

## Modernizing Access to Specialized Treatment

### A PROPOSAL TO ADDRESS FUNDAMENTAL ISSUES CONTRIBUTING TO LONG WAIT TIMES FOR SPECIALIST CARE AND MEDICALLY NECESSARY ELECTIVE SURGERY

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#### EXECUTIVE SUMMARY

Long wait times for specialist care and medically necessary elective surgeries are a multifaceted and persistent challenge within Canada's healthcare system. Despite higher healthcare spending, wait times are the longest among Commonwealth and many OECD nations. Wait times often extend beyond what is considered clinically reasonable, adversely impacting patients' quality of life, leading to psychological distress, reduced productivity, financial losses, and potential long term health complications. Canada's higher cost health system struggles to deliver on value-based objectives of the 'Quadruple Aim' with prolonged wait times negatively impacting population health and patient and provider experience. Urgent policy action is required to mitigate these issues and improve timely access to care.

Canada's healthcare data infrastructure falls behind that of OECD and Commonwealth countries, largely due to the absence of unified leadership and coordinated policies that emerge from the troubled romance between provincial healthcare and Canadian federalism. With no centralized national organization overseeing provincial initiatives, disseminating successful strategies, or assessing the impact of investments aimed at reducing wait times, the lack of cohesion results in fragmented progress and 'perpetual pilot projects' across different health regions. Consequently, substantial inconsistencies and disparities persist among healthcare providers, specialties, and provinces in both reporting and addressing the complete patient wait time experience. Two fundamental issues underlie the extended wait times:

- **Siloed and Fragmented Referral Systems** lead to variability in wait times across specialties and regions. This issue is compounded by the absence of system-level electronic referral systems, resulting in delays and communication breakdowns between providers.
- **Deficiencies in Digital Health Data Systems** resulting from inconsistent definitions and reporting of patient journey stages hinder accurate measurement and monitoring of wait times, essential for effective policy interventions.

**This proposal recommends** establishment of an institute to Modernize Access to Specialized Treatment (MAST) as a pan-Canadian solution that is a feasible and cost-effective strategy to bridge the gap between evidence-based practices and implementation. The mandate driven Institute would work with provinces and territories to establish interoperable digital health systems and open data provision to **modernize, measure, and monitor** access to specialized treatment over a 5-year time horizon. Core activities include:

1. **Data Governance and Interoperability Drawing on International Best Practice**
2. **Standardized Reporting Across the Entire Patient Journey**
3. **Streamlined Implementation of Single-Entry Referral Models**

Promising pockets of implementation of electronic referrals, pooled waitlist, national standards, and data infrastructure already exist across Canada on a smaller scale. The MAST Institute would scale and spread these initiatives to systems level through implementation approaches that are patient and provider centered, considering local needs, and balancing intrinsic provider motivation with system level leadership and incentives. The establishment of MAST could be achieved by amalgamating existing Federal organization expertise and budgets and leveraging Federal funding agreements prioritizing data-driven solutions in electronic health information. Critically, it would be empowered to use its policy levers for accountability to benchmarks.

**A Path Forward:** The proposed MAST Institute offers a viable and necessary pan-Canadian approach to facilitate value driven interoperability solutions demonstrated to enhance the patient experience, reduce provider administration and burnout, reduce the cost of care, and improve population health outcomes.

## INTRODUCTION: FUNDAMENTAL ISSUES LEADING TO PROLONGED HEALTHCARE WAIT TIMES

Patients experiencing excessive wait times for specialist care and medically necessary elective surgeries is a defining characteristic of Canadian healthcare. Despite spending more than other high-income OECD countries with universal healthcare systems, Canada's wait times for specialist care are the longest among all Commonwealth and many OECD countries [1, 2]. Often these wait times, which have worsened over the past decade and were further exacerbated by the COVID-19 pandemic, are longer than what is clinically reasonable and inflict a range of hardships upon Canadians [3].

