#### **BRIEF REPORT**

# Proton Therapy in Canada: Toward Universal Access and Health Equity With a Publicly Funded Facility



Amir H. Safavi, MD, MSc,\*\*† Carolyn Freeman, CM, MBBS, FASTRO,<sup>‡</sup> Sylvia Cheng, MD, MScCH,<sup>§</sup> Samir Patel, MD, Gunita Mitera, PhD, Vijayananda Kundapur, MD, Rob Rutledge, MD,\*\* and Derek S. Tsang, MD, MSc\*\*†

\*Department of Radiation Oncology, University of Toronto, Toronto, Ontario, Canada; †Radiation Medicine Program, Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario, Canada; †McGill University Health Centre, Montreal, Quebec, Canada; \*BC Children's Hospital, Vancouver, British Columbia, Canada; \*Division of Radiation Oncology, University of Alberta, Edmonton, Alberta, Canada; \*Canadian Association of Provincial Cancer Agencies, Toronto, Ontario, Canada; \*Saskatchewan Cancer Agency, University of Saskatchewan, Saskatoon, Saskatchewan, Canada; and \*\*Department of Radiation Oncology, Dalhousie University, Halifax, Nova Scotia, Canada

Received Jul 31, 2022; Accepted for publication Dec 11, 2022

#### Introduction

Proton beam therapy (PBT) is a form of external beam radiation therapy that provides dosimetric and clinical advantages over photon therapy for treating some children and adults with benign or malignant tumors. The physical properties of proton beam distribution allow for both delivery of the prescribed dose at the end of the beam range within the tumor target as well as near-zero exit dose, thereby reducing the volume of irradiated normal tissues. Clinical evidence indicates that PBT is at least as isoeffective in tumor control as photon radiation therapy, but with potential reduction in long-term toxicities.<sup>2,3</sup> Therefore, PBT is commonly recommended for treatment of pediatric tumors, tumors in adolescent/young adult (AYA) populations, and some adult tumors requiring radiation therapy that may compromise pituitary, visual, intellectual, or auditory functions, or in the setting where normal tissue tolerances may be exceeded with conventional photon radiation therapy.

As of May 2022, there were 114 PBT facilities in clinical operation across 20 countries.<sup>4</sup> Canada is the only G8 country without a clinical PBT facility in operation or under construction. In British Columbia, approximately 200 patients

with ocular melanoma were treated at TRIUMF, a nonclinical particle accelerator center in Vancouver, before this program was terminated in 2018. In Canada's single-payer health insurance system, health care expenditures and capital investments are administered by provincial governments, and tax revenues are transferred to each province by the federal government to partially support costs. The Canada Health Act is federal legislation mandating reasonable access to health services for insured persons across all provinces without financial or other barriers.6 The Canadian health insurance system is governed by 5 principles: public administration, comprehensiveness, universality, portability, and accessibility.<sup>6</sup> Although there is no domestic clinical PBT facility in Canada, PBT is an insured health service for select patients across several provinces through provincially administered, out-of-country prior approval programs. These patients receive PBT outside Canada (typically in the United States because of geographic proximity) upon approval of applications submitted to provincial health ministries by a referring radiation oncologist.

Although there is access to publicly funded PBT in many Canadian provinces, the actual number of patients traveling for proton therapy is low. In 2016, 45 patients nationally received PBT through these programs.<sup>3</sup> In Ontario,

Corresponding author: Derek S. Tsang, MD, MSc; E-mail: derek. tsang@rmp.uhn.ca

Disclosures: D.S.T. received travel funding in 2022 from Mevion Medical Systems and Elekta AB. No other disclosures were reported.

Canada's most populous province, 57 patients were approved for PBT through the provincial out-of-country prior approval program from its inception in 2010 through September 2019.<sup>3</sup> Fewer than 30% of pediatric patients eligible for PBT in Ontario have been referred through the provincial program, raising concerns about inequities in access. Health equity is defined by the Canadian Institute for Health Information (CIHI) as the absence of unjust, avoidable differences in health care access, quality, or outcomes.8 Health equity is a fundamental domain of health care quality. Within the United States, inequities in PBT access exist because of socioeconomic status, geography, access to private insurance, and race, 10-14 even among Children's Oncology Group study participants. 11 In Canada, there are known inequities in cancer outcomes along strata of structural marginalization 15,16; inequities in PBT may contribute to disparate outcomes for these populations.

This article summarizes the current state of PBT access in Canada, domains of health inequities among Canadians receiving PBT, and strategies for addressing health equity in PBT in Canada, including an equity-oriented approach to planning for a publicly funded facility. Information on PBT in Canada was compiled from a literature review of publicly available documents from provincial health organizations, <sup>3,17-20</sup> reports from national organizations, <sup>21-23</sup> peerreviewed literature, <sup>24-26</sup> press releases, <sup>27,28</sup> and news articles. <sup>29,30</sup> Authors with expertise regarding the PBT referral process in their province provided supplementary information that is not publicly available.

#### **Current Access to PBT Across Canada**

Of the 10 provinces and 3 territories in Canada, 7 provinces -British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, and Nova Scotia—currently have structured out-of-country PBT referral programs, according to publicly available information. <sup>3,21,24,25</sup> Nova Scotia's out-ofcountry PBT referral program also facilitates referrals for patients residing in the provinces of New Brunswick and Prince Edward Island. Each province uses different processes and criteria to determine access to PBT. 21,22,25 Although there is gray and peer-reviewed literature regarding the out-of-country referral processes in Ontario,3 Quebec, <sup>17</sup> British Columbia, <sup>18</sup> and Alberta, <sup>19</sup> there is limited publicly available information about which diseases and populations are eligible for PBT referrals in other provinces, as well as which secondary treatment-related costs, such as travel and lodging costs, are covered by the provincial governments. A summary of out-of-country programs in the 7 Canadian provinces offering such referrals is provided in Table 1.

