



Canada's Drug and  
Health Technology Agency

2024 Watch List

# Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity





# The Watch List

The final Watch List was arrived at through consensus in a priority-setting session in November 2023.

Although it is enumerated, the list is not ranked; the fifth item is not more or less important than the first.

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**The top 5 technologies** related to caring for children and youth with medical complexity to watch are:

- 1 New models of care
- 2 Technologies and systems that improve communication
- 3 Genetic testing
- 4 Monitoring devices that improve patient experience
- 5 Mental health support for caregivers.

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**The top 5 issues** related to caring for children and youth with medical complexity are:

- 1 The need for increased interoperability between health systems
- 2 Disparities in access to, implementation of, and diffusion of new technologies
- 3 Evolving practice for health care providers
- 4 Need for strategies to improve sustainability
- 5 Need for additional support for caregivers.

## Key Messages

### What Is the 2024 Watch List?

The Watch List annual Horizon Scan report presents emerging technologies and issues that have the potential to shape the future of health care in Canada.

CADTH's 2024 Watch List focuses on care for children and youth with medical complexity. This top 10 has been divided in 2 parts – the top 5 technologies and top 5 issues related to children and youth with medical complexity that have the potential to make a significant and meaningful impact in transforming health systems in Canada over the next 5 years. These technologies and issues could shape the future of health care for not only children and youth with medical complexity, but also for others with chronic health conditions.

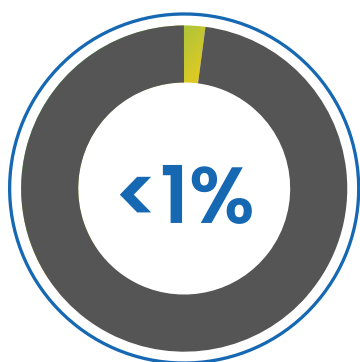
### Why Is This an Issue?

Children and youth (aged 24 years and younger) with medical complexity are a diverse group with a range of needs (e.g., single or multiple conditions, rare diseases). There is no single definition, but common characteristics include significant functional limitations often causing reliance on technology; high health care utilization, often requiring specialized care and services from different providers in multiple settings; and high health care service needs, such as care provision in the home and care coordination, which can have significant social and financial impacts on caregivers and the family.

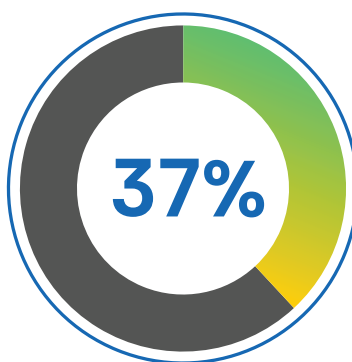
Children and youth with medical complexity account for less than 1% of all children and youth in Canada, but they account for 37% of hospital stays and 17% of emergency department visits. Due in part to the high number of health care interactions, this group experiences the effects of challenges within the health care system more acutely than their less medically complex peers.

The Watch List annual Horizon Scan report presents emerging technologies and issues that have the potential to shape the future of health care in Canada.

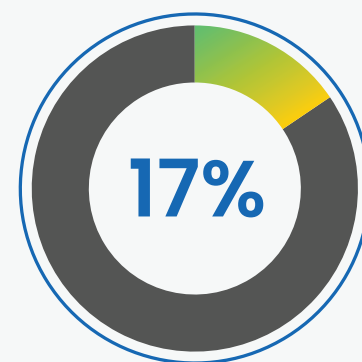
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Percentage of children and youth in Canada with medical complexity



Percentage of hospital stays by children and youth in Canada



Percentage of emergency visits by children and youth in Canada

## What Is the Potential Impact?

The Watch List highlights areas for innovation, systems change, and investment. Advances in medical care have resulted in more children living with conditions that previously would not have been survivable in infancy and childhood. Now there are more children and youth with medical complexity, and they are living longer. Our current health systems were not designed to meet the complex needs of this group of people and their caregivers, including that many of them face challenges in accessing needed care. This year's Watch List spotlights new and emerging technologies and key issues that could have a major impact on how patient care is provided to children and youth with medical complexity.

## What Else Do We Need to Know?

In the 2024 Watch List, we identify and describe the top 5 new and emerging technologies that could shape the future of health care for children and youth with medical complexity in Canada. We also explore some considerations for health care decision-makers about the potential impact of these technologies on care pathways, health care human resources, health care infrastructure, and health equity.

The 2024 Watch List also identifies the top 5 issues that limit health systems from providing optimal quality of care for children and youth with medical complexity. Key issues such as the need for increased interoperability between health systems and the need for strategies to improve sustainability warrant more attention and will influence the wider adoption, diffusion, and implementation of new and emerging technologies for children and youth with medical complexity.

Monitoring ongoing developments and evidence related to the top technologies and issues highlighted in the 2024 Watch List can help guide health system planning in Canada and improve access to high-quality care.

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## Caregiver Experience

A person with lived experience shared her journey as a family member and caregiver for a youth living with a complex medical condition. As she recounted the complex medical journey of her son, who was born with a rare genetic disorder, she reflected on the decade-long search for a diagnosis that finally came with the advent of new genetic testing. Her son's profound physical and developmental disabilities necessitate support for all daily activities and, because he is nonverbal, it is difficult for her to discern when he is in pain or discomfort.

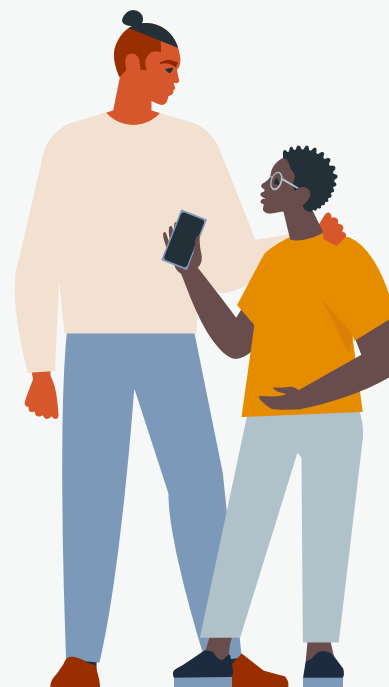
Despite partial funding and partial insurance coverage, the financial strain is significant, with a constant tally for necessary equipment and modifications (e.g., mobility devices, adapted vehicles), which add to the significant costs. The role of caregiving is constant and sometimes exhausting, with her son requiring undivided attention, a reality that led them to independently fund a caregiver for many years. The family dynamic has inherently revolved around her son's needs, often at the expense of what might be considered typical childhood experiences. Both her children have grown up in a world where medical appointments and therapies have replaced playdates and extracurricular activities.

The diagnosis brought with it a beacon of hope because it connected them to a community facing similar challenges. The late-night research sessions, filled with tears and frustration, were a stark contrast to her professional experiences working in health care.

She expanded on the challenges of navigating health care without a clear guide, emphasizing the critical role of early intervention support and proactive outreach to specialists who have become crucial in her son's care. Systemic issues such as lengthy waitlists, a lack of pediatric-specific services, and the inaccessibility of many health facilities have compounded the challenges. The advent of virtual care options, which became more prevalent during the pandemic, has been a game-changer, providing necessary health care access while mitigating the risks associated with in-person hospital visits.

Looking ahead, the transition to adult care is on the horizon as her son approaches adulthood, a time fraught with uncertainties but made more navigable through a support program available to their family. She expressed that in her life, balance is an elusive concept, with caregiving demands often eclipsing her own well-being. Yet, the support from other families in similar situations and the unwavering support of her own family have been indispensable, providing not just practical help but emotional support and alerting her to her own needs.

As technology advances, she sees potential, especially in communication aids that could unlock the world for nonverbal children like her son. It is her hope that such technologies will continue to evolve, offering a voice to those who, like her son, have so much to share but lack the typical means to do so.



Children with medical complexity require consistent, comprehensive support — support that extends to accessible, funded technologies that do not just offer care but enhance quality of life.

### Thank You

CADTH extends our special thanks to Laura and her family who provided their insights and experiences on their journey of caring for a youth living with a complex medical condition.

## Introduction

Each year, CADTH produces a Watch List to identify technologies that have the most potential to transform health systems and shape the future of health care in Canada, providing early signals to help guide health system planning. The [2023 Watch List](#) centred on precision medicine technologies.<sup>1</sup>

### The 2024 Watch List also focuses on a specific theme: children and youth with medical complexity.

This Horizon Scan focuses on new and emerging technologies and the issues that may arise concomitantly when implementing them. The Watch List is not exhaustive; rather, it reflects a set of priorities arrived at by consensus by a group of experts with lived and living experience.

## Who Are Children and Youth with Medical Complexity?

There is no standard definition for children and youth with medical complexity. They include a range of diagnoses and needs; for example, they may have a single condition or multiple conditions, which may include rare diseases. However, as outlined in the column on the right, there are commonalities in definitions.

In this report, we have used the Canadian Institute of Health Information (CIHI) definition of children and youth with medical complexity to include patients up to 24 years old. In Canada, patients typically shift from pediatric to adult care between the ages of 16 and 19 years.<sup>7</sup> Families have reported the transfer from pediatric to adult care is challenging for them and their children.<sup>8,9</sup> We chose this higher age limit to be consistent with CIHI and so we could consider technologies and issues related to transferring into adult care for this report. Other definitions use different age limits (e.g., 18 or 21 years)<sup>4,10,11</sup> or do not specify an age limit.<sup>2,12</sup>

Advances in medical care have resulted in more children living with conditions that were once not survivable in infancy and childhood, including extreme prematurity and congenital anomalies. This has also resulted in more children and youth with medical complexity.<sup>13-15</sup> However, the current health care system is not designed to meet the complex needs of these children and youth, which results in increased hospital admissions and readmissions as well as other health consequences.<sup>16</sup>

Several definitions agree that children and youth with medical complexity:

- live with chronic conditions
- live with functional limitations (i.e., have limits in their ability to do age-appropriate tasks; for example, they may rely on technology for communication and/or mobility)
- have high need for health care, often from multiple settings and health care providers
- have high need for caring from their family or other informal caregivers.

## Caring for Children and Youth with Medical Complexity

Providing care to children and youth with medical complexity involves a variety of challenges. For people with multiple conditions, introducing a new treatment for a specific symptom or condition could aggravate other symptoms or conditions. For those who require multiple medications, there is the potential for the medications to interact with one another and cause negative outcomes.<sup>17</sup> Published evidence related to the effectiveness of interventions specific to children and youth with medical complexity is scarce. Clinical decisions may be based on data from adults, which may have limited effectiveness — or may be harmful — for children and youth.<sup>16</sup>

Due to their chronic condition(s), children and youth with medical complexity require specialized and multidisciplinary care coordinated across settings and services over time. Families have reported that care is often fragmented and difficult to find and access.<sup>3</sup> There can be a lack of documentation, communication, or understanding from both health care teams and families regarding what programs and supports are available. There are other issues as well, as outlined in the column on the right.

