HEARTWISE FOUNDATION

YOUTH HEART HEALTH OBSERVATORY

UNDERSTAND

CANADA 2026

What Canada knows, and does not yet know, about the cardiovascular health of its young people.

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ABOUT THE OBSERVATORY

The HeartWise Youth Heart Health Observatory is an evidence-review project of HeartWise Foundation, a registered Canadian nonprofit and youth-led organization focused on cardiovascular health among people 30 and under. The Observatory exists to answer a narrower and more useful question than "is there a crisis": what does Canada actually know about the cardiovascular health of its young people, and where does that knowledge run out.

An observatory, in the sense used here, is not a laboratory and not an advocacy campaign. It is a structured review of the best available Canadian evidence, organized so that health authorities, clinicians, researchers, school systems, funders, and young people themselves can see the same picture. Where good evidence exists, the Observatory reports it, with its population, geography, and age range intact. Where evidence is thin, contradictory, or simply absent, the Observatory says so directly, using a defined confidence framework rather than filling the space with assumption.

This pilot examined seven questions: whether Canada can measure youth cardiovascular health at all; how it tries to detect problems before they become emergencies; whether geography changes a young person's path to specialty care; what can be reliably said about First Nations, Inuit, and Métis youth; what happens to continuity of care as people with congenital heart disease move from pediatric to adult systems; how prepared Canadian environments are to respond when a young heart stops; and where Canada already has practices worth watching.

The Observatory does not conduct primary clinical research. It does not diagnose, treat, or offer individual medical guidance. It does not claim to speak for any community, including Indigenous communities, whose own data governance and leadership must guide any conclusions about their health. What it offers instead is a disciplined accounting: what is known, what is uncertain, and what Canada cannot yet see clearly when it comes to the hearts of its young people.

LETTER FROM HEARTWISE

We started this Observatory with a question that seemed like it should have a straightforward answer: what do we actually know about cardiovascular health among young people in Canada.

It does not have a straightforward answer. That, on its own, became one of the more useful things this pilot found.

HeartWise is a registered Canadian nonprofit and youth-led organization built around youth heart health education and evidence, through work like our #KnowYourMurmur course and this Observatory itself. Building this pilot meant reading through the Canadian evidence base directly, and the same gap kept surfacing. National statistics about heart disease describe adults. Pediatric data stop at childhood. Screening guidance is written for competitive athletes, not for the wider population of young people living ordinary lives. Somewhere between the end of pediatrics and the start of adult cardiology, a lot of what Canada could know about its youngest hearts simply is not being asked, or is being asked in ways that cannot be compared across the country.

We want to be precise about what this report is and is not. It is not a discovery of a hidden epidemic. The strongest evidence we reviewed does not support that claim, and we are not going to make it. What we found instead is closer to a visibility problem: real infrastructure, real expertise, and real pockets of strong practice across Canadian cardiology, sitting alongside surveillance systems, registries, and policies that were not built with a coherent youth population in mind. In some places, such as the guidance against blanket ECG screening of young athletes, Canada has made a deliberate, evidence-informed choice within a debate that remains unresolved internationally. In others, such as what happens to a young person's cardiac follow-up in the years after their eighteenth birthday, or what is reliably known about First Nations, Inuit, and Métis youth heart health, the evidence runs out sooner than we expected.

This is a pilot. We are publishing it because we think the questions themselves, and the honest state of the answers, are useful to health authorities, clinicians, school systems, and other organizations working in this space, even before every question has a full answer. We expect to revise our approach as we learn where this Observatory model works and where it needs to change.

We are grateful to the researchers, clinicians, and Indigenous-led organizations whose published work made this review possible, and we recognize that the most important gaps we identified, particularly around Indigenous youth cardiovascular health, are not ours to close. That work belongs with Indigenous leadership, on Indigenous terms.

Misha Panesar

Founder & President, HeartWise Foundation

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What we investigated

The Observatory reviewed published Canadian evidence across seven questions concerning cardiovascular health in people roughly 12 to 29 years old: whether Canada can measure youth cardiovascular health as a coherent whole; how the country approaches detection of cardiovascular problems before a serious event; whether geography changes access to cardiac assessment and specialty care; what can be reliably established about cardiovascular health among First Nations, Inuit, and Métis young people; what happens to continuity of cardiac care as people with congenital heart disease move from pediatric to adult systems; how prepared Canadian schools and public spaces are to respond to sudden cardiac arrest; and where Canada already has practices worth watching.

Wherever a source reported a narrower or different age band than 12 to 29, such as 15 to 24, 18 to 45, or 16 and older, that age band was preserved rather than relabelled as "youth." Where age bands across sources could not be reconciled, that incompatibility is reported as a finding in its own right.

The central picture

Canada has substantial cardiovascular expertise, established surveillance infrastructure for heart disease in general, and specific examples of strong clinical and research practice relevant to young people. What the Observatory could not identify is a single, coherent, youth-specific picture of cardiovascular health assembled from routine national data.

This is not because Canada collects no relevant information. Pediatric cardiology data exist. Congenital heart disease has been studied in detail, particularly through work based in Quebec. Inherited arrhythmia and cardiomyopathy patients are followed through a dedicated national research registry. Sudden cardiac arrest is now tracked through a purpose-built multi-province surveillance network. The problem is that these systems were built around different conditions, different age bands, and different provinces, and they were not designed to be combined into one youth-specific view. National chronic disease surveillance for heart disease is structured around adults; the newest usable national index of youth cardiovascular health the Observatory could identify is now roughly fifteen years old; and the strongest congenital heart disease prevalence estimate available describes one province, not the country.

The result is a measurement and integration gap rather than a demonstrated crisis. Where Canada has made a deliberate choice, such as recommending against blanket ECG screening of competitive athletes, the Observatory treats that as a considered position within an ongoing, unresolved international debate, not as a failure and not as a validated best approach. Where the evidence itself runs out, particularly for Indigenous youth cardiovascular outcomes and for nationally comparable specialty-access data, the Observatory reports that directly rather than filling the space with inference.

Final Observatory Findings

Six findings survived this Observatory's evidence test. Each states what was observed, why it matters, and how confident the underlying evidence is.