There are several similarities and differences between out-of-country PBT referral programs in Ontario, Quebec, British Columbia, Alberta, Manitoba, Saskatchewan, and Nova Scotia. Curative intent treatment is prioritized for a subset of patients with pediatric and adult cancers across

these provinces. In Quebec and Alberta, second-line treatment, metastatic disease, and reirradiation are not excluded from consideration for PBT. 17,19 Eligibility criteria in Quebec, Alberta, and Saskatchewan also include an expected survival of more than 5 years and good performance status. Quebec and Alberta's PBT referral programs require an assessment of the potential benefit of PBT over photon therapy. The assessment of the potential benefit of PBT over photon therapy is also found in the Netherlands, where a model-based approach is used for proton therapy patient selection.<sup>31</sup> Specific clinical indications eligible for PBT in each province are outlined in Table 1. All 7 provinces require expert case review to confirm suitability for PBT before approval. The use of expert case review to determine suitability and approval for PBT is also found in Sweden, Denmark, and the Czech Republic.<sup>32</sup> Although medical costs for PBT are covered by prior approval programs in all these provinces, indirect costs of PBT are not. Ontario, British Columbia, and Nova Scotia's programs do not cover indirect costs, 3,18 while Quebec, Alberta, Manitoba, and Saskatchewan's programs cover some travel costs. 17,19

#### **PBT Health Inequities in Canada**

There are several domains of health inequities in PBT access and patient experience in Canada. The eligibility criteria for out-of-country referrals vary across the country, as a function of competing priorities within each provincial health care system as well as the ongoing accumulation of evidence for PBT across various clinical indications.<sup>22</sup> The Canadian Association of Provincial Cancer Agencies (CAPCA) collaborated with clinical experts and administrators across provinces to publish national guidelines regarding PBT funding. However, the implementation of these recommendations is at the discretion of each province. Therefore, a situation could arise in which a patient from one province could be approved for PBT, but a similar patient who resides in a different province could be denied PBT.

Furthermore, there is no national database of all pediatric and adult patients treated with PBT in Canada, precluding an assessment of practice and approval patterns across the country. The Cancer in Young People in Canada (CYP-C) Program maintains a national database that captures incident cases of cancer in children and adolescents, along with postal code data that can be linked to area-level socioeconomic status. However, we have found that patients who received proton therapy out of country are not fully captured in the database. Barriers also exist to national harmonization of PBT referral processes and comprehensive data collection because administration of health care is the responsibility of each province.

There are concerns that the out-of-country referral programs may preferentially favor patients who have the financial and social resources to relocate out of country for several weeks.

Table 1 Characteristics of out-of-province access programs for proton therapy in 9 Canadian provinces

	Ontario <sup>3</sup>	Quebec <sup>17</sup>	British Columbia <sup>18</sup>	Alberta <sup>19,24,25</sup>	Manitoba	Saskatchewan	Nova Scotia and nearby Atlantic provinces
Population	14,223,942	8,501,833	5,000,879	4,262,635	1,342,153	1,132,505	969,383 (NS), 775,610 (NB), 154,331 (PEI)
Government program	Out-of-Country Prior Approval Program (Ontario Health)	Régie de l'assurance maladie du Québec	British Columbia Ministry of Health	Alberta Health Out-of Country Health Services Committee	Manitoba Health Out of Country Prior Approval Program	Out of country prior approval program provided by Ministry of Health through Saskatchewan Cancer Agency	Application is on a case-by- case basis to the provincial departments of health
General eligibility	Curative intent A subset of pediatric and adult cancers	Curative intent A subset of pediatric and adult cancers May be considered for second-line treatment Expected survival of >5 y ECOG PS 0-2 PBT should confer significant benefit over available radiation modalities	Curative intent A subset of pediatric and adult cancers	Curative intent A subset of pediatric and adult cancers Metastatic disease and reirradiation not excluded Expected survival of ≥5 y ECOG PS 0-2 Comparative proton and photon plans are generated for assessment of the magnitude of the potential benefit of PBT Age ≤40 y	Curative intent A subset of pediatric and adult cancers All cases discussed in dedicated disease site group rounds	Curative intent A subset of pediatric and adult cancers Expected survival of ≥5 y ECOG PS 0-2	Selected curative-intent pediatric cases
Examples of tumor types eligible	Medulloblastoma, ependymoma, Ewing sarcoma, orbital sarcoma, osteosarcoma, rhabdomyosarcoma, Hodgkin lymphoma, non-Hodgkin lymphoma, astrocytoma, adenoid cystic carcinoma, meningioma, craniopharyngioma, glioma, malignant myxoid lesion, thymic carcinoma	Intraocular melanomas Skull base and spinal chordomas Skull base chondrosarcomas Tumors whose treatment with photon therapy could damage adjacent tissues (eg, meningiomas, intracranial tumors, spinal and paraspinal soft tissue and bone sarcomas) Pediatric: ependymomas, craniopharyngiomas, PNET, Ewing sarcoma, pineal gland tumors, lymphomas, rhabdomyosarcomas, retinoblastomas	Medulloblastoma, ependymoma, malignant rhabdoid tumor, intracranial germ cell tumors, gliomas, pineal tumors, craniopharyngioma, vascular tumors, meningioma, CNS sarcoma, Ewing sarcoma, rhabdomyosarcoma, chordoma, neuroblastoma, Wilms tumor, Hodgkin lymphoma	All patients: chordoma, chrondrosarcoma, craniopharyngioma, CNS germ cell tumors, low-grade gliomas, AVM, mediastinal lymphoma; any other diagnosis can be approved by multidisciplinary tumor board Pediatric: any diagnosis requiring CSI, pituitary and pineal tumors, ependymoma, pelvic sarcomas, rhabdomyosarcoma, Ewing sarcoma Adults: paranasal sinus and nasal cavity tumors, intraocular melanomas not suitable for brachytherapy	Intraocular melanomas, Skull base and spinal chordomas Skull base chondrosarcomas Tumors whose treatment with photon therapy could damage adjacent tissues (eg, spinal area) Pediatric: ependymomas, craniopharyngiomas, PNET, Ewing sarcoma, pineal gland tumors, lymphomas, rhabdomyosarcomas, retinoblastomas Case-by-case evaluation permitted, depending on clinical scenarios	Intraocular melanomas Skull base and spinal chordomas Skull base chondrosarcomas Pediatric: ependymomas, craniopharyngiomas, PNET, Ewing sarcoma, rhabdomyosarcomas, optic nerve glioma, medulloblastoma	Medulloblastoma, ependymoma and other selected pediatric CNS tumors, highly selected non-CNS tumors
							(Continue