These issues may contribute to care needs going unmet and lead to frequent hospital and emergency department visits. Children and youth with medical complexity account for less than 1% of all children and youth in Canada, but they account for 37% of hospital stays (57% of costs) and 17% of emergency department visits (21% of costs).<sup>3</sup> These unmet needs can also cause children and youth with medical complexity to miss school due to exacerbated symptoms or lack of needed resources (e.g., a nurse to accompany them to school).<sup>18,19</sup>

Another challenge is the lack of medical devices developed and designed for children and youth. There are multiple factors influencing this, including the complexity and heterogeneity of pediatric patients as well as financial barriers for medical device manufacturers. Many devices used by and for pediatric patients were developed for adults and subsequently modified and used off-label (i.e., used for children when indicated for adult use). Clinicians may be reluctant to endorse an off-label device; however, without formal options, some families choose to seek out off-label alternatives to care for their children. This can result in the use of interventions that are ineffective or that have not been proven to be safe.<sup>20,21</sup>

In recent years, new regulatory initiatives, funding programs, and competitions have been introduced to encourage the development of medical devices for children.<sup>22</sup>

Some care issues families face may include:

- specialized services may only be available in specific jurisdictions and/or hospitals, requiring some families to travel frequently, consider moving away from their community, or forego care
- services may have long wait lists or strict acceptance criteria that prevent timely access
- pediatric complex care services are often more comprehensive than adult health care services, resulting in lost access to needed care once a patient is transferred out of pediatric care.

New models of care specific to children and youth with medical complexity have also been piloted and introduced, with an aim to improve the quality of care and outcomes. The development and adoption of new technologies and strategies to improve care for children and youth with medical complexity have the potential to impact health care providers and infrastructure and raise ethical and equity concerns.

The 2024 Watch List aims to alert decision-makers to the technologies and issues related to children and youth with medical complexity that are likely to have a significant impact on Canada's health care systems within the next 5 years.

Notably, many of the new and emerging technologies and issues highlighted in this report are not relevant only to children and youth with medical complexity. These children and youth often experience systemic issues more acutely than their less medically complex peers, and there is a significant opportunity to improve their health care experience. These new technologies could be beneficial to other patient groups, including children and youth in general, as well as adults with medical complexity. Similarly, the issues spotlighted in the list are also applicable to these other patient groups and addressing them could help to improve their health care experience as well.

## Developing the 2024 Watch List

For the 2024 Watch List, we have defined technologies as medical devices, diagnostic tests, clinical interventions (including mental health interventions), and models of care used in the pathway of care for children and youth with medical complexity. It does not include interventions that are defined as drugs by Health Canada (e.g., most stem cell products) or technologies that are not directly part of clinical care with patient or family caregiver outcomes (e.g., building design). Drugs were excluded to narrow the focus of this report, as children and youth with medical complexity are a broad population with many different drug treatments.

To be considered for the list, the technologies had to be new or emerging, which we defined as not yet available or widely adopted in Canada beyond a limited number of jurisdictions, health care centres, or initiatives. Specific examples of technologies, ongoing research studies, or other initiatives are provided to illustrate the items in practice and are provided for general awareness. Items on the Watch List are not ranked in order of importance, potential impact, or timing of that impact. However, some technologies on the list are further along in their development than others.



**We have defined technologies as medical devices, diagnostic tests, clinical interventions (including mental health interventions), and models of care used in the pathway of care for children and youth with medical complexity.**



The Watch List also identifies the top issues — policy, social, legal, ethical, or regulatory considerations — that could affect the ongoing development, adoption, or implementation of these new and emerging technologies in Canadian health systems.

This list is not an endorsement of any specific technology mentioned and is intended to be used for information purposes only. Although effort was made to separate technologies and issues into discrete items, due to the interconnectedness of themes, there may be some overlap. Additional details about the definitions we used are available in the Appendix 1.

CADTH developed the Watch List through a modified [James Lind Alliance \(JLA\) priority-setting partnerships approach](#). A list of emerging technologies and issues was identified from published literature and industry news with input from an expert advisory group. The final items on the Watch List were selected by a panel through a consensus-based decision-making process. The panel brought together diverse views and experiences, and included family caregivers, policy and legal experts, researchers, industry representatives, and health care professionals from across Canada. Further details about the selection and identification process of the items are described in Appendix 1.

### Watch List Objectives

The 2024 Watch List identifies and describes technologies and issues related to children and youth with medical complexity that are likely to affect health care delivery and planning in Canada over the next 5 years.

This will help health care decision-makers anticipate future challenges and opportunities for improving the delivery of care for children with medical complexity. It highlights new and emerging technologies, including how and why they could affect health systems in Canada, as well as issues that could affect their development, adoption, and implementation.



The 2024 Watch List will help health care decision-makers anticipate challenges and opportunities for improving the delivery of care for children with medical complexity.

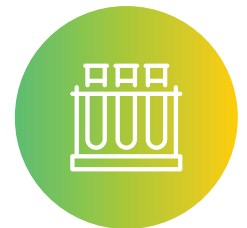
# **Top 5 Technologies** Related to Caring for Children and Youth with Medical Complexity

## Top 5 Technologies

# New Models of Care

Children and youth with medical complexity have a high need for health services, often from multiple providers and in multiple settings. Meeting those complex needs requires coordination, integration, and communication. Typical models of care (defined as how health services are organized and delivered) are not designed to meet these complex needs.<sup>16</sup> Traditional models of care are better suited to meeting acute rather than chronic and complex health care needs because they often lack integration and coordination between providers and settings.<sup>16,23</sup> This results in fragmented care, which can increase the risk of adverse events.<sup>3,23</sup>

New and emerging models of care aim to improve care delivery for children and youth with medical complexity. These models often include enhanced care coordination (i.e., coordinating procedures, appointments, and tests) to reduce unnecessary procedures.<sup>24</sup> These new models can also include early crisis recognition, partnership with family caregivers, and active co-management across all care providers (e.g., having proactive shared care plans, regular communication through multidisciplinary team meetings).



Assistance during transitions of care, such as from pediatric to adult care or hospital to home, can be an important part of these models. This includes services such as education for family caregivers (e.g., how to use medical technologies) and offering appointments with health care providers during transition points to determine if additional supports are needed.

A variety of models of care for children and youth with medical complexity have been tested and/or implemented. Some models focus on delivering continuous, coordinated care through a primary care centre, while other models may be based in tertiary care centres.<sup>24</sup> It is unlikely that there is a single model of care that leads to the best outcomes for all children and youth with medical complexity; each approach has its own set of advantages and disadvantages based on local needs, values, and available resources.

New models of care have the potential to reduce the workload of family caregivers who often do the work of coordinating care and finding resources. This would allow them to provide better care for their children. These models may also be cost-effective for health care systems through reduced emergency department visits and inpatient stays.<sup>25</sup> Models of care that reduce loss of information at transition points would contribute to better care continuity and quality of care.

## Transitions of care, particularly from pediatric to adult care, are an especially difficult time for youth with medical complexity and their families,...

...often leading to a break in the delivery of health care.<sup>26</sup> A family caregiver noted that many children and youth with medical complexity do not change significantly – physically, mentally, and/or developmentally – when they reach the age they must transition into adult care, which makes the transition even more difficult for caregivers.

Many health care providers in adult care have limited training and experience in caring for this growing patient population.<sup>9</sup> In addition, complex care services are often more limited for adults than for children, which can negatively impact the quality and comprehensiveness of care.<sup>8,9</sup> Increased collaboration between pediatric specialists and health care providers in adult care may help to bridge this gap and allow for continuous, high-quality care.<sup>24</sup> Increased collaboration within adult care (e.g., between family physicians and specialists) may also help to meet patients' complex needs, reduce the work for family caregivers, and reduce visits to the emergency department.

These new models may increase demands on the health care system and staff. This is discussed in more detail in the Evolving Practice for Health Care Professionals section.

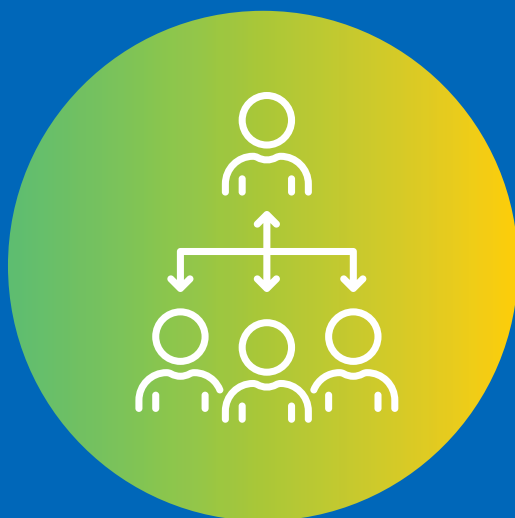
### Examples of emerging models of care to watch include:

**Complex Care for Kids Ontario (CCKO)**<sup>27</sup> is a program led by the Provincial Council for Maternal and Child Health (PCMCH) for children and youth with medical complexity. Through individualized care plans, CCKO provides integrated and coordinated care across health, social, and community services to improve access to care close to home. It operates under a “hub-and-spoke” model: “hubs” are tertiary hospitals’ pediatric complex care clinics that support large regions and “spokes” are the community-based clinics. A key clinical and system worker coordinates the connections between these sites. Results from a randomized controlled trial indicate that this program led to improved health outcomes for parents and reduced health care costs.<sup>28</sup>

**LIFEsan Service** is a collaboration between Holland Bloorview Kids Rehabilitation Hospital and the University Health Network Toronto Rehabilitation Institute (UHN-Toronto Rehab) for youth with cerebral palsy or an acquired brain injury. For youth aged 14 to 18 years, the team at Holland Bloorview assists with preparing the youth for the transfer to adult care. Once patients are 18 years, they are referred into the adult transitional service at UHN-Toronto Rehab, which provides a single access point for specialized rehabilitation. Available services include nutritional counselling, pain management, and a variety of consultations.

There is also the potential for care disparities if new models of care are only implemented in specific jurisdictions or health care facilities. Decision-makers will need to assess their resourcing and needs and determine what model or models would best suit the needs in its context. Integrating mental and behavioural health care as well as nonmedical services (e.g., social services) could further improve quality of care and quality of life. However, this would require additional resources and planning.<sup>24</sup>

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**Examples of emerging models of care to watch include:**

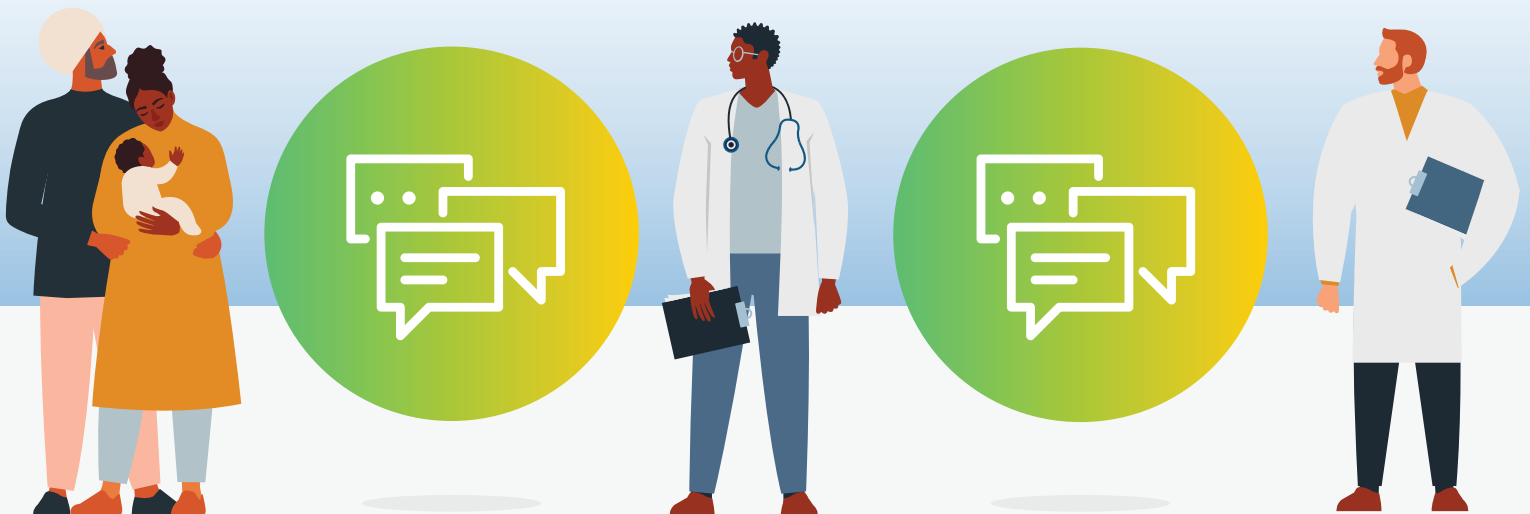
**Connected Care** is a program at The Hospital for Sick Children (SickKids) that improves transitions of care when patients move from hospital care to home or community care. The program includes family education (one-on-one training on medical technologies); joint review of the child's care plan with families, hospital, and home care providers; and a virtual visit within 1 week of discharge to offer education or other supports as needed.