The consequences have a broad reach. An estimated twenty percent of Canadians face adverse effects due to wait times, leading to significant impacts on their quality of life and financial well-being [2, 4]. These effects include psychological distress, reduced quality of life, financial losses, absenteeism from work, and delays in both diagnosis and treatment [3-8]. Furthermore, extended wait times can result in serious health repercussions, as treatable conditions can progress into chronic illnesses or permanent disabilities when not addressed.

Wait times for elective surgeries and specialist care, the focus of this paper<sup>1</sup>, require urgent policy action from provinces/territories and the federal government to improve timely access. Canada's healthcare data infrastructure lags OECD and Commonwealth countries and grapples with a lack of unified leadership and coordinated policies, leading to fragmented developments across health regions. Canada is 'a country of perpetual pilot projects', with no national organization coordinating provincial efforts, spreading promising practices and evaluating initiatives and investments to reduce wait times [9]. As a result, dramatic variability and disparities exist across providers, specialties, and provinces in reporting on and addressing the full patient wait time journey (Figure 1).

Reducing prolonged wait times is a complex and multifaceted 'wicked problem' without any singular solution. However, two fundamental issues underlie these extended wait times:

**Issue 1: Siloed and fragmented referral systems** hamper the efficiency of referrals.

**Issue 2: Lack of coordinated health data systems** compromises the ability to effectively measure and monitor to optimize wait times.

Robust, coordinated digital health infrastructure that accurately gauges demand and performance is indispensable for healthcare administrators aiming to strategize human resource allocation and implement supply or demand side wait list reduction initiatives [5, 10]<sup>2</sup>. Without such a foundation, any attempts to curb wait times are rendered ineffective.

This brief provides background on the issues that result from fragmented referral systems and lack of coordinated health data systems and details a recommendation to establish a pan-Canadian institute to Modernize Access to Specialized Treatment (MAST), to drive change.

<sup>1</sup> Provision of specialist care and surgery must consider different urgency associated with care required. While there are different classifications typically surgery or specialist care can be categorized into emergency (immediate), urgent (required often prior to discharge from hospital), elective (medically necessary but timing can be scheduled for a later date).

<sup>2</sup> Locally and internationally supply-side policy approaches increase resources and productivity (e.g., funding additional surgeries/surgical capacity, activity-based funding). Demand-side approaches prioritize based on need (e.g., clinical guidelines for triage, reducing inappropriate referrals).

## BACKGROUND ON THE ISSUES

### *Coordinated Electronic Referrals – A Critical Need*

The current practice of using multi-queue models results in a patchwork of thousands of specialist wait lists of variable length [11]. The referral process is unique to individual physicians/clinics. Primary care providers have individual criteria (often grounded in personal relationships and experience) for selecting specialists to refer patients to, while specialists independently manage their referrals and waitlists [12–15]. Consequently, wait lists differ substantially within specialties and geographical regions with many not audited.

Furthermore, the absence of system level electronic referrals is a challenge. Referral letters sent via fax are still a common form of communication between primary care providers and specialists and are linked to delays in the referral and booking processes [16]. Breakdowns in communication are frequent, with a significant portion of referrals (one-third) not receiving acknowledgment within a 7- week timeframe and/or being rejected, leaving the primary care provider to manage the patient’s needs without specialist guidance while restarting the process. [17]. The Canadian Medical Association has highlighted the urgent need for enhanced communication between primary care and specialist providers, as well as a streamlined patient transition from primary to specialty care [18]. At a system level, provinces that collect this crucial information must gather individual data from physicians and undergo laborious data cleaning.

### *Deficiencies in Digital Health Data Systems*

International evidence highlights a clear correlation between improved wait times and the availability of high-quality, standardized data that is transparently presented through regular public reports on progress and key performance indicators [5, 19]. Canadian wait time data falls short. Data reported by provinces is simply an aggregate of individual provider variability, which fails to accurately represent the full patient journey (Figure 1). Provinces compile data retrospectively on waits for individual specialists to produce a ‘provincial’ wait time. Even when considering median wait times, the range spans from 10 to 41 weeks across provinces [3, 20].