Тъ	h	le 1	1 (	Ca	nti	1111	<i>A</i>
ıа	n	e		U.A	ทก	ทนเ	201

	Ontario <sup>3</sup>	Quebec <sup>17</sup>	British Columbia <sup>18</sup>	Alberta <sup>19,24,25</sup>	Manitoba	Saskatchewan	Nova Scotia and nearby Atlantic provinces
Requirement for expert case review	Reviewed by physicians selected by the program	Reviewed by the Comité provincial de protonthérapie	Reviewed by the institutional multidisciplinary tumor board	Reviewed at the CancerCare Alberta Proton Therapy Referral Rounds	Reviewed by the institutional multidisciplinary disease site group rounds attended by oncologists from all disciplines involved in the circle of care	Reviewed and recommended by site- specific radiation oncologist or by the institutional multidisciplinary tumor board	Reviewed and approved by tumor board and Department of Radiation Oncology
Medical costs of PBT	Covered	Covered	Covered	Covered	Covered, if approved. For approved cases: physician fees covered, at the same rate a Manitoba doctor would receive for similar services; and hospital bills, up to 75% of insured hospital services	Covered	Covered
Indirect costs of PBT	Not covered; transportation is often covered by philanthropic agencies for children only	Travel costs, including accommodation and transportation, are covered	Not covered	Flights for the patient and 1 parent or guardian for children are covered; housing, food, and transportation are often covered by philanthropic agencies for children only	For approved cases, may be reimbursed for reasonable transportation costs; accommodations, meals, taxis, ambulance, and other expenses are not covered	Adult patients may have to take separate insurances; for pediatric patients, depends on the referring facility giving a global package that also includes the stay, and food that will be paid as a package by the health ministry directly to the facility	Not covered

Abbreviations: AVM = arteriovenous malformation; CNS = central nervous system; CSI = craniospinal irradiation; ECOG PS = Eastern Cooperative Oncology Group performance status; NB = New Brunswick; NS = Nova Scotia; PEI = Prince Edward Island; PNET = primary neuroectodermal tumors.
\*Nova Scotia also supports New Brunswick and Prince Edward Island.

As part of a health technology assessment, Ontario Health conducted interviews with 10 patients to characterize lived experiences of undergoing out-of-country PBT through the provincial prior approval program.<sup>3</sup> Patients expressed concerns regarding the financial toxicity of secondary expenses of treatment such as travel costs, lodging, accommodation, food, travel medical insurance, and cell phone costs. In Alberta, the indirect costs associated with out-of-country referral for PBT of adult and pediatric patients have been surveyed and there are concerns that financial toxicities may affect referrals for PBT.<sup>24</sup> This may represent an important driver of health inequities for patients accessing PBT. Additionally, patients noted effects of participating in the out-of-country referral program on family functioning, specifically on employment, children's schoolwork, emotional, and mental health effects of being separated from family and friends.<sup>3</sup> Better family functioning is associated with improved quality of life (QOL) in children with cancer and mediates the effect of socioeconomic status on QOL.34,35

There is a patient perception that expert review requirements of out-of-country referral programs may contribute to inequitable access to PBT. Patients participating in the Ontario Health qualitative study raised concerns about potential inequities in access to and delays in receiving PBT if unique cases felt to require PBT by a patient's radiation oncologist were not approved after expert review by physicians not directly involved in the patient's care as part of the out-of-country referral program. Similar issues regarding access to and delays in receiving PBT have been noted in Europe and the United States because of prior authorization requirements from health insurance providers. Ultimately, final funding decisions for PBT remain the jurisdiction of the patient's insurer—in the case of Canadian patients, the insured individual's provincial health insurance program.