The **Children's Hospital of Eastern Ontario (CHEO)** and **BC Children's Hospital** are building centres specifically for children and/or young people with complex health needs. Typically, children and youth with complex health needs must travel to various sites to access different services and health care providers (e.g., different specialists at different clinics and/or hospitals). Having these services and care providers in a single location should help improve access to care (e.g., reduced need for travel) and improve quality of care (e.g., improved coordination of services and interdisciplinary treatment programs).<sup>29,30</sup> Both will also provide supportive services, such as lockers for long days with multiple appointments (CHEO) and overnight suites for families when they need extra support, including during transitions of care (BC Children's Hospital). Both centres are scheduled to be complete by 2028.<sup>31,32</sup>

Top 5 Technologies

# Technologies and Systems that Improve Communication

Children and youth with medical complexity often require care from multiple health care providers in multiple settings. This can include primary care providers' offices, specialist clinicians in hospitals, rehabilitation centres, community care, and emergency departments, as well as health care providers in different provinces and/or cities. There are multiple barriers to effective and efficient communication and information sharing between different providers as well as between health care providers and family caregivers, which can lead to miscommunication and increased burden on families.



The inability to efficiently communicate health information between care providers often results in family caregivers needing to create their own medical records for their child and repeatedly share health information with every care provider they visit.<sup>33</sup> At our workshop, family caregivers reported creating their own documentation and health records. They described the need to repeatedly share health information as traumatic for them and their child.

Discussing events such as medical emergencies that require resuscitating their child is difficult for caregivers, making it feel like they are reliving those events. This is an inefficient method of sharing information. It reduces the time spent addressing the child's health concerns and can result in delays or suboptimal quality of care (e.g., prescribing a medication that has resulted previously in an allergic reaction due to not having a record of allergy or medication history).

While the use of electronic medical records has been increasing in Canada, these systems are often designed for record-keeping and, due to privacy concerns, either do not allow or only allow for limited sharing of health information (e.g., within a single practice or institution).<sup>34</sup> We discuss this in more detail in The Need for Increased Interoperability Between Health Systems section.

**A clinician who participated in our workshop stated that electronic medical records were not designed for the complex needs of this population, which leads to errors and increased work for health care providers.**

A family caregiver highlighted the need for improved communication between health care systems and schools so teachers and staff are aware of potential health issues and what they should do if unexpected events occur (e.g., who to contact and how).

Children and youth with medical complexity require a system that will allow their care team to communicate and access all up-to-date health information in a centralized place.<sup>34</sup> The data should be integrated in a single system and should be easily searchable. Systems that allow caregivers to communicate with the health care team easily would be beneficial. Easier communication will lift the burden of remembering and communicating enormous amounts of health information from family caregivers, save time, and reduce errors. The increased communication could also reduce visits to hospitals and emergency departments. User-friendly design and ease of registration are also important.

Investments by health care systems will be required, including equipment to store large amounts of data and secure, stable internet. Data security and confidentiality must also be a priority, ensuring access to highly sensitive health data is only provided to those who require it. Health care providers and support staff may require additional training to learn how to use new systems, and new staff may be required to assist. These technologies come with the potential for disparities in access to care if family caregivers do not have, for example, access to a smartphone capable of running mobile applications.

**Examples of emerging technologies:**

**DigiComp Kids**<sup>35</sup> is a virtual hospital-to-home health system for children with medical complexity that was designed and tested in southern Ontario. Family members and home-based clinicians receive an at-home Connected Health System kit, while hospital-based clinicians receive access to the hospital's Connected Health System clinician portal. Hospital-based clinicians can review biometric data and health information submitted by family and home-based clinicians and then send health information to assist with decision-making at home. The kit includes a tablet and Bluetooth-enabled devices to allow for remote monitoring of physiological measures, which can be uploaded and submitted into the hospital's cloud-based system.

**EnrichMyCare** (UK) is a personal health platform designed to help children with disabilities. It is intended to allow family caregivers and health care professionals to view and access all relevant information through a single platform, including the child's health profile, care team, health records, and appointments. Family caregivers can collaborate with health care providers, upload information, and receive reports instantly through a smartphone, tablet, or computer. Health care providers can also review information from remote monitoring devices through their portal and easily access information and records from their patients' other health care providers.

## Top 5 Technologies

# Genetic Testing

Personal genetic data can help diagnose certain disorders and conditions more quickly than other testing options and can help guide treatment decisions. For pediatric patients, including children with medical complexity, established genetic tests include chromosomal microarray analysis (detects missing or duplicated pieces of DNA) and exome sequencing (characterizes the DNA code of all protein-coding regions).<sup>36</sup> There is also growing interest in using whole genome sequencing (characterizes the entire DNA code of an individual) for children and youth with medical complexity, potentially providing more diagnostic information than more established genetic tests which could have a greater impact on a patient's care.<sup>36,37</sup>

Genetic testing can be used to:

- identify genetic causes of nonspecific symptoms (e.g., global developmental delay, seizures)
- assess rare and/or hard-to-treat cancers
- help identify new targets for treatment, leading to the development of new treatment regimens or changes in management.<sup>38</sup>





Pharmacogenomic testing (i.e., assessing genes that influence how an individual may react to drugs) is another use for genetic sequencing. Traditional assessment of treatment effectiveness and side effects can be difficult for children and youth with medical complexity due to factors such as neurologic impairment, multiorgan system disease(s), and prescriptions from multiple specialists.<sup>39</sup> At least 1 study has examined the rate of clinically relevant drug-gene interactions in a population of children and youth with medical complexity, and found a high percentage of children (68%) were prescribed at least 1 drug with an interaction.<sup>39</sup> Pharmacogenomic testing and genomic sequencing early on in care management has the potential to:

- identify when a prescribed drug has a known drug-gene interaction, which could reduce the risk of negative side effects
- reduce the risk of harmful drug-drug interactions, as children and youth with medical complexity are often prescribed multiple medications<sup>39-41</sup>
- allow children to be prescribed medications that are likely to work earlier instead of requiring them to sequentially try several drugs before finding 1 that works
- identify a patient's ideal dosages for medications, which could reduce the risk of overdosing.

Personalized testing based on a patient's unique genetic data can allow for faster diagnoses, which in turn can allow health care providers to provide appropriate treatment sooner and lead to improved patient outcomes.<sup>42,43</sup> It may also help guide the development of treatment options for patients with rare genetic disorders or rare cancers.

Reducing the use of drugs that are unlikely to work for a patient can reduce costs for families and the health care system and prevent the emotional exhaustion experienced by patients and families when ineffective drugs are used. Sequencing has also become less expensive. In 2001, sequencing the human genome cost more than \$1 billion.<sup>44</sup> Currently, genome sequencing is estimated to cost several thousand dollars (excluding the upfront costs, such as equipment, infrastructure, staffing).<sup>45,46</sup> Sequencing (including exome, genome, and gene expression) technologies will become more available for use in routine care as these technologies become less expensive and are accompanied with the infrastructure to analyze the data.



68% of children and youth were prescribed at least 1 drug with an interaction, according to 1 study examining the rate of clinically relevant drug-gene interactions

**Examples of initiatives to watch related to genetic testing include:**

**SickKids' Precision Children Health**<sup>49</sup>

focuses on delivering care based on a child's unique genes, biology, and environment. As part of this strategy, they have introduced SickKidsSeq, a service enabling access to whole genome sequencing to children who do not have access through standard care or research initiatives.

**PROFYLE (Precision Oncology For Young People)**<sup>50</sup>

is a pan-Canadian initiative with investigators and collaborators from across the country helping to treat patients from across Canada. Research centres, scientists, and clinicians from across Canada work together to take the molecular profile of young patients with cancer. This includes assessing genetic characteristics; this information can then be used to identify and create new therapies. For children who live in an area without a molecular profiling site, their tumour sample can be sent to a distant molecular profiling site.

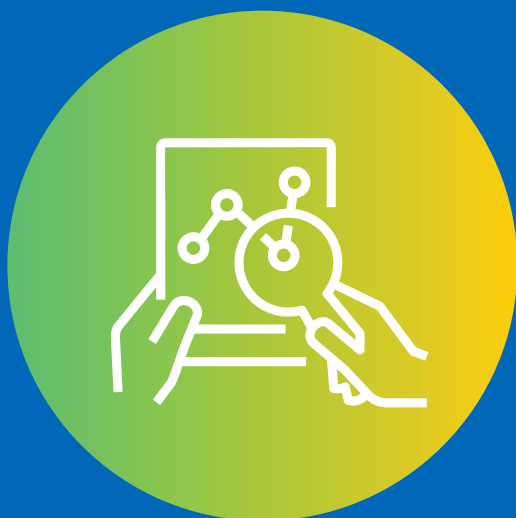
If adopted into routine care, additional infrastructure will be needed to conduct whole exome and/or whole genome sequencing (e.g., training staff, obtaining equipment, and storage for physical equipment and large amounts of data), analyze and interpret the results, and ensure data privacy and security.

Other challenges include limitations in genomic databases (e.g., due to certain demographic groups being underrepresented in these databases), how to communicate the results to families and patients, and ethical and legal<sup>47</sup> issues related to consent and the future use of data (e.g., who is responsible for telling the patient if new information becomes available, such as based on reanalysis or new interpretations of genetic data?).<sup>48</sup> As highlighted in last year's Watch List about precision medicine and by family caregivers at this year's workshop, it is important to separate the hype from the hope regarding genomic sequencing – there is an emotional impact on a family if a genetic test does not provide a diagnosis or affect care pathways.

**Examples of emerging models of care to watch include:**

The [Newborn Genomes Programme](#) aims to sequence the genomes of 100,000 newborn babies in the UK, the goal of which is to diagnose rare but treatable genetic conditions to fast-track access to treatment. Samples will be taken for a 2-year period, then there will be a cost-benefit analysis. The data will be used by the UK National Screening Committee to provide advice on genome screening policies for newborns.<sup>51</sup> These data may also be applicable to help inform newborn genome screening programs in other countries.

Sequencing technologies will become more available for use in routine care as they become less expensive and are accompanied with the infrastructure to analyze the data.