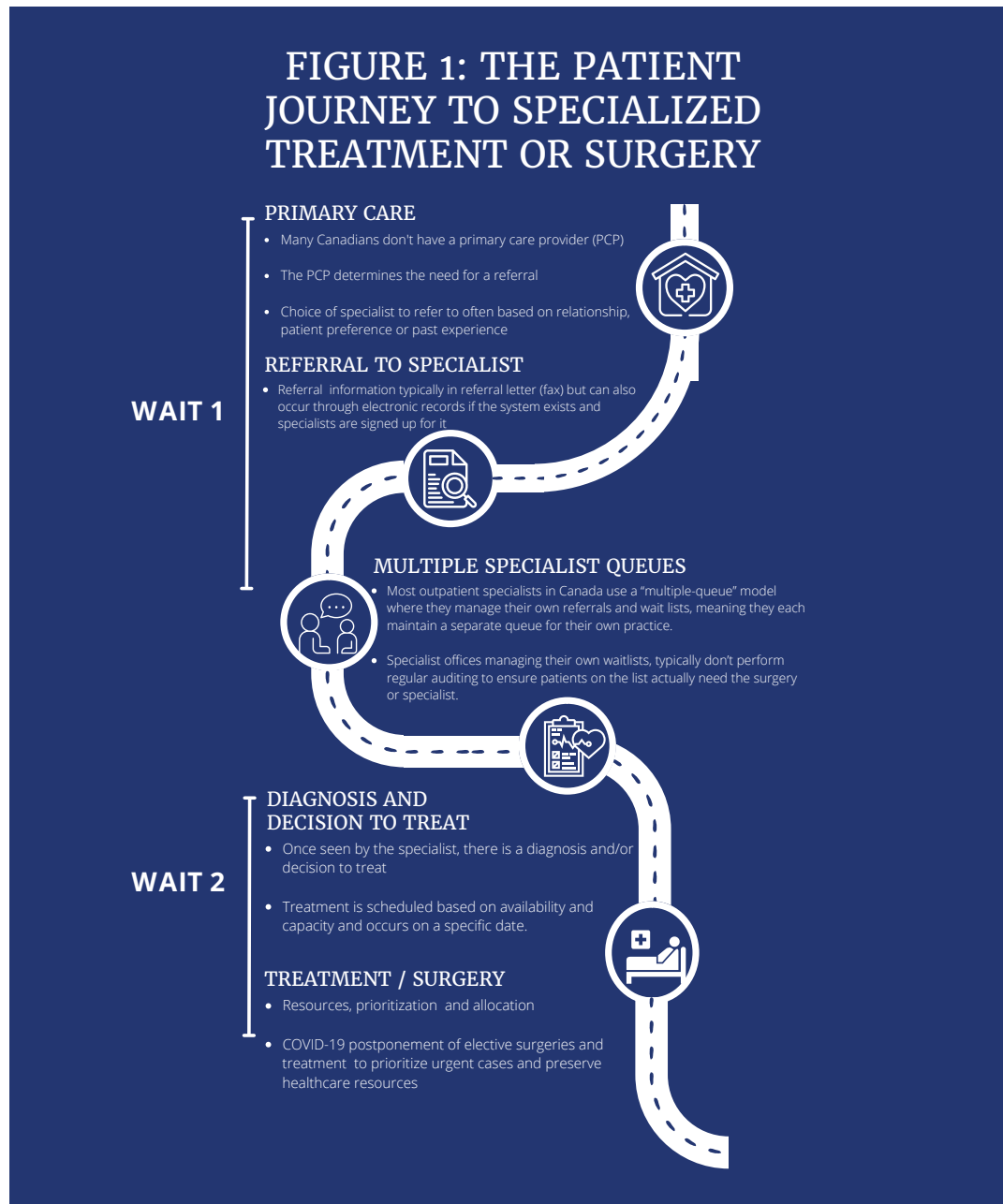
Key data issues for Canadian learning health systems [21] include:

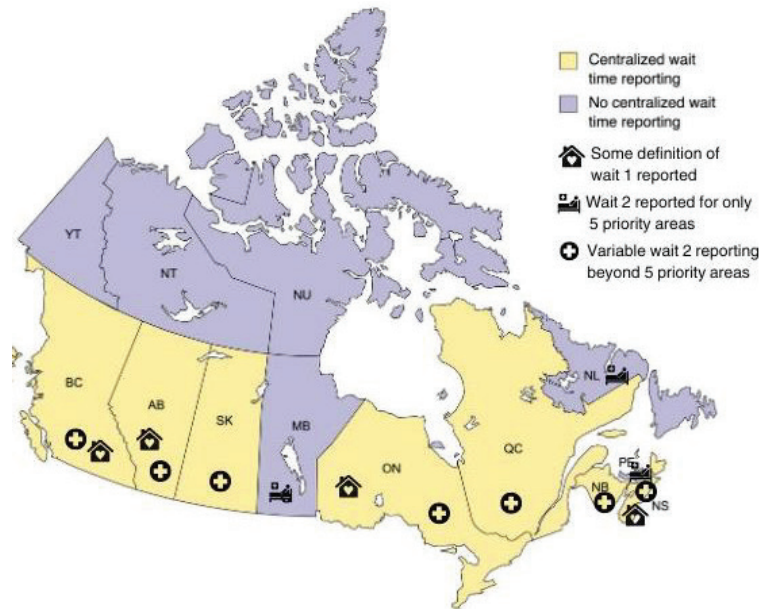
- **Absence of standardized definitions** resulting in data that doesn’t reflect the patient journey [22]. Inconsistencies in the definitions of the patient journey for wait times 1 and 2 across provinces are summarized in Table 1 [17, 23, 24].
- **Lack of common data architecture and reporting** meaning data sources vary (survey data, chart reviews, and administrative data) and are incomplete and outdated. Figure 2 depicts the variability in reporting across provinces.

### *Critical Issues with Implications for the Quadruple Aim*

The lack of referral system coordination and standardized data collection profoundly hinders the ability for Canadian learning health systems to deliver on the “Quadruple Aim”: improving population health and patient and provider experience while reducing costs [25]. At the systems level, decision makers lack accurate, reliable and integrated

digital information systems necessary to effectively assess capacity requirements, pinpoint bottlenecks, and strategically direct cost-effective policy interventions to improve population health outcomes [26]. At the individual level, patients and providers are left on their own to navigate and manage referrals, missing key information on specialist wait times.





**Figure 2: Variability across provinces and territories in reporting of wait times across the patient journey.**

*Adapted from Segall et. al 2020*

**Table 1: Waiting periods in the patient journey and issues with definitions and reporting.**

WAIT PERIODS IN PATIENT JOURNEY	ISSUES WITH DEFINITIONS, REPORTING	DESCRIPTION
<b>Wait 1: Referral by Primary Care Provider to Specialist Consultation</b> Average estimated wait: 12.6 weeks, 242% [3] increase over 20 years	Wait 1 not consistently reported	Some provinces fail to report wait time 1, despite its significance as one of the lengthiest waiting[20, 27, 28]
	Gap between wait 1 and 2 not often reported	A gap exists in accounting for the time between the conclusion of Wait 1 (first specialist appointment) and the commencement of Wait 2 following the decision to proceed with treatment[29].
<b>Wait 2: Specialist Consultation to Treatment Reception</b> Average estimated wait: 14.8 weeks, 164% [3] increase over 20 years	Inconsistent definition of wait time 2	Wait time 2 varies among provinces, with some focusing on the period between scheduling treatment (rather than the decision to treat) and the actual treatment date. This approach fails to account for potential system delays in data entry process [29].
	Variable reporting beyond established benchmarks in 5 priority areas	Only some provinces report on procedures beyond the 5 priority areas. Benchmarks for some priority areas have yet to be established <sup>3</sup> [30].
	Reporting on non-surgical specialty waits limited or absent	Reporting on wait time 2 for non-surgical specialty care is either limited or absent in many instances[29].

<sup>3</sup> Some standards were established during the 2004 federal-provincial health negotiations, particularly for acceptable wait times in key priority areas such as cataract surgery, cardiac care, joint replacements, cancer surgery, and diagnostic imaging tests, these only address a portion of specialist care.