Patients noted areas of dissatisfaction with accessing PBT outside of Canada, including navigating logistics of the prior approval program, preparing for time away from home, uncertainty about the timing and location for relocation to the United States for PBT, and organizing travel medical insurance.<sup>3</sup> These patients wondered why capital investment in a domestic PBT facility is lacking when there are clear indications for referring these patients for PBT. Lastly, the Ontario Health qualitative study found that patients perceived the creation of a PBT facility in Ontario to improve access to treatment and help reduce potential health-related inequities exacerbated by travel to the United States.<sup>3</sup> Complementing this finding, the Advocacy for Canadian Childhood Oncology Research Network has called for the development of PBT facilities in Canada.<sup>29</sup>

#### **Toward PBT Health Equity in Canada**

The number of patients eligible for PBT has been growing annually. Assuming that 6% of all patients requiring curative-intent radiation therapy may benefit from PBT, 20 4534 out of 75,573 patients across Canada are expected to

potentially be eligible for PBT annually.<sup>39</sup> Based on patterns of uptake of PBT in Ontario's Out-of-Country Prior Approval Program, a minimum of 3% growth per year in the number of patients requiring PBT is expected.<sup>23</sup> Within Ontario, Canada's most populous province, up to 1,627 patients across 13 tumor types are expected to potentially be eligible for PBT annually.<sup>3,20</sup> However, it is currently expected that only 12 to 14 patients per year may receive out-of-country PBT in Ontario, based on prior patterns of referral.<sup>3</sup> The discrepancy between the number of patients believed to be eligible for PBT and the number currently referred for out-of-country treatment may in part be driven by factors including lack of fitness of some patients for international travel (eg, those with postoperative complications and need for intensive rehabilitation), travel costs, loss of employment, potential effects on family functioning, difficulties with securing a passport, or immigration barriers with international travel.

There is a need for improved standardization across the country regarding access to PBT. CAPCA has developed evidence-based consensus recommendations regarding patient eligibility, program requirements, and system level requirements to promote consistent and equitable access to PBT in Canada.<sup>22</sup> These guidelines should be evaluated and adopted by all provinces. Furthermore, there is a need to develop a national database of patients receiving PBT to quantify referral and practice patterns, as well as potential barriers in interprovincial or out-ofcountry access across clinical indications and domains of health inequities. Individual patient-level data, including postal code information linked to area-level socioeconomic status, are needed to identify inequities among patients being referred for PBT and improve future access to care planning.

Additionally, there is a need to develop strategic priorities at the institutional and provincial government levels to develop local capacity for PBT and improve health equity of patients requiring these treatments. In 2018, a private company, CDL Laboratories, announced an agreement with the Quebec Ministry of Health and Social Services to privately fund, build, and operate a standalone, non-hospital-based PBT facility on the island on Montreal. A contract was negotiated between CDL and the provincial government to pay for treatment costs, on a per patient basis.<sup>27</sup> However, some clinicians raised concerns regarding the center not being based in an academic hospital, as it would preclude multidisciplinary hospital-based support for anesthetic complications and intensive supportive care for pediatric patients, as well as research and training in academic radiation oncology departments.<sup>26,30</sup> In addition, some raised concerns that treatments at a private center would be less cost-effective per patient for the provincial health system overall.<sup>26</sup> There have been no announcements regarding the project since the Quebec provincial election in October 2018.

In 2022, the Ontario government announced a planning grant toward a publicly funded, hospital-based PBT facility

in Toronto.<sup>28</sup> A health technology assessment by Ontario Health projected that a 4-room facility would permit treating up to 1080 patients per annum, substantially improving access to PBT over the current out-of-country referral program.3 A province-wide, shared care model of care would be used for patients traveling for treatment, 28 with active participation of the patient's local radiation oncologist in proton planning, on-treatment review, and local follow-up care of the patient to promote continuity of care and to maximize engagement across the province. A similar shared model of care exists in Sweden; the Skandionkliniken serves patients in collaboration with 8 hospitals in 7 counties across the country, so that patients receive local consultation and simulation, treatment at a centralized proton center, and then local follow-up care. 40,41 Furthermore, the aforementioned technology assessment accounted for receiving referrals from other Canadian provinces, suggesting that a capital investment for PBT capacity in Ontario should reduce the need for out-of-country referrals in some provinces as well.

## Health Equity Considerations for Planning a PBT Program

A publicly funded PBT facility in Ontario would not be independently sufficient to improve health equity among all Canadian patients receiving PBT. In the United States, racial disparities in receipt of PBT increased despite growth in PBT facilities over time, <sup>10</sup> suggesting that additional equity needs and mitigating factors must be addressed to eliminate disparities. Patients have noted that although having a center in Ontario would help reduce many health inequities resulting from treatment in the United States, there would still be inequities secondary to travel away from home to

another part of the province or country.3 The health technology assessment of the Canadian Agency for Drugs and Technologies in Health estimated that the average travel costs for patients in the same province as a new PBT facility would be reduced by 50%, and average costs for patients in other provinces would be reduced by 25%, compared with international travel.<sup>23</sup> Although these cost reductions would be meaningful, they suggest that an outstanding travel cost may continue to differentially impose financial health inequities among patients. In addition, if a single facility is developed without comprehensive social and financial supports to facilitate access, this facility may contribute to known variation in access to radiation therapy by geography in Canada. 42 Although 4 single-room centers in Ontario may allow for the treatment of the same number of patients across a broader geographic area, a health technology assessment determined that such a scenario would be less cost-effective for Ontario's publicly funded health care system than a centralized, 4-room facility.3 Nonetheless, given the vast geographic distribution of Canada's population, multiple PBT facilities are likely required in the future to improve access and reduce patient financial burden across the country.