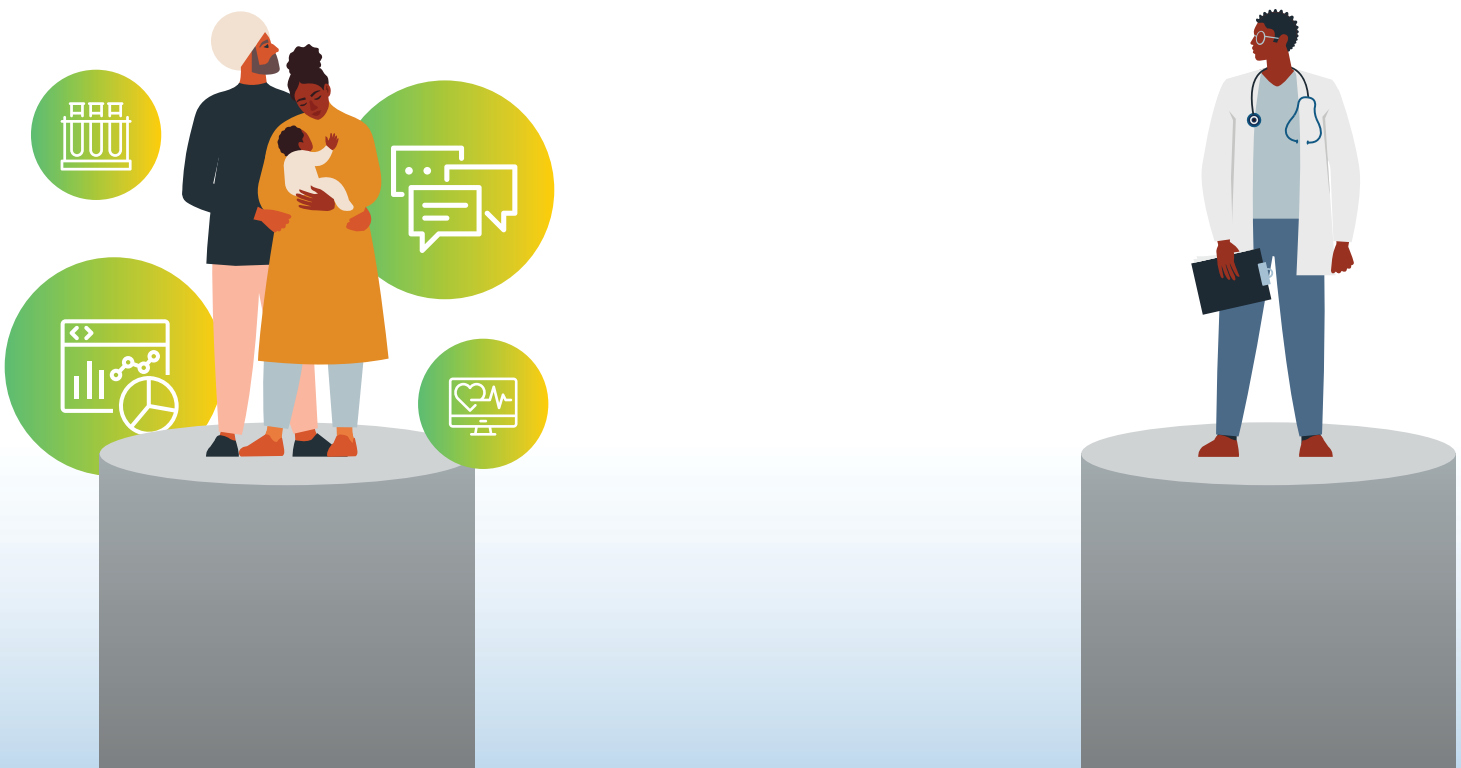


Top 5 Technologies

# Monitoring Devices that Improve Patient Experience

Children and youth with medical complexity require frequent medical testing, which sometimes requires travel. Some procedures (e.g., blood draws) can be invasive, painful, and distressing. This can make medical appointments more difficult for children, their families, and health care providers.

New technologies could replace these uncomfortable procedures with something less painful or entirely painless. This could reduce reluctance related to medical appointments, reduce risk of infection, and reduce workload for health care providers (e.g., requiring someone to do a blood draw). A less distressing procedure would be particularly beneficial in already stressful situations, such as visits to the emergency department. A monitoring device capable of taking measures every hour, or even continuously, may provide more insight than traditional procedures done once every few hours. New sensors may also be able to send information wirelessly to hospital equipment or smartphones.



Depending on the type of device and the care required, monitoring could be done in new locations. For example, instead of travelling to a specialty pediatric hospital, patients may be able to be assessed at their local primary care provider or at home.

Reducing the need for frequent and long-distance travel could be a significant benefit for children and families, improving access to care for those who do not live close to specialty pediatric hospitals (including those in rural or remote areas).

However, new devices should avoid adding more work and responsibilities for family caregivers who already devote significant amounts of time caring for their child. Although reduced need for travel could be beneficial, new technologies intended for home use may place more work on family caregivers. At our workshop, some family caregivers pointed out it is important not to assume that families want to avoid going to the hospital or other medical facilities, even if it requires travel — some feel isolated and unsupported if all their care is provided at home.

New devices should avoid adding more work and responsibilities for family caregivers



**Examples of emerging technologies to watch include the following:**

[ANNE Chest Sensor](#) and [ANNE Limb Sensor](#) are monitoring devices that are wireless, reusable, and rechargeable. They were designed to be gentle enough for newborns' fragile skin, while still providing accurate readings of physiological measures. They can also send data wirelessly to a nurse station display or a smartphone or tablet.<sup>52</sup>

[BioSense](#) has developed a noncontact electrocardiogram. Unlike traditional electrocardiograms that require direct skin contact, which can lead to skin tears, infections, and sores — especially for babies and young children with thinner, more fragile skin — the BioSense sensors can be used through clothing layers and will not tear skin.

**Electronic skin** (also referred to as e-skin) is a flexible film with an adhesive surface that sticks to the skin like a bandage.<sup>53</sup> These can be used to measure a variety of physiological measures comfortably, including during exercise or sleep, and send information to a smartphone.<sup>53,54</sup> Samsung has also developed a version that comes with a stretchable organic light-emitting diode (OLED) display that can display biometric data on the film adhered to the person's skin.<sup>55</sup> Other advances include developing sensors that do not require Bluetooth chips or batteries, which will make them lighter and more comfortable.<sup>53</sup>

Top 5 Technologies

# Mental Health Support for Caregivers

As more children and youth with medical complexity are being cared for primarily at home, the workload for their family caregiver(s) increases. Family caregivers provide a substantial amount of care for children and youth with medical complexity, including but not limited to coordinating medical appointments, communicating information, and providing medical care at home.

This work is often unpaid and underappreciated, which can have a negative impact on family caregivers' mental health and overall well-being. Parents of children with medical complexity are more likely to report poorer mental health than parents of children with special health needs (but who are not medically complex).<sup>56</sup> Another study found that, compared to parents of children without special health needs, family caregivers of children who rely on medical technology tend to have fewer hours of sleep per night, higher levels of fatigue, excessive daytime sleepiness, and higher levels of depressive symptoms.<sup>57</sup> Financial stress can also add to poorer mental health.



The level of care required by children and youth with medical complexity often requires a family caregiver to give up paid employment, which in combination with the high expenses of caring for their child, can result in additional stress and anxiety.

In 2020, CIHI reported that 37% of surveyed primary family caregivers for children and youth with medical complexity expressed distress, anger, or depression. This distress can come from traumatic experiences related to their child's health status and the uncertainty of their child's future. It can also come from interactions with the health care system, such as when health care providers make decisions about their child without consulting them.<sup>58</sup> Parents struggle with the dual role of being both a parent and a provider of medical care to their child, the latter of which can be distressing to their child, as well as with the impact on the rest of their family, particularly their other children.<sup>3</sup>

## Improving the mental well-being of family caregivers could lead to improved health outcomes and quality of life for themselves and their children.

Designing and implementing interventions for family caregivers will require additional resources, including health care providers and support staff to operate these programs. Involving family caregivers during the design phase and incorporating their suggestions could not only help improve uptake but also ensure that the care provided is helpful for them. A proactive approach focused on prevention could help to address needs before crises emerge. Care must also be taken to help ensure access to these programs is equitable; for example, programs that are only available at large urban centres could hinder access for family caregivers who live in rural or remote areas. Programs that are available in multiple languages could also help to improve access to services.

At our workshop, family caregivers highlighted the need for mental health support for the entire family, including their other children. Not only do family caregivers experience poorer mental health, but siblings of children with medical complexity may also experience challenges, such as they may feel sad or anxious because of their sibling's health issues or guilty because they can do activities their sibling cannot.<sup>59</sup> Family caregivers noted the existence of sibling support for patients with cancer, and suggested a similar approach could be useful for siblings of children and youth with medical complexity. They also suggested that health care providers should take a trauma-informed care approach and that mental supports should be easy to access and the timing should be convenient for them. A family caregiver pointed out that they did not want to be asked about their mental health during or after a medical appointment for their child because they want the focus to be on her child during that time.

### Emerging pilot studies and initiatives to watch include the following:

**Caring for the Caregiver (C4C)**<sup>60</sup> is an integrated, stepped care model developed in a partnership between SickKids' Complex Care program and Women's College Hospital's Reproductive Life Stages Program in the Department of Psychiatry. An external psychiatrist is integrated in the Complex Care program to provide psychiatric care to caregivers who have suspected depression, trauma, anxiety, or related disorders.

**Holland Bloorview Kids Rehabilitation Hospital** has a [Sibling Support Program](#) for children and youth (aged 7–18 years) who have a sibling with a disability, diagnosis, or medical complexity. This program provides these children and youth a place to meet and talk about their shared experiences.

**Caregivers Alberta** offers services to caregivers (for children with disabilities or serious and/or chronic diseases). Their programs include [Caregiver Coaching](#) (a coach provides one-on-one advice, and can request support for the caregiver's health and well-being) as well as [COMPASS for the Caregiver](#) (a multisession workshop aimed at helping caregivers deal with guilt and grief and to manage stress).

A clinical trial assessed the impact of a psychoeducational intervention (cognitive behavioural therapy, mindfulness training) through videoconferencing by a social worker for parents or guardians of children who are technology dependent (on a ventilator at home).<sup>61</sup> This preliminary study reported reduced anxiety, depression, and fatigue for the parents. We also identified ongoing clinical trials assessing the impact of virtual interventions for family caregivers of patients with special health care needs.<sup>62,63</sup>

# **Top 5 Issues** Related to Caring for Children and Youth with Medical Complexity

Top 5 Issues

# Need for Increased Interoperability Between Health Systems

Digital technologies, such as electronic health records and mobile health apps, are being increasingly adopted in Canada.<sup>64</sup> Ideally, the data stored in these health information systems should be able to flow seamlessly across the care continuum and different information technology systems.<sup>65</sup> This would allow patients, caregivers, and clinicians timely access to personal data, such as clinical notes, laboratory results, diagnostic imaging, current medication lists, and patient history, when needed to inform care decisions.

However, health care in Canada is primarily administered through provincial and territorial systems that often involve health care providers and organizations operating independently of one another, with limited integration across care settings (i.e., primary care clinics, urgent care centres, hospitals) and jurisdictions (e.g., geographic regions, health authorities).<sup>66</sup> This has led to the development and implementation of systems that are not interoperable, such as electronic medical records that can only be accessed through separate portals.<sup>67</sup> This lack of interoperability results in disorganized, fragmented, and inaccessible medical information, potentially compromising the quality of or delaying patient care and leading to the wastage of health care resources, including redundant testing.<sup>65</sup>





## 2024 Watch List: Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity

Despite ongoing efforts to improve health system interoperability across Canada,<sup>68-70</sup> data from Canada Health Infoway's 2022 Canadian Digital Health Survey<sup>71</sup> reveals that 24% of survey respondents reported that their care providers did not have access to their health history before or during their visit, and that 31% of people experienced issues with coordination of care between health care providers in the past 12 months. These communication and coordination issues were even more prevalent among those patients with chronic conditions (38%) and those with frequent health care encounters (47%).<sup>71</sup>

Because children and youth with medical complexity have frequent health care encounters, lack of interoperability is a significant challenge to their care.