01

OBSERVATORY FINDING

The youth cardiovascular picture is fragmented, not absent

Canada's routine cardiovascular surveillance systems do not currently combine into a single, coherent, youth-specific picture across the roughly 12 to 29 age range. Useful pediatric and condition-specific data exist, but they sit in separate systems built around different age bands, provinces, and conditions.

WHAT WE OBSERVED

National chronic disease surveillance for heart disease is organized primarily around adults aged 20 and older.[1] Congenital heart disease, the best-documented youth-relevant condition, has its strongest lifetime prevalence estimate from a single-province registry.[3] Inherited arrhythmia and cardiomyopathy data are held in a dedicated national research registry rather than routine public health surveillance.[5] The most recent national index attempting to summarize youth cardiovascular health broadly is based on data collected in 2009 and 2010.[6]

WHY IT MATTERS

Without a combined view, it is difficult for health authorities, funders, or researchers to know whether youth cardiovascular health in Canada is improving, worsening, or holding steady, or to identify which conditions and populations most need attention.

EVIDENCE CONFIDENCE · **MODERATE.**

02

OBSERVATORY FINDING

Canada has adopted a deliberate, evidence-informed position within an unresolved international debate

Canadian cardiology guidance recommends a tiered history-and-physical approach to cardiovascular screening of competitive athletes and recommends against routine, blanket, first-line 12-lead ECG screening as the initial strategy. This reflects a specific, considered position, not an absence of screening or an oversight, and it sits inside a live international disagreement this Observatory did not find evidence to resolve.

WHAT WE OBSERVED

The joint 2018 and 2019 position statement from the Canadian Cardiovascular Society and Canadian Heart Rhythm Society sets out this approach.[7] It sits within an international debate that remains unsettled: some European and Italian screening programs favour ECG as a first-line tool. Ontario evidence on sudden cardiac arrest during competitive sport, drawn from ages 12 to 45, found the event to be uncommon.[8] ECG can detect some conditions that a history and physical examination would miss, but detecting more abnormalities is not the same as demonstrating that a screening strategy reduces population-level sudden cardiac death, and recent research in this area has continued to sharpen ECG's diagnostic performance without settling that harder, population-level question.

WHY IT MATTERS

Readers should not interpret the absence of mandatory ECG screening in Canada as a gap in care, nor should they assume the Canadian approach is unquestionably correct. Both are live positions internationally, and this Observatory did not identify evidence resolving that debate.

EVIDENCE CONFIDENCE · **HIGH on what current Canadian guidance says; MODERATE on how the underlying international debate will ultimately resolve.**

03

OBSERVATORY FINDING

Cardiac follow-up can break down around the transition to adulthood

Continuity of cardiology follow-up for people with congenital heart disease can and does break down around the transition from pediatric to adult care, and the strongest available Canadian evidence for this comes from a single-province birth cohort with real limitations. Canadian intervention evidence, however, suggests this discontinuity is at least partly modifiable.

WHAT WE OBSERVED

A Quebec cohort of people born with congenital heart disease in 1983 found that 61 percent had not received cardiology follow-up in the years after their eighteenth birthday, and that even among those with the most severe lesions, only 79 percent had been seen by a cardiologist after turning 18.[19] A systematic review of the international literature estimated loss to follow-up among congenital heart disease patients worldwide at roughly 26 percent.[20] A separate meta-analysis found this varies significantly by geography, with country-level estimates of 34.0 percent in the United States, 25.7 percent in Canada, and 6.5 percent in Europe, and found that patients who had gone through a structured transition program had a substantially lower rate of discontinuity (12.7 percent) than those who received usual care (36.2 percent).[21] A Canadian randomized trial of a structured, nurse-led transition intervention found that adolescents who received it were 1.8 times more likely than those who received usual care to have their first adult cardiology appointment within one month of the clinically recommended time.[22]

WHY IT MATTERS

This is one of the more actionable findings in this review. The underlying cohort data are decades old and specific to Quebec, so they should not be read as a current national prevalence figure. But the pattern they describe, discontinuity of care around a major life transition, recurs in more recent and more geographically varied evidence, and Canadian trial evidence points toward a concrete intervention that appears to help.

EVIDENCE CONFIDENCE · **MODERATE to HIGH.**

04

OBSERVATORY FINDING

A coherent Indigenous youth cardiovascular picture could not be identified

This Observatory review did not identify suitable youth-specific cardiovascular outcome estimates for First Nations, Inuit, and Métis populations that could support a coherent national picture. Available evidence is generally adult-focused, risk-factor-focused rather than outcome-focused, or affected by incompatible age bands and geographic coverage exclusions.

WHAT WE OBSERVED

Survey data on youth overweight and obesity, and on smoking, exist for First Nations, Inuit, and Métis youth separately, though age bands vary across surveys (commonly 12 to 17, sometimes 6 to 14 or 12 to 24) and some surveys exclude on-reserve or remote populations by design.[13,14] A regional Nunavik health survey found rising rates of measured elevated blood pressure among Inuit adults, but reported this for people 16 and older as a combined group, not disaggregated for youth specifically.[15] Adult First Nations cardiovascular risk has been estimated at roughly two and a half times that of non-Indigenous Canadians, but this too is an all-age estimate.[16] No comparable youth-specific measured cardiovascular outcome data, such as diagnosed heart conditions or measured blood pressure in a youth-only sample, were identified across all three populations.

WHY IT MATTERS

Without youth-specific outcome data, disaggregated by First Nations, Inuit, and Métis, it is not possible to know whether cardiovascular risk is rising, falling, or stable among Indigenous young people in Canada, or to design services responsive to their actual needs. Closing this gap is not a task for HeartWise to define unilaterally. It requires Indigenous leadership, ownership, and governance of any future data work, consistent with the First Nations principles of OCAP®, the registered trademark of the First Nations Information Governance Centre.[17]

EVIDENCE CONFIDENCE · **HIGH that the gap exists; the underlying risk-factor patterns should be read as LIMITED to MODERATE evidence, not as outcome data.**

05

OBSERVATORY FINDING

Cardiac emergency policy varies across Canadian jurisdictions

Legislative, regulatory, and educational approaches to public-access defibrillation, school AED access, and CPR education vary meaningfully across provinces and territories. This finding concerns policy variation itself; this review does not have the nationwide implementation data needed to say how that variation translates into actual, on-the-ground emergency readiness.