A health equity approach informed by the Canadian context is required to plan a publicly funded PBT center and continually evaluate implementation efforts for health disparities. This approach involves not only data-driven detection of disparities, understanding factors driving disparities, and positing solutions to reduce these disparities, but also using justice and community-oriented approaches to enacting comprehensive interventions to address inequalities. The Pan-Canadian Health Inequalities Reporting Initiative outlines key principles for action relevant to Canadian society. Table 2 summarizes this health equity approach for planning a publicly funded PBT center in Canada.

Table 2 Summary of a health equity approach to planning a Canadian PBT center

Approach	Examples			
Human rights and community-based engagement	Surveys and focus groups targeted to patients, families, and advocates			
Use intersectional approaches	Analyze experiences of transgender individuals with care along with additional equity stratifiers to account for unique experiences of individuals at intersecting social identities			
Decolonization and cultural safety	Design educational materials about PBT with cultural contextualization through Indigenous leadership and collaboration with community members and health advocates  Engage Indigenous patient navigators and community members to optimize domains of patient experience, such as culturally safe housing that accommodates traditional healing practices			
Using universal interventions by proportionality of need	Advocate for a national "Proton Travel Grant" program to cover patient costs of traveling for PBT			
Equity-oriented program evaluation	Use continuous data-driven program evaluation Embed equity stratifiers in development of internal health databases and link health and equity stratifier data at patient and area levels			
Abbreviation: PBT = proton beam therapy.				

## Human rights and community-based engagement

A human rights approach centering communities most affected by health inequities can be used to identify and design relevant and effective interventions for improving access to a PBT facility across dimensions of systemic marginalization. Community-based participatory research such as surveys and focus groups can be used to involve patients, families, and advocates in planning and decision making. To encapsulate the spectrum of perspectives and needs, targeted engagement is required with the communities most at risk for health inequities.

#### Use intersectional approaches

Intersectionality refers to a framework in which people with multiple social identities may have unique experiences compared with members of each individual demographic group they may belong to. 45 As a result, people may be subject to unique health inequities not captured by examining characteristics of populations by individual sociodemographic strata. Recent work indicates that patients with intersectional identities may be at high risk for inequitable cancer care outcomes. 46 In planning for a PBT program, an intersectional approach may be used to better identify populations with unmet supportive care needs, such as sociocultural and family functioning considerations, and address those needs, particularly for those traveling away from their homes and communities for treatment. As intersectionality is a newer concept in oncology practice, 46 examples of its application are found in other health care domains. The Trans Pulse Project was a community-based research project investigating the effects of social exclusion and discrimination on transgender health in Ontario. 47,48 This project used an intersectional approach, with specific analysis along strata including racialized and Indigenous gender-diverse status, employment, poverty, mental health, and housing status. Results from this intersectional approach have identified areas for improvement in the delivery of health care to transgender people, such as in breast and cervical cancer screening, access to family physicians, and management of HIV risk among racialized populations.49

#### **Decolonization and cultural safety**

In addition to addressing material social determinants of health, such as incidental costs related to travel for PBT, it is paramount to address structural and sociocultural determinants, such as the legacy of Canadian colonialism and its effects on the relationship between Indigenous peoples and the health care system. Indigenous peoples account for 4.9% of Canada's total population<sup>50</sup> yet have a disproportionately increasing incidence of cancer and worse cancer-related outcomes compared with non-Indigenous Canadians.<sup>51</sup> For many Indigenous people, cancer treatment may require travel to a remote cancer center; consequently, this may

result in significant time away from their homes, families, communities, language, and culture. 52,53 Indigenous peoples' experiences and sense of safety with the health care system may be shaped by the history of Canadian colonization and medical racism resulting in generational health inequities. 54-56 The Truth and Reconciliation Commission of Canada has put forth calls to action to improve health care with cultural contextualization through Indigenous leadership and collaboration. 57,58 To mitigate these dimensions of marginalization in a PBT program, it is necessary to provide culturally safe health and social services for patients. This is particularly relevant for pediatric patients who are engaging with the health care system in a sensitive period of social development that can critically shape future health outcomes and equity. Initiatives may include providing educational materials about PBT in different languages and designing them with the engagement of Indigenous community members and health advocates to account for non-Western epistemologies regarding health and wellness. Additionally, meaningful participation from Ontario Health Indigenous Health Navigators and community members may identify other domains that may be optimized as part of the patient experience when traveling for PBT, such as culturally safe housing with arrangements to accommodate traditional healing practices.

### Using universal interventions by proportionality of need

Financial barriers must not be an impediment to accessing PBT in Canada, so that the spirit of the Canada Health Act's principle of accessibility is met. However, patients who live far away from a future Canadian proton facility will face increased costs for lodging, food, and travel. Currently, Ronald McDonald House Charities provides inexpensive accommodation for families of children receiving treatment at Canadian cancer centers. Many cancer centers also provide patients living far away with a lower-cost accommodation, owned and operated by cancer charities or the hospital. Ensuring these resources are well-supported to care for PBT patients is essential. As part of their recommendations regarding PBT access in Canada, CAPCA recommended that provincial insurance provide coverage of reasonable incidental costs arising from travel for PBT.<sup>22</sup> Within Ontario, the Northern Travel Grant provides patients with partial travel cost support to specialized care for patients living in Ontario's northern region.<sup>59</sup> A similar "Proton Travel Grant" program, ideally with a national scope to cover patients traveling between provinces for PBT, would reduce the financial burden for patients with cancer living away from the PBT facility and enhance equitable, universal access to PBT.