The workshop participants, including family caregivers and health care providers, shared insights into the challenges caused by lack of interoperability, such as the burden on patients and caregivers who must manage multiple log-in accounts for different health portals across various apps. Children and youth with medical complexity visit multiple health care providers for different levels of care (e.g., primary care, emergency care, specialist care at pediatric hospitals in large urban centres). Patients or caregivers are often responsible for gathering, compiling, and communicating all their health information to each health care provider.

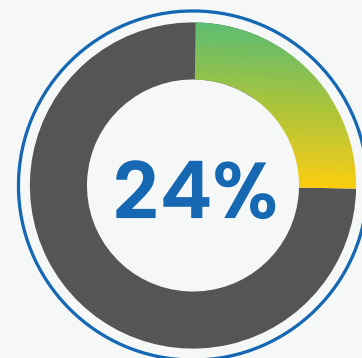
At our workshop, a family caregiver reported that the hospital closest to where they live and the hospital their child primarily receives care at are managed by different regional health authorities, despite being in the same province. As a result, when their child needs to go to the emergency department close to home, this hospital does not have access to their child's medical records.

Improvements in interoperability would alleviate burden on patients and caregivers, could increase the documentation of patient and caregiver concerns, and reduce the risk of information gaps – resulting in improved patient safety. It would also improve communication between health care providers, which could significantly improve quality of care for children and youth with medical complexity (discussed in the Technologies and Systems That Improve Communication section).

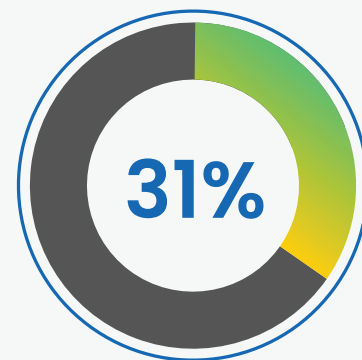
Furthermore, the workshop participants emphasized the potential impact of increased interoperability in enhancing care transitions, such as interhospital transitions from pediatric centres to adult centres or transitioning from hospital care to home care. These transitions can be complex and stressful processes. Greater care coordination enabled by access to patients' medical history and data would facilitate transitions, improving patient and caregiver experiences.

As health systems increasingly incorporate digital technologies for monitoring and recording patient health data, interoperability across technologies and systems is an important design consideration. Interoperability is likely to promote wider adoption and improve care for children and youth with medical complexity.

## Need for Increased Interoperability Between Health Systems



Percentage of respondents reporting that their care providers did not have access to their health history before or during their visit.



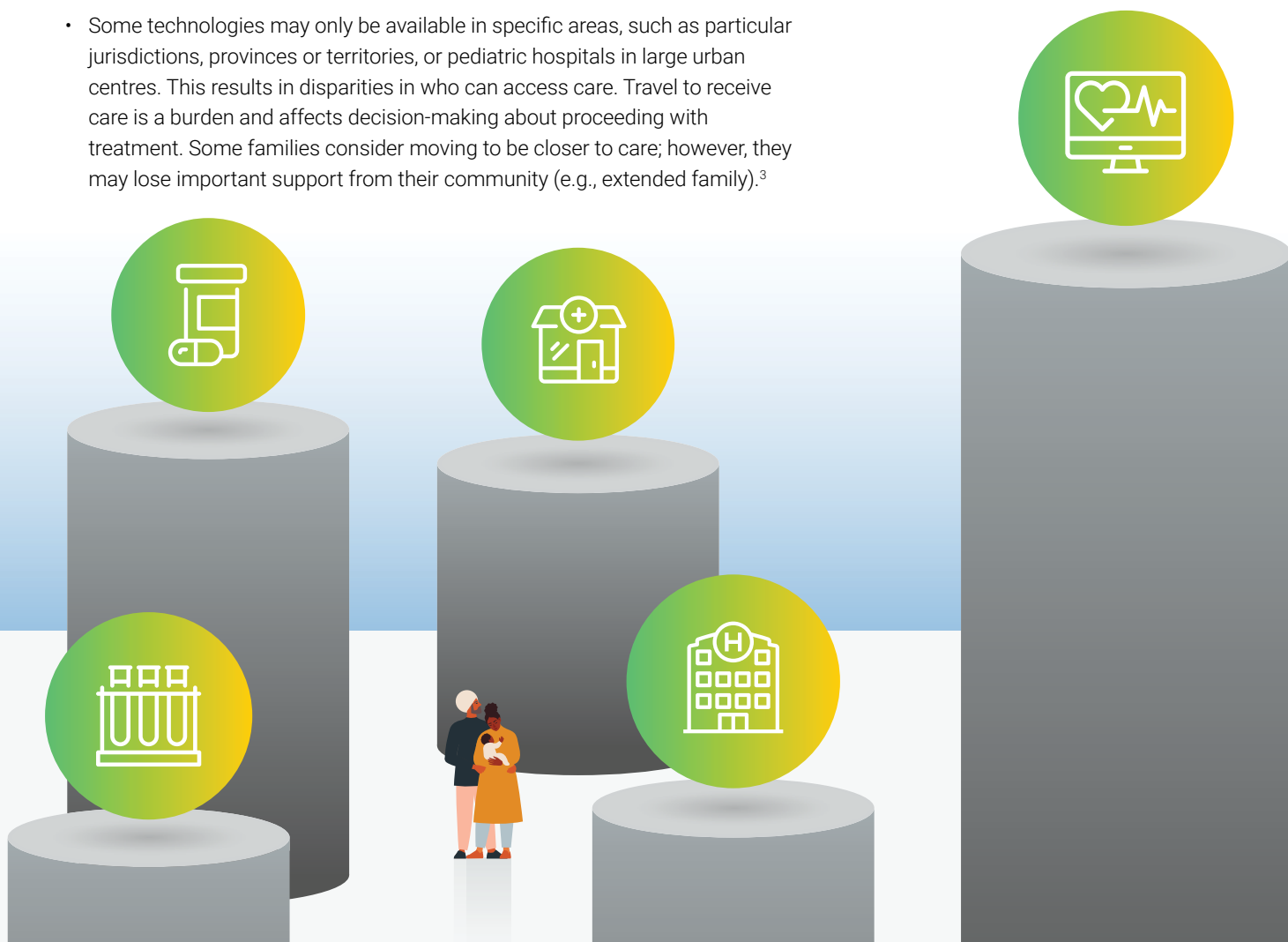
Percentage of respondents that have experienced issues with coordination of care between health care providers in the past 12 months

Top 5 Issues

# Disparities in Access to, Implementation of, and Diffusion of New Technologies

Across health systems in Canada, disparities exist in the access and use of new and existing technologies for the care of children and youth with medical complexity.<sup>72</sup> These disparities may be due to practical limitations or to inequities such as geographic barriers or systemic issues, all of which lead to a range of challenges.

- Some technologies may only be available in specific areas, such as particular jurisdictions, provinces or territories, or pediatric hospitals in large urban centres. This results in disparities in who can access care. Travel to receive care is a burden and affects decision-making about proceeding with treatment. Some families consider moving to be closer to care; however, they may lose important support from their community (e.g., extended family).<sup>3</sup>



- New digital technologies often rely on access to devices with high-speed, reliable internet for both health care providers and patients. Although these technologies could improve accessibility for some, they could also contribute to and worsen inequities between those who can easily access and use technology and those who cannot (i.e., the “digital divide”).<sup>72,73</sup>
- Inequitable access may also occur if technologies have limited availability through specific reimbursement methods (e.g., confined to specialized research centres supported with research funding). Similarly, complex reimbursement mechanisms can create barriers to accessing necessary technologies, as demonstrated by the story of Jordan River Anderson and the subsequent implementation of Jordan’s Principle.<sup>74</sup>
- Technologies, particularly new or off-label use of existing technologies, are not always reimbursed under provincial and territorial health plans.<sup>3,75</sup> This can result in families without the financial means or without insurance coverage being unable to access new technologies. Although financial support programs may be available, obtaining support can be a time-consuming process, including identifying programs, determining eligibility, applying, and waiting to receive payments.<sup>76</sup>
- Children and youth with medical complexity from racialized or other equity-deserving groups can face barriers when trying to access care.<sup>56,77</sup> For example, if a family caregiver is not fluent in the dominant local language, they may experience difficulties accessing resources and care due to the language barrier. Communication challenges can also lead to lower quality care because communicating care between caregivers and health care providers is key for children and youth with medical complexity.<sup>77-79</sup> A review found that children with chronic health conditions who were Black or Hispanic had worse health and health care outcomes than children who were white.<sup>80</sup> Parents of children with medical complexity are also less likely to know where to go for help if their child is Black or Hispanic or if they have a lower household income.<sup>56</sup>

Patients from racialized or other equity-deserving groups have also been underrepresented when developing and testing new technologies.<sup>81</sup>

In clinical trials that included pediatric patients, children who were Indigenous, Black, Asian, or Hispanic were often underrepresented, or their parents were more likely to decline participation in the trial.<sup>82-84</sup> Families and patients with low incomes are also less likely to participate in research due to barriers such as cost of participating in research (e.g., travel costs) and scheduling conflicts with work.<sup>85,86</sup> Lack of inclusion in the development and testing of new devices can perpetuate or exacerbate existing inequities and disparities in health outcomes.<sup>81</sup>

**If a family caregiver is not fluent in the dominant local language, they may experience difficulties accessing resources and care due to the language barrier.**

## 2024 Watch List: Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity

Methods to increase involvement of underrepresented groups include conducting research where patients receive care and addressing barriers to participation (e.g., having bilingual and/or multilingual research staff, as well as all information available in multiple languages).<sup>87</sup> It is also important to be aware of harms perpetuated by health care systems toward these equity-deserving groups.

Discussion at the workshop underscored the challenges associated with accessing care and technologies for children and youth with medical complexity. Many families are forced to relocate to large urban centres where health care providers and resources are more readily available.

Relocation can cause financial burdens, family fragmentation, negative impacts on social lives, loss of local community support networks, and mental health issues. Additionally, an industry representative at the workshop mentioned the potential for international inequities if new technologies adopted in countries around the world are not accessible in Canada.

To address these issues, health systems must explore strategies to remove systemic barriers and ensure equitable access to resources for children and youth with medical complexity.

Disparities in Access to, Implementation of, and Diffusion of New Technologies

Relocation can cause financial burdens, family fragmentation, negative impacts on social lives, loss of local community support networks, and mental health issues.

Many families are forced to relocate to large urban centres where health care providers and resources are more readily available.



Need for Increased Interoperability Between Health Systems

Disparities in Access to, Implementation of, and Diffusion of New Technologies

**Evolving Practice for Health Care Professionals**

Need for Strategies to Improve Sustainability

Need for Additional Support for Caregivers

Top 5 Issues

# Evolving Practice for Health Care Professionals

The field of complex care is relatively new and as it has developed, the needs of the group of patients this field aims to serve have also evolved. In turn, these patient needs have changed the expected approach and practice of care for health care professionals. Improved survival rates for children and youth with medical complexity also contribute to the need for new types of care because the goals of care have shifted toward maximizing health, function, development, and family well-being, and to facilitate transitions to adulthood.<sup>2</sup>



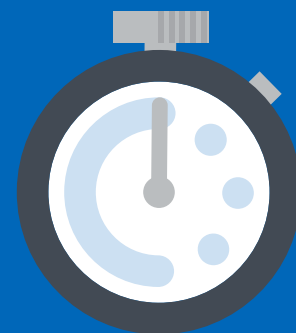
Together, these changes require providers of complex care to evolve how they deliver care within their respective practice. Examples of this include the following:

- Health care providers will have new duties and responsibilities as new technologies are implemented into clinical practice and new ways of providing care are adopted, such as virtual care, family-centred models of care, and increased care coordination.<sup>88</sup> For example, responding to questions from caregivers of children and youth with medical complexity (e.g., through mobile health apps or phone calls). In areas where there is limited availability of specialists and subspecialists, other health care providers may also be required to step in to fulfill care tasks.<sup>89</sup>
- Expanded care coordination roles require dedicated time, such as a set number of hours per week for care coordination for an existing staff member, such as nurses, or even creating new, dedicated part- or full-time positions.<sup>89</sup> It will also require health care providers to change how they organize and provide care, such as requiring additional time for multidisciplinary meetings to share information and improve care coordination.