WHAT WE OBSERVED

Some provinces have enacted legislation requiring or funding public-access

defibrillators, in some cases naming schools specifically;[24,25,26] others rely on non-legislated ministry policy, funding programs, or voluntary adoption; and for several jurisdictions, this review could not identify a clear, current, government-sourced policy position at all. British Columbia's Ministry of Education set a target, through a ministerial order and supporting policy, for AEDs and naloxone kits to be accessible in all secondary schools by December 31, 2025, with elementary and middle schools following by September 8, 2026, a date that had not yet arrived as of this Observatory's evidence cutoff.[27] Prince Edward Island has adopted a mandatory CPR and AED curriculum requirement.[28] Enacted legislation, an implementation deadline, and documented on-the-ground implementation are three different things, and this review could confirm the first two more reliably than the third in most jurisdictions.

WHY IT MATTERS

Because provincial and territorial policy approaches differ, the formal requirements surrounding AED access and CPR education depend on jurisdiction. This review could not determine whether those policy differences translate into comparable differences in actual school-level readiness, and it does not attempt to estimate any individual young person's likelihood of encountering a functioning defibrillator.

EVIDENCE CONFIDENCE · **HIGH that policy variation exists; DATA GAP on whether that variation corresponds to differences in actual emergency readiness. The policy matrix in Investigation 6 should be independently reverified before any operational use.**

06

OBSERVATORY FINDING

The best available national youth cardiovascular index is now outdated

The strongest national index of youth cardiovascular health identified in this review, a composite measure of ideal cardiovascular health among Canadians aged 12 to 19, is based on data collected in 2009 and 2010. No more recent comparable national measure was identified.

WHAT WE OBSERVED

That index found that only 16.6 percent of Canadian youth aged 12 to 19 met criteria for ideal cardiovascular health on the measures used, with just under half classified as having poor cardiovascular health on the same composite.[6] Whatever the current state of youth cardiovascular health in Canada actually is, this review found no evidence updating that specific national picture in the fifteen years since.

WHY IT MATTERS

Data age is not a neutral detail. A generation of Canadian youth has grown up since this index was last measured, spanning significant shifts in physical activity patterns, screen use, and the COVID-19 pandemic period. Whether the 2009 to 2010 picture still describes today's youth is simply unknown from this evidence base.

EVIDENCE CONFIDENCE · **MODERATE. The original measurement is credible; the conclusion here concerns its age, not its accuracy at the time.**

Canada at a glance

The following figures are presented with their population, age range, geography, and data year intact. They should not be read as a single unified national youth cardiovascular dashboard, because they measure different things in different populations at different times.

8.21

per 1,000 live births

Congenital heart disease lifetime birth prevalence: 8.21 per 1,000 live births, Quebec, based on data to 2005, published 2014. *Ref. 3*

16.6%

met criteria for ideal cardiovascular health

Ideal cardiovascular health among Canadian youth aged 12 to 19: 16.6 percent, based on 2009 to 2010 data. *Ref. 6*

66%

of the Quebec CHD population are now adults

Adults now make up an estimated 66 percent of the total Quebec congenital heart disease population, as of 2010. *Ref. 3*

0.76

per 100,000 athlete-years

Sudden cardiac arrest during competitive sport, ages 12 to 45: 0.76 per 100,000 athlete-years, Ontario, 2009 to 2014, with 43.8 percent surviving to hospital discharge. *Ref. 8*

61%

no cardiology follow-up after age 18

Failure to receive cardiology follow-up after the eighteenth birthday among a congenital heart disease birth cohort: 61 percent, Quebec, cohort born 1983. *Ref. 19*

~60,000

out-of-hospital cardiac arrests per year (all ages)

All-age national context only: an estimated 60,000 out-of-hospital cardiac arrests occur in Canada annually, with roughly 1 in 10 people surviving, according to a 2024 Heart & Stroke Foundation report drawing on national resuscitation registry evidence.[23] This figure describes all ages, not youth specifically, and an earlier commonly cited estimate of roughly 40,000 reflects changes in data ascertainment over time rather than necessarily a true increase in events.

The Data Gaps

This review identified several specific, well-defined gaps in publicly available Canadian evidence rather than a single generic absence of data. These include the absence of a routinely published, integrated

national surveillance product covering youth cardiovascular health specifically, the absence of a pan-Canadian congenital heart disease registry, the lack of comparable pediatric cardiology and adult congenital heart disease wait-time data across provinces, the absence of youth-specific cardiovascular outcome data for First Nations, Inuit, and Métis populations, the lack of youth-specific sudden cardiac arrest incidence and survival data, and the absence of consolidated national information on school AED presence, maintenance, and readiness. Each is described in full in the Data Gaps Register.

What the evidence points toward

The evidence reviewed here does not support a call for universal youth ECG screening, a ranked scorecard of provincial performance, or firm conclusions about Indigenous youth cardiovascular outcomes. It does support closer attention to continuity of cardiac care around the transition to adulthood, where a concrete Canadian intervention already shows promise; closer attention to the currency and comparability of national youth health surveillance; and a clear, non-extractive starting point for future Indigenous-led work on youth cardiovascular data. These directions are developed further in the sections that follow.

HOW THIS REVIEW WAS CONDUCTED

Methodology

How the Observatory investigated

This Observatory review examined publicly available evidence relevant to cardiovascular health among young people in Canada, organized around seven core questions. It is best described as a structured evidence review, or Observatory review, rather than a formal systematic review in the technical sense, since it did not follow a pre-registered protocol with dual independent screening of every identified record. Where the underlying methodology approaches that standard, such as in the treatment of peer-reviewed congenital heart disease and transition literature, that is noted; where it does not, readers should treat conclusions accordingly.

The primary population of interest was approximately 12 to 29 years old. Wherever an authoritative source reported a different age band, that band was preserved rather than relabelled. Age-band incompatibility across sources is treated as a substantive finding in its own right rather than smoothed over.

Evidence was prioritized in the following order: national Canadian sources first, including federal agencies, national registries, and legislation; provincial and territorial government and health authority sources next; Canadian peer-reviewed research; recognized professional body guidance; and international evidence only where Canadian evidence was insufficient or where a labelled international comparison had genuine analytical value. United States or other international statistics are never presented as though they describe Canada.