#### **Equity-oriented program evaluation**

Following inception of a publicly funded PBT facility and program, there will be a need for ongoing, data-driven

program evaluation and monitoring of implementation efforts. However, using only aggregate outcomes in health system performance reports may result in making insufficient progress on health equity. As such, outcomes must be stratified along equity, sociodemographic, and racial domains. CIHI recommends using standard definitions of equity stratifiers in the Canadian context, embedding these stratifiers in development of internal health databases, and linking health and equity stratifier data at the patient and area levels.8 The Canadian Index of Multiple Deprivation (CIMD) is a postal code-based index using data from the 2016 population census to measure 4 domains of systemic marginalization at the area-level: residential instability, economic dependency, situational vulnerability, and ethnocultural composition. 60 CIMD can be used to analyze patient access and satisfaction data along these area-level strata to identify areas for improvement. It will be critical to ensure a future PBT program adequately supports patients and their caregivers so that access to this treatment modality is universal and equitable across all populations.

#### **Summary of Recommendations**

We propose the following 6 recommendations for improving health equity in PBT for Canadian patients (Table 3):

- 1. Individual patient-level data should be comprehensively collected and regularly reported on PBT use across clinical indications and socioeconomic groups.
- 2. All provinces and territories should adopt national guidelines on equitable access to PBT.<sup>22</sup>

- 3. Multiple PBT facilities should be created across different geographic areas of the country to minimize patient travel time and improve access.
- 4. A travel grant should be created to support the indirect costs of PBT.
- 5. Lower- or no-cost accommodation near PBT centers should be made available to patients and their families.
- 6. A health equity approach should be used in the development of Canadian PBT programs.

#### **Conclusions**

The number of patients eligible for PBT in Canada is expected to increase annually, yet the number accessing PBT based on prior patterns of uptake is much lower. Publicly funded access to PBT is currently available through out-of-country referral programs in some, but not all, provinces. Several drivers of health inequities are present: eligibility criteria and practice patterns for out-of-country referrals vary across provinces, and financial and social barriers are present in accessing and benefitting from PBT. Efforts to standardize eligibility criteria for PBT access across the country should be made; future initiatives could include the development of a national database of patients receiving PBT to characterize referral and practice patterns. The PBT planning grant recently announced by the Ontario government represents the first step in prioritizing a publicly funded hospital-based PBT facility in Canada. A health equity approach, using community-based engagement, intersectional approaches, decolonization, targeted and universal interventions, and equity-oriented program evaluation may aid in developing a publicly funded, domestic PBT program that can improve health equity in PBT and cancer

Table 3 Summary of recommendations for improving health equity in PBT for Canadian patients

Theme	Sources of inequity	Recommendations
Administration	No national database of patients treated with PBT in Canada	Individual patient-level data should be comprehensively collected and regularly reported on PBT utilization across clinical indications and socioeconomic groups
Comprehensiveness	Not all provinces and territories have a structured out-of-country PBT access program Eligibility criteria for PBT may differ between provinces	All provinces and territories should adopt national guidelines on equitable access to PBT <sup>22</sup>
Accessibility	Patients have difficulty accessing PBT because of financial barriers from indirect costs, travel barriers, and socioeconomic factors <sup>3,24</sup>	Multiple PBT facilities should be created across different geographic areas of the country to minimize patient travel time and expenses A travel grant should be created to support the indirect costs of PBT Lower- or no-cost accommodations near PBT centers should be made available to patients and their families A health equity approach should be used in the development of Canadian PBT programs

care in Canada. The approaches proposed may also be applicable to other jurisdictions around the world seeking to ensure equitable access to PBT for their patients with cancer.