## RECOMMENDATION: A PAN-CANADIAN INSTITUTE TO MODERNIZE ACCESS TO SPECIALIZED TREATMENT (MAST)

To address these issues, it is recommended to create a pan-Canadian arm's length institute to modernize learning health systems and quality improvement. The vision of this Institute would be to foster cross-system collaboration with provinces, facilitating the expansion and adoption of evidence-based practices under the umbrella of "Modernize Access to Specialized Treatment" (MAST, a temporary name) to reduce wait times for specialist care and medically necessary elective surgeries.

The MAST Institute would have a mission to bridge the gap between evidence and implementation by providing consistent communication and leadership across provinces and territories, facilitating common policy guidance, resource allocation, and cross-system collaboration.

The Institute would have impact as an:

- *Equalizer* in standardizing common measurement of the full patient journey to ensure consistent, comparable, and accurate data is reported across provinces, regions, specialties and providers;
- *Capacity builder* for decision makers implementing single-entry models, e-referrals, and other digital data infrastructure in learning health systems;
- *Regulator* with legislative, policy and financial resources to hold Canadian health systems accountable.

### *A Mandate to Modernize, Measure and Monitor*

At the heart of the MAST Institute's mandate would be the pursuit of evidence-based practices that **modernize**, **measure**, and **monitor** access to specialized treatment over a 5-year time horizon, by working with provinces and territories to establish interoperable digital health systems and open data provision. Interoperability solutions in healthcare have been demonstrated to address all aspects of the Quadruple Aim framework by enhancing the patient experience, reducing provider administration and burnout, reducing the cost of care and improving population health outcomes [21, 31].

This proposal will detail three critical contributions of the Institute, working in partnership with provinces and territories, to address the wait time issues described, including:

1. **Data Governance and Interoperability Drawing on International Best Practice**
2. **Standardized Reporting Across the Entire Patient Journey**
3. **Streamlined Implementation of Single-Entry Referral Models**

Considerations around feasibility of organizational formation, cost effectiveness and system level implementation that is patient and provider centered are described.



### ***Data Governance and Interoperability: Drawing on International Best Practice***

Most OECD countries (15 out of 23) monitor and publicly disclose standardized national wait times data for specialists and elective surgeries (with a much broader scope compared to the limited 5 priority areas in Canada)<sup>4</sup>[32–34]. An example is Healthcare Improvement Scotland, recognized worldwide for its leadership in wait time reporting, which provides the Scottish National Health Service with a comprehensive range of surgical and non-surgical (including mental healthcare) domains, metrics and quality indicators [34–37]. Reporting is on the entirety of the patient journey, spanning both wait 1 and wait 2 [38]. This information has been instrumental in driving improvements in both quality and wait times, amplifying the effectiveness of healthcare delivery.

In contrast, Canada remains an anomaly within OECD and Commonwealth nations, lacking modern data infrastructure capable of effectively measuring and monitoring wait times. While several countries, such as England, Ireland, and Finland, responded to the COVID-19 pandemic's impact on wait lists by introducing explicit recovery targets, Canada's deficiency in comprehensive data infrastructure is a hurdle [39]. This discrepancy underscores the pivotal role of a pan-Canadian MAST institute in addressing this challenge, facilitating common data governance and interoperability across the nation.

Drawing from international best practices of other OECD countries' learning health system infrastructures, MAST will facilitate the establishment of province-wide interoperable digital health systems by creating a platform for the synthesis, dissemination, and exchange of critical information across provinces and internationally. The digital ecosystem will be built from existing promising practices in Canada and internationally to develop fully integrated systems, incorporating centralized scheduling, patient portals, single-entry referral systems, case management, electronic medical records, wait time reporting, location registries, and electronic health records. The Institute will provide critical leadership and capacity in interoperability standards, pan-Canadian data strategy development, navigation of health information linkage, modern regulatory frameworks, and health information legislation.