Within Canadian and international peer-reviewed literature, priority was given to systematic reviews, meta-analyses, large registry studies, and Canadian cohort studies. Recent evidence, generally from 2021 through 2026, was prioritized for surveillance statistics and descriptions of current systems, while

older foundational studies were retained where they remain the best available evidence and have not been superseded. Where the newest usable Canadian statistic was unexpectedly old, that is stated explicitly rather than presented as current.

For statistics considered important enough for the Master Statistics Ledger, this review tracked the exact statistic, its metric definition, the population and age range it describes, its geography, its measurement and publication years, its original source, and known limitations, and attempted to verify it against a second authoritative source referring to the same underlying evidence where reasonably possible. Two sources repeating the same original figure were not treated as independent confirmation. Search-result summaries were not treated as evidence in themselves; underlying sources were examined directly. No citation, statistic, dataset, policy, or law referenced in this report was fabricated; where something could not be verified to a reasonable standard, it was excluded from the findings rather than included with a caveat.

Where credible evidence conflicted, this review documented what differed between the studies, including differences in geography, age band, definition, and evidence quality, rather than selecting whichever result made a stronger claim. Causal language such as "causes" or "leads to" is used only where the underlying evidence supports a causal conclusion; elsewhere, this report uses language such as "associated with," "linked to," or "observed among."

Evidence confidence framework

Each major finding in this report is assigned one of four confidence levels:

HIGH CONFIDENCE. Strong national or Canadian evidence, or multiple high-quality sources in substantial agreement.

MODERATE CONFIDENCE. Evidence generally points in a consistent direction, but important limitations remain, such as a single province, a dated dataset, or an incomplete population.

LIMITED EVIDENCE. Evidence is sparse, indirect, geographically narrow, methodologically weak, or inconsistent across sources.

DATA GAP. No evidence adequate to answer the underlying question was identified in this review.

What counts as an Observatory Finding

Before a statement is presented in this report as a formal Observatory Finding, it is tested against five questions: what evidence supports it, how much of that evidence is Canadian, whether the underlying data are genuinely comparable, whether credible contradictory evidence exists, and whether the proposed wording overstates what the evidence demonstrates. Where the wording was stronger than the evidence justified, it was weakened. This review did not force a fixed number of findings; it retained only the findings that survived this test, and the resulting six findings should be read as the strongest, evidence-supported conclusions this pilot could responsibly reach, not as an exhaustive account of youth cardiovascular health in Canada.

What counts as a Data Gap

A Data Gap in this report is a specific, well-defined question this Observatory attempted to answer, together with a description of what evidence would be needed, what was actually found, and why what

was found is insufficient. This review avoided the blanket claim that "Canada has no data" on a topic. Where a suitable national estimate could not be identified, that is stated as such, distinct from a claim that the underlying information is not collected anywhere at all.

Limits of this approach

This is an evidence synthesis, not primary research. HeartWise did not collect original clinical, survey, or registry data for this pilot. Conclusions are only as strong as the underlying published evidence, and in several areas, particularly Indigenous youth cardiovascular health and cross-provincial specialty-care access, that underlying evidence is itself limited. These limitations are discussed further in the Limitations section.

01

OBSERVATORY INVESTIGATION

THE MEASUREMENT PROBLEM

Can Canada see its own young hearts clearly?

CORE QUESTION ***Can Canada construct a coherent picture of cardiovascular health among young people?***

Canada's largest cardiovascular surveillance systems were built to track heart disease in an aging population, and they do that well. The Public Health Agency of Canada's Canadian Chronic Disease Surveillance System, the Canadian Institute for Health Information's hospital discharge data, and Statistics Canada's vital statistics together provide a detailed national picture of cardiovascular disease from age 20 onward.[1,2] Below that threshold, the picture changes shape. Cardiovascular disease is a minor cause of death among people aged 15 to 34, well behind unintentional injury and suicide, so the youth cardiovascular signal is small relative to the rest of the mortality data and is rarely broken out on its own.[2]

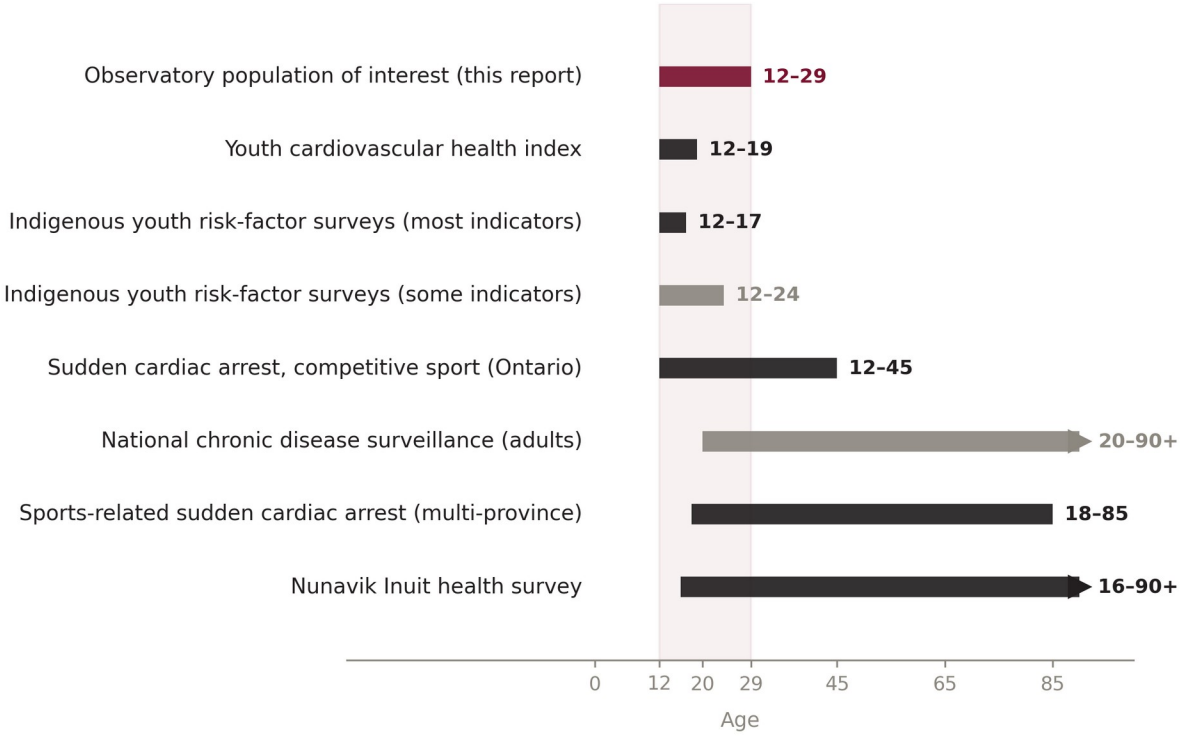
Where youth-relevant cardiovascular data do exist, they tend to live in separate, condition-specific systems rather than a shared surveillance structure. Congenital heart disease is the best quantified example. The most detailed lifetime prevalence estimate available, 8.21 cases per 1,000 live births, comes from a Quebec population study covering births through the mid-2000s, and the same research group has documented that adults now make up an estimated 66 percent of the province's total congenital heart disease population.[3] This is genuinely strong evidence, but it describes one province. A separate national analysis using the Canadian Institute for Health Information's Discharge Abstract Database found more than 100,000 congenital heart disease hospitalizations, specifically 103,034, across roughly 61,000 patients over a ten-year period ending in 2012, with adult hospitalizations growing 4.0 percent per year compared with 1.3 percent per year in children, evidence that the population living with these conditions is aging even as national registry coverage has not kept pace.[4]