Additional educational initiatives may also be needed to build capacity.<sup>7</sup> The workshop participants, including family caregivers and clinicians, recognized the challenges associated with accessing care providers trained to care for children and youth with medical complexity, particularly in regions where specialists are not readily available. Some health care professionals feel uncomfortable and ill-equipped to provide care to this population of patients due to their diversity and complexity of needs.<sup>9,90,91</sup> Health care providers need training, education, capacity-building, support, and collaboration to empower them to provide high-quality care for children and youth with medical complexity. These initiatives require resources and time from care providers, and could help maximize the workforce's potential and combat the ongoing human health resources crisis being experienced in Canada and globally.<sup>92</sup> Health systems may also need to consider how to incent and support the need for increased coordination of care.<sup>24</sup>

Clinicians participating in the workshop highlighted the role that technology could have in improving care coordination and capacity building across jurisdictions. We have provided some examples in the Technologies and Systems That Improve Communication and The Need for Increased Interoperability Between Health Systems sections. Other examples include:

- Technologies to allow for shared expertise beyond specialized pediatric hospitals (e.g., enable consultations between clinicians in specialized urban centres and those in rural and remote locations)
- Decision-making tools and 24/7 consultation lines to support caregivers and unregulated care providers in the community (e.g., personal support workers, educational assistants)
- Technologies that can enhance the skills and capacities of home care providers.



**Expanded care coordination roles require dedicated time, such as a set number of hours per week for care coordination for an existing staff member, such as nurses, or even creating new, dedicated part- or full-time positions.<sup>89</sup>**

Top 5 Issues

# Need for Strategies to Improve Sustainability

New technologies, treatment programs, and models of care for children and youth with medical complexity are often introduced through pilot projects or clinical trials supported by time-sensitive funding mechanisms. Although these initiatives provide early access to innovative technologies and models of care that could benefit patients, they create uncertainties regarding what will occur once the trial period ends for patients, caregivers, and providers:

- Families of children and youth with medical complexity may hesitate to engage with new technologies or models of care due to concerns about continuity of care after the trial period ends, when changes to funding may affect availability. In addition, the families and children who do engage with these pilot programs may struggle once the program ends (e.g., finding an alternative treatment), resulting in lost continuity of care.



- Health care providers may be reluctant to learn new processes and implement them into their practice if they anticipate it is likely they will have to return to their previous methods in the future because learning, adjusting, and incorporating new processes can take up significant amounts of time.<sup>93</sup>
- If health care providers or other staff are not adequately reimbursed for their work (e.g., tasks related to care coordination), new models of care or technologies may not be adopted or retained in the long-term.<sup>24</sup>

The workshop participants, including family caregivers, clinicians, and industry representatives, acknowledged the necessity of pilot programs to assess the feasibility, effectiveness, and safety of new technologies and models of care. They described a need for clear pathways to continue successful pilot projects that demonstrate the value of innovations. This would ensure effective innovations are implemented as standard of care and are made available to more people who could benefit from them. Furthermore, caregivers and families described some of the challenges associated with care continuity, including gaps that can arise due to resource constraints (e.g., funding, availability of community nursing or care coordination).<sup>94</sup>

### Implementing strategies to improve the sustainability of new technologies and models of care could create opportunities to improve the care of children and youth with medical complexity.

This could be by:

- Creating mechanisms and infrastructure to ensure continuity of care for patients who participate in pilot initiatives and who are experiencing care transitions
- Supporting care providers with ongoing training to facilitate the adoption of innovative technologies and models of care (robust evaluations of new technologies followed by process refinement could help to improve outcomes following technology adoption)
- Implementing alternative payment models for clinicians that factor in activities underestimated in traditional fee-for-service payment models, such as care coordination, chart reviews, and communications with school and home care teams.<sup>24,95</sup>

**The workshop participants, including family caregivers, clinicians, and industry representatives, acknowledged the necessity of pilot programs to assess the feasibility, effectiveness, and safety of new technologies and models of care.**



Top 5 Issues

# Need for Additional Support for Caregivers

Families and other caregivers (e.g., friends, neighbours) provide a substantial amount of care for children and youth with medical complexity, including emotional support, medication and medical device management, care coordination, household support, transportation, and personal care tasks, such as feeding, dressing, and bathing.<sup>96</sup> On average, children and youth with medical complexity in Canada receive 44 hours per week of informal care from family and friends.<sup>3</sup>

However, caregivers often have limited support; their work is time-consuming, underappreciated, and often unpaid.<sup>97</sup> In many countries, including Canada, much of this unpaid care is provided by women.<sup>97-99</sup> Although this gender gap could be due to multiple factors (e.g., attitudes about gender roles), the presence of public care services may be a key factor, and improving the availability of formal services could reduce this gender inequality.<sup>100</sup>



## 2024 Watch List: Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity

### Need for Additional Support for Caregivers

A large proportion of care for children and youth with medical complexity is provided in the community. The implementation of new home care technologies and practices, such as portable dialysis machines and at-home blood draws, has resulted in the handing off of health care tasks and responsibilities that had traditionally been performed in acute care settings by health care providers to family caregivers.<sup>101</sup> These additional responsibilities only add to the large burden already on caregivers, and potentially contribute to issues such as increased stress and poorer quality of life for both children and youth with medical complexity and their caregivers.<sup>102</sup>

During our workshop, caregivers and families highlighted the many challenges they face, including financial burden, stress, fatigue, and social isolation. Participants discussed how siblings of children and youth with medical complexity often miss out on typical childhood experiences and adventures because their parents dedicated so much of their time to providing care.

One caregiver suggested that when caregivers are cared for, the children are better cared for.

Although the workshop participants strongly supported the inclusion of this issue on the 2024 Watch List, family caregivers emphasized that addressing the needs of the caregiver is secondary to addressing the needs of children and youth.

Family caregivers of children and youth with complex health needs often feel unable to prioritize their own health due to lack of time and energy. Even if they are aware they should attend health checks, they prioritize caring for their child.<sup>103</sup> This can lead to caregivers skipping medical appointments and developing frequent and/or serious physical and mental health issues.<sup>97</sup> There is a need to provide multifaceted support to caregivers, including psychosocial, physical, financial, and mental health support, to give them time and energy to provide better care for their children and themselves. Examples of the types of support and services that could help address the needs of caregivers include:

- Respite care services: Caregivers need better in-home respite care in which health care professionals come to their home to take over caregiver responsibilities. These services provide caregivers with temporary relief, allowing them to attend to their personal needs, take time for themselves, and rest and recharge. However, there is currently a shortage of staff available to provide respite care, especially those trained to work with children and youth with medical complexity.<sup>18</sup> Some families may not qualify unless their child meets specific criteria, such as uses multiple medical technologies.<sup>3</sup> Increasing the availability of respite care may reduce caregiver burnout and improve their physical and mental health.

Participants discussed how siblings of children and youth with medical complexity often miss out on typical childhood experiences and adventures because their parents dedicated so much of their time to providing care.

Family caregivers of children and youth with complex health needs often feel unable to prioritize their own health due to lack of time and energy. Even if they are aware they should attend health checks, they prioritize caring for their child.<sup>103</sup>

## 2024 Watch List: Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity

## Need for Additional Support for Caregivers

- Financial support or compensation: Due to the significant demands of caring for a child or youth with medical complexity, 1 parent may leave the workforce to focus on providing care for their child.<sup>3</sup> Formalizing the role of caregivers could help to address related challenges. For example, in some parts of the US, caregivers can receive training to become certified as care providers (e.g., as nursing assistants) and can then be hired by home care agencies to be paid for providing care to their child.<sup>104</sup>
- Mental health and emotional support: Caregivers often experience high emotional stress, fatigue, and social isolation.<sup>56,57,105</sup> Access to mental health and emotional support, such as counselling services and peer support programs, could help to alleviate these challenges. We discuss this in greater detail in the Mental Health Support for Caregivers section.
- Care coordination and navigation services: Professional help with care coordination and system navigation could help to alleviate responsibilities and burden on caregivers.
- Informational support: The workshop participants, including caregivers and families, described the role that informational support could have in empowering families to make decisions that are informed with reliable information rather than relying on internet searches. Providing caregivers access to formal training in managing new technologies (e.g., home care medical devices) could increase their adoption and diffusion.
- Practical support: Assistance with home maintenance, shopping, and cooking could help caregivers balance their many responsibilities more effectively. For example, in New Zealand, eligible families (with a child who has a disability or long-term impairment) can receive help with household management, including cleaning, laundry, and meal preparation.<sup>106</sup>

The workshop participants suggested that supports for caregivers should be implemented with careful consideration for equity to ensure these resources are available and accessible to all.

**Family caregivers emphasized that addressing the needs of the caregiver is secondary to addressing the needs of children and youth.**



## Final Thoughts

The items on the 2024 Watch List were selected by people with lived experience caring for or have themselves been children or youth with medical complexity. The technologies and issues are intertwined and require systems-level planning to improve care and avoid unintended consequences.

Adding technologies without improving communication and interoperability, for example, could create additional burden on families as they troubleshoot and adapt to an additional set of data to relay to health care providers. Homes of children and youth with medical complexity already contain medical devices and are places where health care is delivered.

Family caregivers provide unpaid health care to their children, often foregoing employment and their own personal development. Prioritizing improved experiences for children and youth with medical complexity and their families was underscored throughout the process of selecting the Watch List as not only beneficial for patients but for the health system as well. Professional health care providers, researchers, policy-makers, industry representatives, and family caregivers alike highlighted the potential of the items on the Watch List to improve health care services for children and youth with medical complexity in Canada.



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## Advisory Group

CADTH is grateful to the Advisory Group for the 2024 Watch List. They provided project oversight, suggested considerations about items to include, helped refine the short list, and reviewed earlier versions of the draft report.

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## **Workshop Participants**

CADTH is grateful to the workshop participants for giving their time, sharing their expertise and experiences, and selecting the final items included in the 2024 Watch List. Their participation, insights, and willingness to collaborate were integral to forming the list. Participants were generous with their stories and their time – we thank you for your collaboration and expertise.

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## 2024 Watch List: Top 10 Technologies and Issues Related to Caring for Children and Youth with Medical Complexity

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## Conflicts of Interest

Advisory group members declared the following conflicts: Jacqui Cameron has received fees from 2 health technology assessment agencies and 1 assistive medical technology registry group; Abby McFee is employed by British Columbia's Ministry of Health; Laura Williams received speaking and consulting fees from 1 academic society and is the spouse of the CEO of CureGRIN (a patient advocacy organization).

Workshop participants declared the following conflicts: 1 participant has participated in a research study for children dependent on technology and spoke at an event regarding the care of children with medical complexity (no fees received); 1 participant is employed by a pharmaceutical company, has previously been employed by another pharmaceutical company, and is a board member of a professional medical research association; 1 participant is working with an advisory group for rare diseases; 1 participant has received fees related to research projects related to medical complexity and rare diseases, publishes research related to medical complexity, and volunteers on committees related to medical complexity; 1 participant is employed at a university as a research partner on projects related to medical complexity, has received funding to present research at conferences, and serves on a complex care committee (no fees received).