#### References

- Mitin T, Zietman AL. Promise and pitfalls of heavy-particle therapy. J Clin Oncol 2014;32:2855-2863.
- Yang JT, Wijetunga NA, Pentsova E, et al. Randomized phase II trial of proton craniospinal irradiation versus photon involved-field radiotherapy for patients with solid tumor leptomeningeal metastasis. *J Clin Oncol* 2022;40:3858-3867.
- Health Ontario. Proton beam therapy for cancer in children and adults: a health technology assessment. Ont Health Technol Assess Ser 2021;21:1-142.
- Particle Therapy Co-Operative Group. Available at: www.ptcog.ch. Accessed July 2, 2022.
- Canadian Agency for Drugs and Technologies in Health. Proton beam therapy versus photon radiotherapy for adult and pediatric oncology patients: a review of the clinical and cost-effectiveness. Available at: https://www.cadth.ca/sites/default/files/pdf/htis/may-2016/RC0779% 20Proton%20Beam%20Therapy%20Final.pdf. Accessed July 10, 2022.
- Health Canada. Canada Health Act annual report 2020-2021. Available at: https://www.canada.ca/content/dam/hc-sc/documents/services/pub lications/health-system-services/canada-health-act-annual-report-2020-2021/canada-health-act-annual-report-2020-2021-eng.pdf. Accessed July 10, 2022.
- Cancer Care Ontario. Funding Proposal to Develop the Business Case for a Proton Beam Radiotherapy Facility in Ontario. Toronto, Canada: Cancer Care Ontario; 2017.
- Canadian Institute for Health Information. In pursuit of health equity:
   Defining stratifiers for measuring health inequality A focus on age, sex, gender, income, education, and geographic location. Available at: <a href="https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf">https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf</a>. Accessed July 10, 2022
- Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001
- Nogueira LM, Sineshaw HM, Jemal A, et al. Association of race with receipt of proton beam therapy for patients with newly diagnosed cancer in the US, 2004-2018. JAMA Netw Open 2022;5 e228970.
- Bitterman DS, Bona K, Laurie F, et al. Race disparities in proton radiotherapy use for cancer treatment in patients enrolled in Children's Oncology Group Trials. JAMA Oncol 2020;6:1465-1468.
- Shen CJ, Hu C, Ladra MM, et al. Socioeconomic factors affect the selection of proton radiation therapy for children. *Cancer* 2017;123:4048-4056.
- Mahal BA, Chen YW, Efstathiou JA, et al. National trends and determinants of proton therapy use for prostate cancer: A National Cancer Data Base study. Cancer 2016;122:1505-1512.
- Odei B, Frandsen JE, Boothe D, et al. Patterns of care in proton radiation therapy for pediatric central nervous system malignancies. *Int J Radiat Oncol Biol Phys* 2017;97:60-63.
- Dabbikeh A, Peng Y, Mackillop WJ, et al. Temporal trends in the association between socioeconomic status and cancer survival in Ontario: A population-based retrospective study. CMAJ Open 2017;5:E682-E689
- Mazerreuw MV, Withrow DR, Nishri ED, et al. Cancer incidence among First Nations adults in Canada: Follow-up of the 1991 Census Mortality Cohort (1992–2009). Can J Public Health 2018;109:700-709.
- L'institut National D'excellence en Santé et en Services Sociaux. Update
  of proton radiation therapy indications in oncology. Available at:
  <a href="https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Oncologie/">https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Oncologie/</a>

- INESSS\_Proton\_radiation\_therapy\_EnglishSummary.pdf. Accessed July 28, 2022.
- BC Cancer. Provincial cancer clinical management guidelines in pandemic situation (COVID-19). Available at: http://www.bccancer.bc.ca/health-professionals-site/Documents/Provincial%20Cancer%20Therapy%20Clinical%20Management%20Guidelines%20posted%20version%20Jun%208%20clean.pdf. Accessed July 28, 2022.
- Guideline Resource Unit. Proton beam radiation therapy. Available at: https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-guide-rt002-proton-beam-RT.pdf. Accessed July 28, 2022.
- Cancer Care Ontario. Proton Beam Therapy in Ontario: A Feasibility
   Assessment to Build a Proton Beam Therapy Facility in Ontario Compared With Out of Country Referrals. Toronto, Canada: Cancer Care
   Ontario; 2019.
- Canadian Agency for Drugs and Technologies in Health. The use of proton beam therapy in Canada, the United Kingdom, and Australia: An environmental scan of funding, referrals and future planning. Available at: https://www.cadth.ca/sites/default/files/pdf/ES0305\_PBT\_ Use\_in\_Canada.pdf. Accessed July 10, 2022.
- Mitera G, Tsang D, McCurdy B, et al. Pan-Canadian consensus recommendations for proton beam therapy access in Canada. *Radiother Oncol* 2022;176:228-233.
- 23. Kim J, Wells C, Khangura S, et al. Proton Beam Therapy for the Treatment of Cancer in Children and Adults: A Health Technology Assessment. Ottawa, Canada: Canadian Agency for Drugs and Technologies in Health; 2017.
- 24. Middleton J, Black K, Ghosh S, et al. Indirect costs associated with outof-country referral for proton therapy: A survey of adult and pediatric patients in Alberta, Canada. *BMC Health Serv Res* 2021;21:683.
- Patel S, Kostaras X, Parliament M, et al. Recommendations for the referral of patients for proton-beam therapy, an Alberta Health Services report: A model for Canada? Curr Oncol 2014;21:251-262.
- **26.** Hijal T, Freeman CR, Seuntjens J. Proton beam therapy should remain in the public domain. *CMAJ* 2019;191:E1284.
- 27. CDL Laboratories Inc. Quebec-based CDL Laboratories to build \$70 M state-of-the-art Proton Therapy cancer centre in Montreal, the first of its kind in Canada. Available at: https://www.newswire.ca/news-releases/quebec-based-cdl-laboratories-to-build-70-m-state-of-the-art-proton-therapy-cancer-centre-in-montreal-the-first-of-its-kind-in-can ada-691462591.html. Accessed July 2, 2022.
- Ontario Newsroom. Ontario building a stronger, more resilient university health network. Available at: https://news.ontario.ca/en/release/1001920/ontario-building-a-stronger-more-resilient-university-health-network. Accessed July 2, 2022.
- Doucette K. Experts, national parents group, call for specialized proton therapy clinic in Canada. Available at: https://nationalpost.com/pmn/news-pmn/canada-news-pmn/experts-national-parents-group-call-for-specialized-proton-therapy-clinic-in-canada. Accessed July 2, 2022
- Perreault M. Protonthérapie: Québec a choisi le privé, déplorent des Médecins. Available at: https://www.lapresse.ca/actualites/sante/201809/ 04/01-5195107-protontherapie-quebec-a-choisi-le-prive-deplorent-desmedecins.php. Accessed July 10, 2022.
- Weber DC, Langendijk JA, Grau C, et al. Proton therapy and the European Particle Therapy Network: The past, present and future. Cancer Radiother 2020;24:687-690.
- Grau C, Durante M, Georg D, et al. Particle therapy in Europe. Mol Oncol 2020;14:1492-1499.
- C17 Children's Cancer & Blood Disorders. Cancer in Young People in Canada Program. Available at: https://c17.ca/committees/CYP-C. Accessed November 9, 2022.
- **34.** Litzelman K, Barker E, Catrine K, et al. Socioeconomic disparities in the quality of life in children with cancer or brain tumors: The mediating role of family factors. *Psychooncology* 2013;22:1081-1088.
- 35. Desjardins L, Solomon A, Sharma W, et al. The impact of caregiver anxiety/depression symptoms and family functioning on child quality of life during pediatric cancer treatment: From diagnosis to 6 months. J Psychosoc Oncol 2022;40:790-807.