Inherited arrhythmias and cardiomyopathies, conditions directly relevant to sudden cardiac events in young people, are followed through the Hearts in Rhythm Organization, a research registry and biobank spanning thirteen Canadian centres.[5] This is valuable infrastructure, but it functions as a research registry built around participating centres and affected families, not as population-level public health surveillance capturing every diagnosed case in the country.

The most direct attempt this review identified to summarize cardiovascular health broadly among Canadian youth is a national composite index, drawing on the American Heart Association's concept of ideal cardiovascular health, applied to Canadians aged 12 to 19.[6] It found that only 16.6 percent of youth in that age range met criteria for ideal cardiovascular health, with nearly half classified as having poor cardiovascular health on the same measures. The data underlying that index were collected in 2009 and 2010. No comparable, more recent national measure was identified in this review.

FIGURE 01

Age bands do not line up across Canada's cardiovascular evidence sources



Source References 1, 6, 8, 13–15 (see Master Statistics Ledger and full reference list).
Important limitation *Illustrates incompatibility of age bands across sources; does not itself represent a new statistic.*

What we can say

Canada has real, credible cardiovascular data relevant to young people. Congenital heart disease has been studied with genuine rigour, at least within Quebec.[3] Inherited arrhythmia patients are tracked through dedicated national research infrastructure.[5] Hospital discharge data can describe cardiovascular hospitalizations across the age spectrum, including among young people, when researchers query it directly.[4]

What we cannot yet say

There is no single national data source that would let a health authority, researcher, or policymaker ask, in one place, "how is cardiovascular health trending among Canadians aged 12 to 29" and receive a current, nationally representative answer. The closest available answer to that question is now fifteen years old. This is the specific, evidence-supported basis for Observatory Finding 01 and Observatory Finding 06, discussed above.

> **DATA GAP CALLOUT** *The absence of a routinely published, integrated youth-specific national surveillance product, and the absence of a pan-Canadian congenital heart disease registry, are both addressed in full in the Data Gaps Register.*

02

OBSERVATORY INVESTIGATION

DETECTION BEFORE DIAGNOSIS

What Canada looks for before a heart gives a warning

CORE QUESTION ***How does Canada approach cardiovascular detection before a serious event?***

For this Observatory, the strongest Canadian evidence on detection before diagnosis concerns cardiovascular screening in competitive athletes. The review did not identify evidence adequate to characterize, at a national level, how cardiovascular abnormalities are first detected across the broader population of young Canadians.

The more studied and more contested part of this question concerns cardiovascular screening of competitive athletes. Canada's current position, set out in a joint 2018 and 2019 position statement from the Canadian Cardiovascular Society and the Canadian Heart Rhythm Society, recommends a tiered approach built on history and physical examination, with 12-lead ECG considered as an adjunct in specific circumstances rather than applied as a routine, blanket, first-line screening tool for every competitive athlete.[7] This is a deliberate, evidence-informed position, not one taken lightly or without international company, and it is also not the only position taken internationally. Some European programs, including screening frameworks associated with the European Society of Cardiology and long-running Italian pre-participation screening programs, use ECG as a first-line tool for competitive athletes. The debate between these approaches remains genuinely unresolved at the international level, turning on real trade-offs: ECG can identify some conditions that a history and physical examination would miss, but it also produces false positives, particularly in young athletic populations with normal exercise-related ECG changes, and demonstrating that a screening strategy improves detection of abnormalities is not the same as demonstrating that it reduces population-level sudden cardiac death. This review did not identify Canadian or international evidence resolving that second, harder question, and more recent research in this space has generally continued to sharpen understanding of ECG's diagnostic performance without settling the population-level mortality question.

The best available Canadian incidence evidence for sudden cardiac arrest during competitive sport comes from Ontario's Rescu Epistry program, covering ages 12 to 45 between 2009 and 2014.[8] It found

the event to be uncommon, at 0.76 cases per 100,000 athlete-years, with a 43.8 percent survival rate to hospital discharge among those who experienced one. This is meaningful evidence, but it is Ontario-specific and spans an age range extending well past what most people mean by "youth," so it should not be generalized into a single "Canadian youth sudden cardiac arrest rate."

Detection capability versus evidence of improved outcomes

These are two different claims, and this report keeps them separate deliberately. Canada can detect cardiac murmurs, syncope, concerning family history, and, in some circumstances, ECG abnormalities in young people. Whether any particular detection strategy, applied at a population level, measurably reduces sudden cardiac death among young Canadians is a much harder question, and the evidence reviewed here does not resolve it either for or against expanded screening. This review does not conclude that all young Canadians should receive ECG screening, and it does not conclude that Canada's current approach is definitively correct either. Both are live positions, and Observatory Finding 02 reflects that directly.