# Appendix I: Approach

Note that this appendix has not been copy-edited.

## Project Overview

### Advisory Group

An advisory group external to CADTH guided this project. In July 2023, we invited 6 experts to participate as members of the Advisory Group; these experts had diverse perspectives and expertise in: patient experience, care pathways, and the social and legal issues related to children and youth with medical complexity. Additionally, they had diverse expertise related to awareness of emerging technologies and issues facing health care systems in Canada. The Advisory Group assisted with refining the project scope including reviewing project definitions, proposed items for the initial list, reviewed the content of the draft report, and suggested potential participants for the workshop. One member of the group also attended the workshop as an observer. All members participated in at least 2 advisory group meetings and were offered an honorarium.

### Project Scope and Definitions

We drafted definitions to assist with project scope and clarity. We revised definitions based on the feedback of the Advisory Group to ensure accuracy and relevance to the topic of children and youth with medical complexity and the purpose of the 2024 Watch List. Definitions are presented in Table 1.

Table 1

## Definitions Used for Project Scope

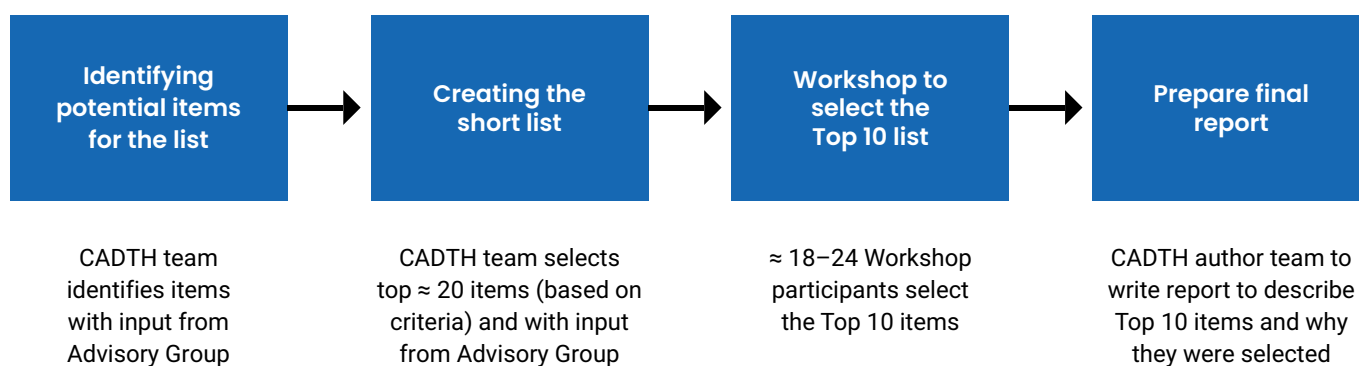
Term	Definition used by project
<p><b>Children and youth with medical complexity</b></p>	<p>Children and youth ages 0 to 24 who live with complex chronic conditions and functional limitations, have a high need for health care across settings and services, and a high need for caregiving from informal carers and family.</p> <p>Note: There is no standard definition for the children and youth with medical complexity population. To operationalize this work CADTH has adopted the CIHI definition from 2018 and changed it slightly to use language that is more patient centred. CIHI definition is: “most of these children and youth share 4 characteristics: complex chronic conditions, functional limitations, high health care utilization and a high need for caregiving.” CADTH has changed high health care utilization to high need for health care across settings and services.</p>
<p><b>Care for children and youth with medical complexity</b></p>	<p>Health technologies (any medical devices and diagnostic tests, but not technologies defined as drugs by Health Canada) used in the pathway of care (e.g., screening, diagnosis, treatment, rehabilitation, prognosis) either specifically or primarily, but not necessarily exclusively for children and youth with medical complexity.</p>
<p><b>Health technology</b></p>	<p>Any medical device or diagnostic test; any medical, surgical, or dental procedure; any other non-drug clinical intervention; or model of care. Drugs or technologies defined as drugs by Health Canada (such as most stem cell products) are not in scope for the list. Technologies without direct patient- or caregiver-related outcomes (e.g., building design, care provider training programs) are excluded.</p>
<p><b>New or emerging health technologies</b></p>	<p>Health technologies that are not yet available in Canada or have been available for clinical use for 1 to 2 years with limited use and are in the launch or early post-marketing stage. It may also refer to technologies available in Canada but with diffusion or availability limited to a few health care facilities or centres. An existing technology with new indications could also be considered new or emerging.</p>
<p><b>Issue relating to the care of children and youth with medical complexity</b></p>	<p>Broader considerations (e.g., clinical, health systems planning, social, ethical, legal, or regulatory) that crosscut the provision and delivery of care for children and youth with medical complexity and could impact how such care and related technologies are developed, adopted, or implemented in Canadian health systems.</p>

## Key Steps

The key steps in developing the 2024 Watch List are briefly described in Figure 1.

Figure 1

## Key Steps Used to Develop the 2024 Watch List



### Step 1: Identifying Items for the Long List

The purpose of the 2024 Watch List development process was to identify and describe new and emerging technologies and issues related to children and youth with medical complexity with the potential to have a substantial impact on health care delivery and planning in Canada in the next 5 years. This impact includes significant and meaningful changes in health and human resources, locations and pathways of health care delivery, patient experiences and outcomes, and health care equity and access. We selected these areas of change because of their relevance to health care policy and planning, including supporting system readiness to adopt and implement precision medicine technologies. We chose a time frame of 5 years to identify technologies that were further along the research phase or have the potential to see greater adoption in Canada or similar health care contexts. This time period was intended to limit technologies that are in early development phase where their potential value proposition remain largely uncertain, or they are not likely to see substantial adoption outside of limited research settings. Similarly, the 5-year time period for identifying issues provides an opportunity for health care decision-makers to make changes that can guide health systems planning at various levels of health care delivery.

We defined “significant and meaningful change” as that which would require the addition of substantial or new types of resources, new policies, new procedures, and reorganization or transformations in health systems to successfully adopt, implement, or diffuse technologies.



We identified these domains using information from other CADTH products and processes, the INHATA position statement on disruptive technologies,<sup>107</sup> CADTH’s Strategic Plan,<sup>108</sup> and CADTH customer needs. We identified relevant and common criteria across these documents to build domains with prompts and key items that included health system, health care facility, and patient-level issues. We circulated and discussed these draft criteria with the Advisory Group, who provided input that enabled additional refinement. The final domains and considerations used to select the technologies and issues for the 2024 Watch List are presented in Table 2.

Table 2

## Criteria for Selecting Items for the Long List

Domains	Area of significant and meaningful change
<b>Patients’ and caregivers’ experiences and outcomes</b>	<ul style="list-style-type: none"> <li>• Patients’ and caregivers’ experiences of delivery of care, e.g., changes in the location of care (need to travel), setting of care (primary vs. specialist care), changes in the pathway of care (e.g., new screening or rehabilitation)</li> <li>• Addressing an unmet need (e.g., rare diseases, patients’ who currently have no or limited treatment options)</li> <li>• Patients’ outcomes (clinical benefits, harms, safety)</li> <li>• Changes in how patients are cared for (e.g., less invasive, quicker recovery), and who cares for patients (changes in responsibility/involvement/burden of informal caregivers)</li> <li>• Patient outcomes (e.g., clinical benefits, autonomy, quality of life, harms, safety)</li> <li>• Caregivers’ outcomes (e.g., quality of life, mental well-being).</li> </ul>
<b>Health care delivery and organization</b>	<ul style="list-style-type: none"> <li>• The pathway of care or treatment</li> <li>• Location or site of care (e.g., point of care, virtual care)</li> </ul>
<b>Health and human resources</b>	<ul style="list-style-type: none"> <li>• The need for more, or less, staffing</li> <li>• The need for new roles or positions</li> <li>• The ability to use staff of a different level of training or qualifications</li> <li>• The need for ancillary equipment (e.g., smart devices, imaging, specimen storage), additional facilities, data storage, and information technology infrastructure</li> </ul>
<b>Health equity and access</b>	<ul style="list-style-type: none"> <li>• Who can and who cannot access care and in what setting (access includes accessibility, availability, and acceptability)</li> <li>• Whether the technology can be used to address or exacerbate inequalities in geographic access to care</li> <li>• Whether the technology addresses or exacerbates health inequities</li> </ul>

We used the criteria in Table 2 to identify items by asking:

Does the technology (either as a discrete technology or as a category or type of technologies) have a value proposition (i.e., what it is intended to do, what its proposed benefits are) that is anticipated or positioned to make a significant or meaningful change in 1 or more of the criteria in Table 2?

Is the issue anticipated or positioned to contribute to a significant or meaningful change in 1 or more of the criteria in Table 2 and/or does it affect the ability for the value proposition of the technology to be realized by patients, caregivers, clinicians, or health systems?

To identify and add a technology to the draft list, the author team reviewed published research, editorials and commentaries, and grey literature (e.g., from market news, blogs, websites, start-ups, venture capitalists). We used the criteria in Table 2 to screen the information sources for eligible and relevant technologies and issues. We compiled information on potential issues and technologies electronically and included the name and a basic description of the technology or issue, its benefit or consequences to patients, caregivers, clinicians, health systems, payers, and the criteria for its inclusion. We drafted the extraction table a priori based on the selection criteria, piloted it between 2 authors, and revised the items for consistency and clarity. We met weekly to discuss findings, identify issues and trends in their observations, and note areas of consistency and discrepancies.

## **Step 2: Short Listing Items for the Watch List**

Once there were approximately 20 items, we individually reviewed the full list of identified items by reflecting on the project scope, definitions, and selection criteria. We discussed the items further to refine definitions of items, and the collapsing, separation, and removal of some items. We shared the draft list with the Advisory Group for validation and assessment of credibility (member checking). Based on the written and oral input of the Advisory Group, we added, removed, and modified items on the draft short list to create the final draft list for Step 3. The final draft list included 9 technologies (Appendix 2 outlines the 4 items that were not selected for the final list) and 9 issues (Appendix 3 outlines the 4 items that were not selected for the final list).

## **Step 3: Workshop to Select the Top 10 Technologies and Issues for the 2024 Watch List**

We used the principles of the James Lind Alliance (JLA) Priority-Setting Partnerships (PSP) to guide the workshop and select the top 10 items for the 2024 Watch List. The James Lind Alliance's principles align with CADTH's priorities of equal involvement and inclusivity (e.g., balanced representation from patients, clinicians, and other CADTH stakeholders), transparency (e.g., visible audit trail of submitted technologies and trends), and a commitment to using and contributing to the evidence base (e.g., using technologies and trends to inform future CADTH products).

## **Identifying and Recruiting Workshop Participants**

We identified potential workshop participants through project scoping, the literature review, and through CADTH networks. On August 1, 2023, an open call on the CADTH website inviting statements of interest in the project was circulated in CADTH's social and professional networks, and through the Advisory Group's recommendations. We invited individuals from a range of geographical settings (i.e., jurisdictions in Canada), and who had a variety of professional experiences and expertise such as clinicians and health care providers, patients and carers with relevant lived experiences, funders, payers, health systems decision-makers, and industry representatives. At least 1 member from each type of expertise was invited to participate in the workshop, recognizing that participants often represented more than 1 category (e.g., academia and clinical). CADTH recognizes the importance of diversity, equity and inclusion, and the composition of the expert panel took these considerations into account. An invitation was sent to potential participants which described the purpose of the workshop and their role, and recruitment continued until 20 participants were confirmed for the half-day workshop.

