aimed at promoting increased cultural safety (Allan and Smylie 2015; Baba 2013; Brascoupé and Waters 2009). Culturally competent healthcare has the potential to improve health disparities by increasing awareness of and addressing root causes such as structural racism and discrimination (Brooks-Cleator et al. 2018; Churchill et al. 2017). Cultural competency is indisputably important for healthcare providers who interact with Indigenous peoples on a daily basis; it is equally important among those contributing to policy development and implementation (e.g., RCP/CCO Leadership). In February 2016, the provincial government declared that Indigenous cultural competency and anti-racism training would be mandatory for all public service employees (Ontario 2016). Cancer screening leadership should be proactive in identifying existing training opportunities and ensuring that their staff is educated and aware of Indigenous realities in Canada in the spirit of reconciliation. This endeavour may present resource capacity challenges specifically within the RCPs, where program leadership will need to find ways to accommodate staffing requirements (e.g., paid time for taking this training). The province should seek to support RCPs in facilitating staff participation with cultural competency training.

It is also important to note that key informants across all levels of the health system cited examples of successful initiatives and expressed optimism for the future of Indigenous cancer screening.

We just recently had a cervical screening clinic in one of our [Indigenous] communities and it was really well attended. [...] It worked. It was evidence of increasing momentum that comes when you keep investing the time to say this relationship and doing this with you is really important and I will come back to keep doing this with you even if the numbers aren't there. You never do the math on the cost per patient.
(RCP Informant)

The political climate in Canada appears to have shifted to be more receptive to and aware of the unique needs of the Indigenous population. As such, cancer screening policy in Ontario should capitalize on this new landscape to develop and produce new initiatives. Sharing information on successful initiatives by leveraging knowledge translation and exchanging opportunities in the cancer system would facilitate the adaptation and adoption of any lessons learned.

The findings in this paper are focused on screening policies and perspectives, as these apply to First Nations populations in Ontario. However, Ontario is also home to growing Métis and Inuit populations, each of which faces unique challenges in accessing cancer screening. Recent research demonstrates that cancer is also an increasing burden for these two groups (Cancer Care Ontario 2015; Cancer Quality Council of Ontario 2016; Chiefs of Ontario and Cancer Care Ontario 2016; Métis Nation of Ontario and Tungasuvingat Inuit and Cancer Care Ontario 2017). It was outside the scope of this study to explore features of the policy context facing Métis and Inuit in the province that are unique to these populations or common to First Nations; future research, however, should build on the current work to explore these features.

In 2015, the TRC put forward 94 calls to action intended to redress the legacy of residential schools and advance the process of Canadian reconciliation. Among the 94 calls to action, seven explicitly focus on improving the health of Indigenous peoples. These include calls upon governments to recognize the current state of Aboriginal health and implement healthcare rights (call 18); establish measureable goals toward closing the gap in health outcomes (call 19); address jurisdictional disputes (call 20); and require medical and nursing students to take a course on Aboriginal health issues (call 24). Our study identifies key structural issues and processes that should be addressed by agencies shaping cancer screening policy to successfully implement the TRC calls to action focusing on health.

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