### ***Standardized Reporting Across the Entire Patient Journey***

The Institute's emphasis on standardized reporting across all specialties and regions aligns with international best practice in illuminating the complete patient journey. While data collection and measurement are provincial jurisdiction, the MAST institute will address the identified deficiencies in coordinated health data systems. The Institute will enable provincial and territorial reporting systems and registries to adopt national standards to enable comparability across Canada and result in more consistent wait time data. The Institute will build on work started from the 2004 health accord negotiations and provide leadership in creating national reporting standards with common definitions of wait time 1 and wait time 2 across each province to ensure consistent reporting on the entire patient journey. The national standards will include a broader range of surgical and non-surgical specialty care wait times beyond the current 5 priority areas [29].

<sup>4</sup> Countries like the Netherlands, Scotland, Sweden, England and Spain, Norway report broadly on wait times by specialty.



## ***Streamlined Implementation of Single-Entry Referral Models***

Single-entry referral models, underpinned by electronic data sharing among primary care providers, specialists, and patients, are an evidence-based approach to address the described issues with the multi-queue models. Drawing on established principles within the service industry, primary care providers refer patients to a reduced number of central queues of qualified specialists managed by health authorities. Surgical candidates are triaged based on their condition's severity and urgency and referred to a specialist with relevant expertise and the shortest waitlist [40]. Non-surgical candidates are directed to specialized supports, including allied health services, encouraging greater team-based care and work to full scope of competency [10, 41]. Introducing auditing mechanisms matches patients with appropriate providers. Single-entry models internationally and locally have demonstrated their effectiveness in harmonizing patient flow to enhance efficiency and equity in care access, easing administrative burdens on primary care, significantly reducing wait times (anywhere from 20 to 50 percent in some Canadian regional implementations), improving outcomes and increasing patient and provider satisfaction [11, 26, 27, 41-45].

A MAST Institute would provide robust pan-Canadian leadership, driving widespread adoption, and partnering with provinces and territories to tailor support to regional considerations and needs, overcoming barriers of transitioning from evidence to system-wide implementation. Rooted in data driven analysis and knowledge synthesis of evidence from across Canada and internationally (working in partnership with Cochrane Canada, EvidenceNetwork.ca and Choosing Wisely) the Institute will adapt information to implement models that are regionally appropriate, values based and ethical. Integration with a booking system fosters interoperability and enables reporting of provincial-level data on wait time 1 [11, 40, 41, 46]. Equipped with system-level data, decision-makers can fine-tune resource allocation, optimizing the utilization of hospital facilities and maximizing publicly funded resources.

## **CONSIDERATIONS FOR THE PATH FORWARD**

### ***Organizational formation, feasibility, and timeline***

The establishment of the MAST institute as an independent pan-Canadian health organization, with a renewable five-year mandate, would emerge through the consolidation of the Canadian Institute for Health Information (CIHI) and Canada Health Infoway<sup>5</sup> [21, 31]. This strategic alignment with 10-year federal funding commitments would harness organizational strengths in interoperability standards, pan-Canadian data strategy development, regulatory frameworks, and implementation of single-entry referral systems. A report from Canada Health Infoway indicates that a fully integrated system can be accomplished in 24 months with subsequent monitoring and evaluation in years 3 to 5 [47]. Operating within the scope of fiscal federalism, this recommendation acknowledges the constitutional and Canada Health Act jurisdictional boundaries while recognizing that a singular health region cannot comprehensively measure and monitor nationwide.

<sup>5</sup> A proposal rooted in recommendations from rigorous Fit for Purpose report on pan-Canadian health organizations identifying these entities require a refined and more targeted mandate 21. Forest, P.-G. and D. Martin, Fit for purpose: Findings and recommendations of the external review of the Pan-Canadian health organizations: Summary report. 2018: Health Canada Ottawa, ON.

## *Realizing value in existing investments with fiscal accountability*

The integration of modernized digital waitlist data infrastructure is vital for cost-effective and sustainable waitlist reduction policies. Forecasts for a comprehensive pan-Canadian wait time management system estimate a budget of \$600 million in 2023 dollars<sup>6</sup> [47]. The implementation of MAST can be achieved leveraging existing fiscal commitments to federal organizations and health transfers to the provinces.