## **Engagement With Indigenous Peoples and Organizations**

CADTH recognizes the sovereignty and jurisdiction of First Nations, and Metis people and Inuit over child, family, and community well-being. We understand that Indigenous Peoples' experiences, values, needs, and priorities are important for understanding and improving care for children and youth with medical complexity and informing decision-making as many barriers exist to accessing necessary technologies, as demonstrated by the creation and implementation of Jordan's Principle. In conjunction with CADTH's Strategic Partner, Inclusion, Equity, Diversity and Accessibility, CADTH is currently fostering relationships with Indigenous Peoples and organizations. Without adequate time to develop respectful and meaningful relationships with Indigenous Peoples to inform this work, CADTH is aware that any attempt to reflect Indigenous Knowledges and voices would not be culturally appropriate or safe and could further perpetuate harm. CADTH acknowledges the lack of engagement and inclusion of Indigenous perspectives and voices as a major limitation and gap. In line with CADTH's commitment to Reconciliation, CADTH is developing relationships and engaging with Indigenous partners to explore the importance of this topic and future CADTH work in this area, which would involve the development of a strengths-based approach and process to conduct the work respectfully and rigorously.

## **The Half-Day Workshop to Select the Top 10 Technologies and Issues**

Prior to the workshop, we provided participants with a workshop guide, the 18-item list with summaries about each technology and issue, and a participant worksheet. Before attending the workshop, participants were asked to individually review and rank the technologies and issues in the list using the participant worksheet.

The half-day workshop took place virtually on November 6, 2023. From the 20 registered participants, 3 were unable to attend; the remaining 17 participants worked together to identify and prioritize the top 10 items from the list of 18 items (Appendices 1 and 2). Workshop participants were located in diverse geographic settings including Alberta (5 participants), British Columbia (2 participants), Manitoba (1 participant), New Brunswick

(1 participant), Nova Scotia (1 participant), Ontario (4 participants), Quebec (1 participant), Saskatchewan (1 participant), and the US (1 participant), and represented many points of views, including clinicians and health care providers, families and caregivers with relevant lived experiences, health systems decision-makers, and industry. Three CADTH team members, including 1 person who is an advisor with the JLA, facilitated the workshop sessions to ensure that all participants were actively included in the discussion and JLA's principle of equal involvement was upheld. Additionally, 5 CADTH team members participated to provide support or to take notes. An emotional support designate was also present to observe and offer support if any of the participants became distressed during the workshop.

The workshop had 2 parts. In the first part, participants were separated into 3 smaller groups, and shared their perspectives and individual rankings of the items in depth. In the second part, a group session was held with all participants, who worked together through a facilitated discussion to select the top 5 technologies and top 5 issues; these 10 items were not ranked. We chose to select 5 technologies and 5 issues for total of 10 for consistency in process and ease in communication. These 10 items formed the 2024 Watch List.

#### **Step 4: Preparing the Final Report**

We prepared a draft of the final report describing each of the top 10 technologies and issues, their impact on health systems, and examples of the technologies or developments on the issue. The descriptions and examples provided in the report used published literature identified during development of the initial list, additional targeted internet searches, and information described or raised during the workshop. A draft version of the report was shared with the Advisory Group and was revised based on their input.

## Appendix 2: List of Technologies Not Included in the Watch List

Note that this appendix has not been copy-edited.

Table 3

### List of Technologies Not Included in the Watch List

Technology (category or intervention)	Description	Insights from the workshop
<p><b>Home care technologies</b></p>	<p>As more care is provided at home, often by informal caregivers, new devices and mobile health apps are being developed to facilitate care outside of health institutions. Examples include:</p> <ul style="list-style-type: none"> <li>• Smart stethoscopes for patients (or their caregiver) to assess their heart and/or lungs at home for remote monitoring</li> <li>• Devices for collecting blood samples</li> <li>• Devices that allow for enhanced virtual visits: patients have the devices in their homes so their health care provider can visualize their skin, throat, and ears, assess their heart and lungs, and so on.</li> <li>• Apps to assist with tracking, such as managing medication or tracking meals (e.g., for patients with specific dietary needs, or multiple medications).</li> </ul>	<p>Participants at the workshop expressed that there are many home technologies – both for intermittent and continuous monitoring – that could be important for children and youth with medical complexity. There are often long wait times to receive specialized equipment and technologies. Clinicians and caregivers alike expressed that some home care technologies improve access and equity and reduce the need for long travel for care.</p> <p>Conversely, some participants expressed not wanting to further increase medical care responsibilities for caregivers. Additionally, it was pointed out that some of the home monitors currently available are not sensitive enough for certain structural abnormalities or do not fit on all bodies, highlighting opportunities for innovation.</p>
<p><b>Robotic and wearable devices for function and mobility</b></p>	<p>Robotic devices that are designed for either rehabilitation purposes (retraining muscles) or as an assistive device (helping in activities of daily living, such as communication or mobility). These devices can be worn like a garment and are designed to be easy to don and off and usually lightweight.</p>	<p>Most participants at the workshop expressed that there seems to be promise and opportunity in these types of technologies for children and youth with certain conditions and disorders but not for others. There are some technologies that seem on the cusp of 'readiness' for children and youth with medical complexity and could improve their autonomy. It was highlighted that the patient and caregiver support with these technologies would be required.</p>

Technology (category or intervention)	Description	Insights from the workshop
<p><b>3D printing</b></p>	<p>Process of producing three-dimensional (3D) objects based on a 3D model or digital file. 3D printing can produce objects that are customized to a patient’s specific needs and can be cheaper than conventional production processes. Advances in 3D printing may allow for new, tailored methods of treatment, such as:</p> <ul style="list-style-type: none"> <li>• Preoperative planning. Printing a model based on a patient’s imaging scan(s) allows for personalized planning based on the child’s specific issues and needs, helping decide on the optimal approach, as well as anticipate and plan for potential issues.</li> <li>• Custom prostheses. This may be especially useful for children with complex and unique health conditions whose needs may not be met by conventional prostheses and will be useful as children and youth grow and change over time.</li> <li>• Medication printing. Custom-designed medication can be printed for treating rare diseases, or multiple diseases in a single pill (rather than requiring multiple different pills). It can also produce medications with specific doses tailored to the patient.</li> </ul>	<p>Participants at the workshop were intrigued by this item and recognized that this item had potential – particularly for those who take multiple drugs. There was the recognition that there is investment and innovation interest and potential in this area. The issue of how to ensure the safety of 3D printed medication was raised by participants with multiple perspectives.</p>

Technology (category or intervention)	Description	Insights from the workshop
<p><b>Virtual reality</b></p>	<p>In virtual reality, users wear goggles or headsets to immerse themselves in a simulated environment and can interact with it using specialized equipment.</p> <p>Virtual reality is being tested and used as a therapeutic intervention to help manage pain or anxiety. For example, children and youth with medical complexity may frequently require procedures that are stressful or painful, such as blood draws or injections.</p> <p>In addition, virtual reality can be used to train health care providers with limited experience treating children and youth with medical complexity, such as through:</p> <ul style="list-style-type: none"> <li>• Training health care providers; e.g., providing training based in realistic scenarios</li> <li>• Virtual surgical planning; e.g., simulating the procedure based on a patient’s unique characteristics. This may be especially useful for patients who present unfamiliar cases to the surgical team (e.g., very young, rare and/or complex conditions).</li> </ul>	<p>For use in training health care providers who are treating structural abnormalities that they do not have experience with, VR was seen as something with a lot of potential. However, the primary conversations related to VR centred around its use in the home and with distraction/therapeutic intervention related to pain and anxiety associated with treatments and procedures and with mental health in general.</p>

## Appendix 3: List of Issues Not Included in the Watch List

Note that this appendix has not been copy-edited.

Table 4

### List of Issues Not Included in the Watch List

Issue	Description	Insights from the workshop
<p><b>Need for increased research collaboration</b></p>	<p>Children and youth with medical complexity make up a relatively small proportion of patients which can make it complicated to undertake research that meets their needs (e.g., small number of patients can mean difficulty recruiting for trials). Collaborating between different stakeholders can help to share information and resources, generate research ideas, develop collaborative solutions, improve efficiencies, and increase impact. For example, families of children and youth with medical complexity have expertise related to their child that is complementary to researchers’ and health care professionals’ knowledge and can contribute significantly to the development of new technologies, educational materials, and policy decisions. Similarly, clinicians can provide knowledge and insights that elevate research, device development, and policy decisions.</p> <p>Increased collaboration could be especially beneficial in the development of new technologies for children and youth with medical complexity with very rare diseases.</p>	<p>Participants in the workshop spoke about collaboration between researchers as happening – they expressed that while more is always a good thing, this was likely not the highest priority item. The need for more collaboration regarding the transition from childhood to adulthood and from the pediatric to adult health care services is needed.</p>
<p><b>Paying out-of-pocket for new technologies</b></p>	<p>Patients may only be able to access technologies through out-of-pocket payment or private insurance. This may include technologies for rare conditions or symptoms, or devices that are being used off-label.</p>	<p>A need for a pan-Canadian effort to fund new technologies for children and youth for medical complexity was expressed by some participants in the workshop. The need to pay out-of-pocket for technologies to be used for this group of children and youth at home was described as not making sense – they are required; those same or similar technologies would be paid for by the health care systems if they were used in the hospital; and this is a population with high technology needs.</p>



Issue	Description	Insights from the workshop
<p><b>Challenges in bringing new pediatric technologies to market</b></p>	<p>Because Canada has a relatively small population, companies that manufacture devices might experience a limited return on investment bringing technologies to market here. This problem is exacerbated when creating and bringing to market new technologies for children as they are only a small fraction of an already limited population.</p> <p>Existing regulatory, health technology assessment (HTA) and/or reimbursement processes may inadvertently hinder the availability of new technologies for children and youth with medical complexity in Canada. For example, compared to adults, children and youth with medical complexity are a smaller and more heterogeneous population (e.g., there is no single diagnosis or prognosis; children and youth grow over time and their needs change). This heterogeneity can make it difficult to conduct clinical trials which often precede a technology's regulatory approval and reimbursement.</p>	<p>While this item was indeed confirmed as important, it was expressed that the regulatory processes are clear and that the current initiatives toward agile regulation should help improve the length of time it takes for a technology to be approved. One of the core issues identified was that the evidence in this clinical area is less mature and dealing with heterogeneity with immature evidence is more challenging. The smaller population was identified as a challenge in funding innovation and evidence generation in this area.</p>
<p><b>Needed improvements in dental care</b></p>	<p>Children and youth with medical complexity are more likely to develop dental health issues than children without medical complexity. In addition, subspecialist dentists who treat complex pediatric patients are rare. Furthermore, children and youth with medical complexity might have specific health issues and/or medications which complicate certain dental procedures. Finally, these children and youth sometimes have sensory sensitivities or preferences which make the provision of dental care very unpleasant for them resulting in a refusal of care.</p>	<p>Improvements in dental care for children and youth with medical complexity was described as an important issue in many but not all geographic areas in Canada. Caregivers expressed that this is an ongoing stress in their lives; pediatric dentistry tends to end at the age of 16 and there is a need for transitional support to adult dental clinics and care. This was described as an area that does not benefit as much from virtual care and that tends to have disjointed care – with many dentists rotating through care instead of a consistent dental provider. The need for sedation and sedation as a bottleneck was also identified as an issue. Some participants hoped that the new federal dental care funding would start to improve issues in dental care for children and youth with medical complexity.</p>

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