- **36.** Tambas M, van der Laan HP, Steenbakkers RJHM, et al. Current practice in proton therapy delivery in adult cancer patients across Europe. *Radiother Oncol* 2021;167:7-13.
- Bishop AJ, Livingston JA, Ning MS, et al. Young adult populations face yet another barrier to care with insurers: Limited access to proton therapy. *Int J Radiat Oncol Biol Phys* 2021;110:1496-1504.
- **38.** Ojerholm E, Hill-Kayser CE. Insurance coverage decisions for pediatric proton therapy. *Pediatr Blood Cancer* 2017;65:e26729.
- Chan J, Brown E, Dennis K, et al. Provincial variations in radiotherapy utilization as a measure of access: A pan-Canadian study. *Radiother Oncol* 2022;167:122-126.
- Skandionkliniken. Treatment step by step. Available at: https://www.skandionkliniken.se/en/treatment-step-by-step. Accessed November 9, 2022
- Montelius A, Björk-Eriksson T, Karlsson M, et al. Distributed competence support of a Swedish proton therapy centre (SPTC). Radiother Oncol 2004;73:S357-S358.
- Mackillop WJ, Kong W, Brundage M, et al. A comparison of evidencebased estimates and empirical benchmarks of the appropriate rate of use of radiation therapy in Ontario. *Int J Radiat Oncol Biol Phys* 2015;91:1099-1107.
- Thomas SB, Quinn SC, Butler J, et al. Toward a fourth generation of disparities research to achieve health equity. Annu Rev Public Health 2011;32:399-416.
- 44. Pan Canadian Public Health Network. Key health inequalities in Canada: A national portrait. Available at: https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research/key-health-inequalities-canada-national-portrait-executive-summary/key\_health\_inequalities\_full\_report-eng.pdf. Accessed July 10, 2022.
- 45. Crenshaw KW. Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist policis. *University of Chicago Legal Forum* 1989;1989: 139-167.
- **46.** Kelly-Brown J, Kelly EP, Obeng-Gyasi S, et al. Intersectionality in cancer care: A systematic review of current research and future directions. *Psychooncology* 2022;31:705-716.
- Trans PULSE. About us: The Trans PULSE Project. Available at: https://www.transpulseproject.ca/about-us. Accessed November 9, 2022.

- National Collaborating Centre for Determinants of Health. Intersectionality and health equity. Available at: https://nccdh.ca/images/uploads/comments/Intersectionality\_And\_Health\_Equity\_EN\_Mar24.pdf. Accessed November 9, 2022.
- Trans PULSE. Research & study results. Available at: https://www.trans pulseproject.ca/research. Accessed November 9, 2022.
- Statistics Canada. Statistics on Indigenous peoples. Available at: https:// www.statcan.gc.ca/eng/subjects-start/indigenous\_peoples. Accessed July 2, 2022.
- 51. Beben N, Muirhead A. Improving cancer control in First Nations, Inuit and Métis Communities in Canada. Eur J Cancer Care (Engl) 2016;25:219-221.
- Matthews M, Ryan D. Publicly funded medical travel subsidy programs in Canada. Can Soc Work Rev 2017;34:123-129.
- 53. Chan J, Friborg J, Chernov M, et al. Access to radiotherapy among circumpolar Inuit populations. *Lancet Oncol* 2019;20:e590-e600.
- Turpel-Lafond ME. In plain sight: Addressing indigenous-specific racism and discrimination in B.C. health care. Available at: https://engage. gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf. Accessed July 2, 2022.
- Shingler B. Investigations launched after Atikamekw woman records Quebec hospital staff uttering slurs before her death. Available at: https://www. cbc.ca/news/montreal/quebec-atikamekw-joilette-1.5743449. Accessed July 2, 2022.
- 56. Schmunk R. B.C. Investigating allegations ER staff played "game" to guess blood-alcohol level of Indigenous patients. Available at: https://www.cbc.ca/news/canada/british-columbia/racism-in-bc-healthcare-health-minister-adrian-dix-1.5619245. Accessed July 2, 2022.
- 57. Truth and Reconciliation Commission of Canada. What we have learned: principles of truth and reconciliation. Available at: https://publications.gc.ca/collections/collection\_2015/trc/IR4-6-2015-eng.pdf. Accessed July 2, 2022.
- Beckett M, Cole K, White M, et al. Decolonizing cancer care in Canada. *I Cancer Policy* 2021;30 100309.
- Ontario Ministry of Health. Northern Health Travel Grant Program.
   Available at: <a href="https://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx">https://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx</a>. Accessed July 24, 2022.
- Statistics Canada. Canadian Index of Multiple Deprivation. Available at: https://www150.statcan.gc.ca/n1/pub/45-20-0001/452000012019002-eng. htm. Accessed July 10, 2022.