- **Amalgamate federal organizations:** MAST would operate independently from the federal government, with a focused mandate derived from repurposed budgets and resources amalgamated from CIHI and Canada Health Infoway (combined operating budgets totaling over \$200 million)
- **Accountability in health transfers:** Reallocation of a bare minimum \$600 million (more recommended) combined allocation from provinces and territories within the 2023 \$46.2 billion Federal funding agreement (responding to the pandemic-induced surgical backlogs) over a decade with a priority for data-driven solutions in electronic health information sharing among healthcare professionals [48]. Only 58 per cent of the 10-year funding deal has strings attached requiring provinces spend on health<sup>7</sup> [38, 49] and this proposal would require more of the agreed upon federal funding be directed to measurable improvements in standardized health system data collection, sharing, utilization, and reporting by the provinces.

The MAST institute would be positioned to be a **capacity builder** and **catalyzer** providing the resources, coordination and policy direction described. Critically, the Institute would also be a **regulator** empowered to use its policy levers (regulatory and spending power through health transfers) to hold systems accountable to benchmarks. The Institute would have fiscal accountability tools available (akin to early learning and childcare bilateral agreements) ensuring provinces' adherence to necessary systemic enhancements. This draws on lessons from the defunct Health Council of Canada and several other Federal organizations which had limitations in terms of governmental independence and the capacity to enforce national standards [21] and actions direct recommendations from numerous Federal health reports to ensure these accountability measures are built into such a pan-Canadian Institute [21, 31].

## *System Level Implementation Through Patient and Provider Centered Co-Design*

Promising pockets of implementation of electronic referrals, pooled waitlist, national standards, and data infrastructure already exist across Canada on a smaller scale. Effective implementation, scale and spread these initiatives necessitates a balanced of intrinsic provider motivation and external system level leadership and incentives [50]. The MAST institute is positioned to be a facilitator in both aspects.

### **Fostering patient and provider engagement**

Resistance to change and technology modernization is one of the biggest implementation barriers [51]. The MAST Institute will have a key role in addressing this by adopting a participatory and transparent co-construction approach with key stakeholders

<sup>6</sup> Estimate indexed to 2023 dollars.

<sup>7</sup> 42 per cent—\$19.5 billion—is not tied to specific spending requirements, which means the provinces and territories will get the money, but they won't have to necessarily spend it on healthcare. This includes the guaranteed five per cent annual increase in the Canada Health Transfer (CHT) payments, the \$2 billion CHT top-up and the territorial travel money. Funding could be used by provinces for non-health related purposes.

(e.g., decision-makers, managers, healthcare providers, patients, technology providers). This co-design capacity for health systems, will develop interoperable real-time data driven learning health systems with a shared vision of the objectives and scope, the nature and extent of changes and adaptations required, and the efforts needed to achieve them [52]. Referring providers and patients, eager for expedited access, are positioned to be champions in implementing [53, 54]. Endorsements from the Canadian Medical Association and numerous healthcare leaders underscore highlight decisionmaker support [11, 55]. While specialists may exhibit resistance, often tied to a preference for independent practice models, the Canadian Association of General Surgeons has acknowledged the potential for change. Critically, most surgeons are open to embracing digital systems and centralized waitlists, provided a coordinated approach is implemented, as no single specialist can drive this transformation unilaterally.

### **Necessary Pan-Canadian Leadership**

Successful implementation of interoperable health systems relies on coordination, leadership, and incentives to scale and spread fragmented pilot projects to sustainable system-level change, a role poised to be fulfilled in part by the MAST Institute. Systems change must balance patient privacy with the importance of rapid data turnaround for evidence-informed decisions. The MAST Institute would promote an informed and empowered patient experience, offering transparent access to patient data and a transparent understanding of referral processes for patients and providers. It would also bring leadership, resources, and incentives for provinces to combat fundamental lack of political will and attraction to quick fixes on a short political cycle. The longevity of the implementation strategy is emphasized, deterring short-term solutions and private outsourcing tactics in favor of an integrated system-level infrastructure [56].

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