Emergency planning as a separate layer

Screening and detection are one layer of protection. A separate and complementary layer is the capacity to respond quickly when an event happens regardless of whether it was anticipated, through CPR-trained bystanders and accessible, functioning defibrillators. That layer is addressed in Investigation 6.

03

OBSERVATORY INVESTIGATION

THE GEOGRAPHY OF CARDIAC CARE

Does location change the path to a cardiologist?

CORE QUESTION ***Does location change the cardiovascular care journey for young Canadians?***

Specialized pediatric cardiology and adult congenital heart disease care in Canada is concentrated in a relatively small number of tertiary centres, connected through the Canadian Adult Congenital Heart Network, which links roughly fifteen ACHD programs across the country, a structure in place since the early 1990s.[10] That concentration is a reasonable and common way to organize genuinely rare, complex, lifelong conditions. It also means that for a meaningful share of young Canadians, reaching that expertise involves travel.

The most directly relevant Canadian evidence on how remoteness affects outcomes comes from a national study of infants with congenital heart disease requiring intervention in the first year of life, using hospital discharge data from 2008 to 2018 and excluding Quebec.[11] Among this specific population, greater remoteness from a cardiac surgical program was associated with higher mortality for moderate-complexity congenital heart disease. The same relationship was not identified for severe congenital heart disease, where outcomes did not differ meaningfully by distance. The study's authors suggested that Canada's universal health insurance system may help explain why the most severe cases, which typically trigger urgent transfer and treatment regardless of distance, did not show a geographic

gradient, while moderate-complexity cases, which may be managed with more local discretion, did. That explanation is the authors' own interpretation, not an established fact confirmed by this review, and it should be read as such.

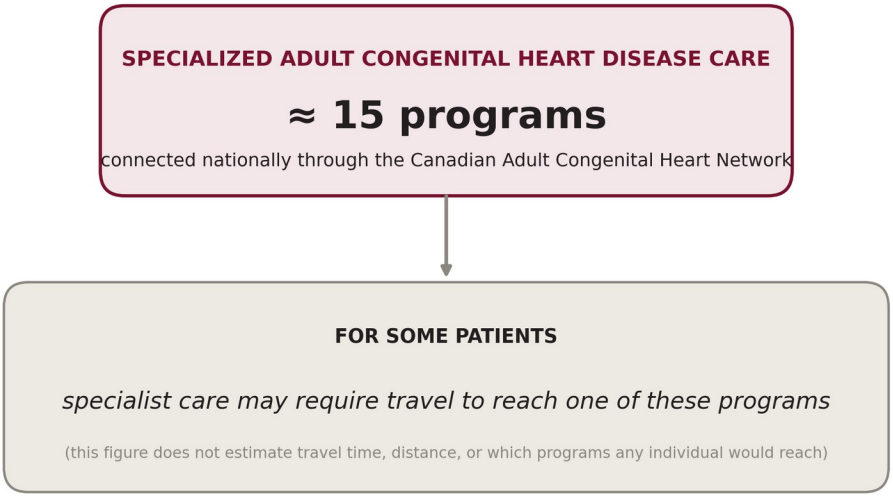
This finding describes infants requiring cardiac intervention in a specific window of early life, in a study that did not include Quebec. It should not be generalized to describe geographic inequity across all Canadian youth cardiovascular care, and this review is not doing so.

Beyond that specific infant population, other evidence points toward remoteness mattering in less quantified ways. Telecardiology and eConsult programs, including outreach cardiology clinics connected to major pediatric centres and electronic consultation services used in Nunavut, exist specifically because in-person specialty access is not evenly distributed, and a study of eConsult use in Nunavut found rapid specialist response times, with a median response of 0.9 days across 165 consultations submitted between 2014 and 2016.[12] Programs built to solve a problem are themselves indirect evidence that the problem is real, even where the problem's exact national scale has not been measured.

What this review could not find is a nationally comparable dataset on pediatric cardiology or adult congenital heart disease wait times across provinces, built on shared definitions. Individual jurisdictions may track wait times internally, but comparing one province's median wait to another's 90th-percentile wait, or comparing figures defined differently, would produce a misleading result, and this report declines to construct one.

FIGURE 02

Specialized ACHD care is concentrated in a small number of connected programs



Source Reference 10 (Canadian Adult Congenital Heart Network).

Important limitation *This is a simplified concentration diagram, not a map. It shows that specialized adult congenital heart disease care runs through a small, nationally connected set of programs, and that this can mean travel for some patients. It does not depict program locations, travel time, distance, quality, wait time, outcome, or any specific province.*

Chapter conclusion

Geography plausibly matters to a young Canadian's cardiovascular care journey, and one credible Canadian study identifies a specific geographic signal within one population, infants with moderate-complexity congenital heart disease requiring early intervention. But the currently available national

data are not adequate to support a broader claim of coast-to-coast geographic inequity in youth cardiovascular access. Canada lacks sufficiently comparable youth-specific specialty-access data to determine the national extent of geographic inequity. That gap, not a disparity claim the evidence cannot support, is this chapter's central conclusion, and it is treated in the Data Gaps Register rather than as a top-level Observatory Finding.

04

OBSERVATORY INVESTIGATION

INDIGENOUS YOUNG HEARTS

What this Observatory could, and could not, reliably determine

CORE QUESTION ***What could this Observatory reliably determine about cardiovascular health among First Nations, Inuit, and Métis young people in Canada?***

This chapter begins with the evidence problem itself, because that problem shapes everything that follows. Canadian health data systems have a long, well-documented history of describing Indigenous peoples poorly, inconsistently, or not at all, and of doing so without Indigenous involvement in how the data were collected, defined, or used. This Observatory review did not attempt to correct that history, and it is not in a position to. What it can do is describe, honestly and specifically, what published evidence exists for First Nations, Inuit, and Métis young people's cardiovascular health, where that evidence stops, and why.

The short answer is that this Observatory review did not identify suitable youth-specific cardiovascular outcome estimates for First Nations, Inuit, and Métis populations that could support a coherent national picture. That is a more precise and more defensible statement than saying Canada has no relevant data at all, and the distinction matters. Real evidence exists. It simply does not, at present, answer the specific question of how many First Nations, Inuit, or Métis young people have measured cardiovascular conditions or elevated cardiovascular risk, in a way that is current, age-disaggregated for youth specifically, and reasonably representative.

First Nations

Survey-based evidence on First Nations youth, drawn primarily from the First Nations Regional Health Survey and related Statistics Canada analyses, describes risk factors such as overweight and obesity rather than diagnosed cardiovascular outcomes. Estimates for First Nations youth aged 12 to 17 have placed overweight or obesity prevalence around one quarter to over a quarter of youth, broadly higher than the same measure among non-Indigenous youth in the same surveys, and earlier on-reserve-specific data placed obesity prevalence among First Nations youth aged 12 to 17 at roughly 14 percent, using a narrower definition and an older survey year.[13,14] First Nations adults overall have been estimated to face roughly two and a half times the cardiovascular disease risk of non-Indigenous Canadians in more recent published work, but that estimate describes adults, not youth, and this review did not identify a youth-specific parallel.[16] First Nations-governed data collection, including the Regional Health Survey, operates under the First Nations principles of ownership, control, access, and possession, commonly

known as OCAP®, which means any future expansion of this evidence base needs to happen through First Nations-led processes, not through external extraction of more data about First Nations communities.[17]

Inuit

Comparable youth risk-factor data exist for Inuit youth, again generally in the 12 to 17 or 12 to 24 age range depending on the survey, showing elevated rates of daily smoking, a known cardiovascular risk factor, relative to non-Indigenous youth in the same period.[13] The most direct measured cardiovascular data available for any Inuit population came from a 2017 regional health survey in Nunavik, which found that 24 percent of Nunavimmiut aged 16 and older had elevated blood pressure on direct measurement, up from 17 percent in an earlier 2004 survey, with the increase more pronounced among men.[15] This is genuine, measured, locally led evidence, and it is a meaningful finding for the Nunavik region specifically. It describes an all-ages-16-and-over population, however, not youth specifically, and Nunavik is one Inuit region among several across Inuit Nunangat, so it should not be generalized to Inuit youth nationally.

Métis

Youth risk-factor evidence for Métis youth, again primarily overweight and obesity prevalence in the 12 to 17 age range, generally shows elevated rates relative to non-Indigenous youth, in the same national surveys referenced above for First Nations and Inuit youth.[13] This review did not identify Métis-specific measured cardiovascular outcome data, comparable to the Nunavik blood pressure survey, for any age group.

What this chapter is not saying

This chapter is not concluding that First Nations, Inuit, and Métis youth cardiovascular health is worse, better, or unchanged relative to non-Indigenous youth, because the evidence needed to make that comparison responsibly, current, youth-specific, and outcome-based rather than risk-factor-based, was not identified. It is also not treating First Nations, Inuit, and Métis populations as one homogeneous group; the evidence available differs meaningfully across the three, in both content and geographic coverage, and has been kept separate here for that reason.

Strengths and Indigenous-led work

Deficit statistics are not the whole picture, and this review looked deliberately for Indigenous-led cardiovascular and health-system work as well. One example is "With Every Step, We Grow Stronger," a community-based, Indigenous-led healthy lifestyle intervention developed with Lytton First Nation, which incorporated sharing circles and culturally grounded programming and measured improvements in participants' aerobic fitness, resting blood pressure, and resting heart rate.[18] The published evaluation involved a small number of participants and was designed around and for that specific community rather than for broad generalization, which is a strength of the model, not a weakness to be corrected. It stands as an example of what community-led, non-extractive cardiovascular health work can look like, distinct from external researchers collecting more data about a community rather than with it. A second, more recent example is a community-led, arts-based project in the James and Hudson Bay region that used sharing circles to document how emotional, spiritual, social, and systemic factors shape heart health and access to culturally safe care, produced in partnership between a First Nations health authority and academic researchers.[16]

Data governance and next steps

Better evidence on Indigenous youth cardiovascular health cannot mean simply extracting more information about First Nations, Inuit, and Métis communities using the same external frameworks that

produced the current gaps. It requires Indigenous leadership, ownership, and governance of what is measured, how, and for what purpose, consistent with frameworks such as OCAP® and with Inuit- and Métis-specific data governance principles where they exist.[17] HeartWise does not propose recommendations on behalf of Indigenous communities in this report, and any future Observatory work in this area would need to be built in genuine partnership rather than designed and then presented to Indigenous organizations after the fact.

05

OBSERVATORY INVESTIGATION

FROM PEDIATRIC TO ADULT CARDIAC CARE

What happens to continuity as young people grow up

CORE QUESTION ***What happens to continuity of cardiac care as young people with congenital heart disease move into adulthood?***

Congenital heart disease used to be, overwhelmingly, a pediatric problem, because most people born with serious heart defects did not survive to adulthood. Advances in pediatric cardiac surgery and cardiology over the past several decades changed that fundamentally. In Quebec, the province with the most detailed published registry data, adults are now estimated to make up roughly two thirds of the total population living with congenital heart disease,[3] a genuine demographic transformation that most of Canada's cardiac care infrastructure, historically organized around pediatric centres, has had to adapt to over a relatively short period.

That adaptation has a specific known weak point: the transition itself, when a young person moves from a pediatric cardiology system, often one they have known their entire life, into an adult system with different clinics, different providers, and, for many, the first real requirement to manage their own follow-up care. The most detailed Canadian evidence on what happens at this transition comes from a Quebec population-based birth cohort of people born with congenital heart disease in 1983. Tracking that cohort forward, researchers found that 28 percent had not received cardiology follow-up by their sixth birthday, 47 percent by their thirteenth, and 61 percent by their eighteenth. Even among those with the most severe lesions, the group for whom ongoing cardiology follow-up matters most, only 79 percent had been seen by a cardiologist after turning 18.[19]

This is strong, specific evidence, and it is also old and geographically narrow. The cohort was born in 1983 and tracked using data available up to roughly 2005; it describes Quebec, not Canada as a whole; and cardiac care, transition programming, and health system navigation have all changed since then. It should be read as strong evidence that this kind of discontinuity can and did happen in a well-documented Canadian population, not as a current national prevalence figure.

More recent and more geographically varied evidence suggests the underlying pattern has not disappeared, even if today's exact Canadian rate is not precisely known. A systematic review pooling loss-to-follow-up data across multiple countries estimated a global rate around 26.1 percent among congenital heart disease patients.[20] A separate systematic review and meta-analysis found this varies

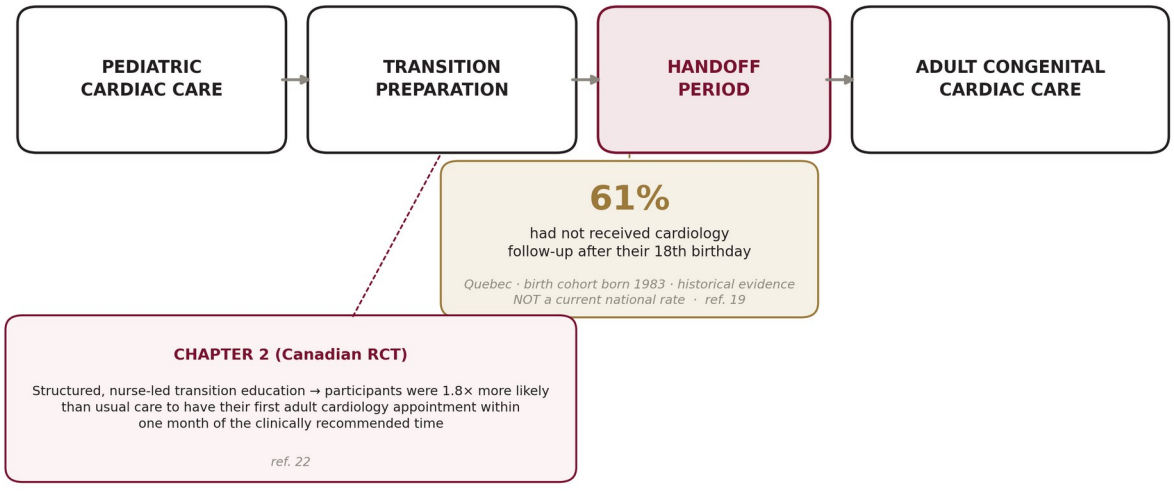
significantly by geography, with pooled estimates of 34.0 percent in the United States, 25.7 percent in Canada, and 6.5 percent in Europe.[21] These figures come from different underlying studies using different methods and time periods, so they should be read as a consistent international pattern rather than as directly comparable point estimates.

It is worth being precise about why this happens, because "loss to follow-up" can sound like patients simply disappearing from the health system altogether, and that is usually not what is happening. Young people with congenital heart disease commonly remain connected to the broader health system, seeing family physicians and other providers, while specifically falling out of cardiology follow-up. Reasons identified in the broader literature include the abrupt handoff from a pediatric provider a patient has known for years to an unfamiliar adult specialist, a lack of clear information about why lifelong follow-up matters for a condition that may feel resolved after childhood surgery, and ordinary life disruptions around this age, including moving for school or work, that interrupt continuity of any kind of specialist care.

This is also the part of the Observatory's findings with the most direct, tested Canadian evidence of what helps, on two fronts. First, the same meta-analysis found that congenital heart disease patients who had gone through a structured transition program had a substantially lower rate of care discontinuity, 12.7 percent, than those who received usual care, 36.2 percent.[21] Second, a Canadian randomized controlled trial, the CHAPTER 2 study, tested a structured, nurse-led transition education intervention for 16- and 17-year-olds with moderate or complex congenital heart disease and found that participants who received it were 1.8 times more likely than those who received usual care to have their first adult cardiology appointment within one month of the clinically recommended time; the intervention also produced sustained gains in participants' knowledge of their condition and self-management skills.[22] Combined with the existence of an established Canadian Adult Congenital Heart Network linking specialized adult programs across the country,[10] this suggests the infrastructure to receive transitioning patients well already exists in many places; the gap is more specifically in the structured handoff into it.

FIGURE 03

The pediatric-to-adult cardiac care transition pathway



Source References 19, 21, 22.

Important limitation *Pathway is descriptive and illustrative; underlying percentages come from a single Quebec cohort and a small number of studies, not a national tracking system. The 61% figure is Quebec, birth cohort born 1983, historical evidence — it is not a current national rate.*

Chapter conclusion

Of the seven questions this Observatory examined, this is the one with the clearest combination of a documented problem and tested evidence of what helps. The problem is not that Canada lacks specialized adult congenital heart disease care; a national network of programs exists. The problem is the handoff into it, at a point in a young person's life when they are also navigating school, work, and independence for the first time. This is the strongest basis in the entire review for Observatory Finding 03, and it is the chapter where "the evidence points toward" language in this report is most confident.

06

OBSERVATORY INVESTIGATION

WHEN A HEART STOPS

How consistently is Canada prepared to respond

CORE QUESTION ***How consistent is Canada's system for cardiac arrest preparedness in environments used by young people?***

Sudden cardiac arrest outside a hospital is a national emergency-response problem long before it is a youth-specific one. A 2024 Heart & Stroke Foundation report, drawing on national resuscitation registry evidence, estimated approximately 60,000 out-of-hospital cardiac arrests occur in Canada each year, with roughly 1 in 10 people surviving.[23] This figure describes all ages and is used here strictly as national context, not as a youth statistic. It is also worth noting that an earlier, commonly cited estimate of roughly 40,000 annual events reflects, at least in part, changes over time in how these events are counted and reported, rather than necessarily representing a true increase in how often cardiac arrest occurs; this review did not identify evidence that would support treating the difference between the two figures as a genuine rise in incidence.

Youth-specific sudden cardiac arrest data are considerably thinner. The best available Canadian evidence on sudden cardiac arrest specifically during competitive sport, discussed in Investigation 2, comes from Ontario's Rescu Epistry program covering ages 12 to 45 between 2009 and 2014, which found the event to be uncommon.[8] A more recent Canadian study, "Sports-Related Sudden Cardiac Arrest in Canada: Incidence and Survival," published in the Canadian Journal of Cardiology, Volume 41, Issue 3 (March 2025), examined sports-related sudden cardiac arrest using data from 2016 to 2020 collected through the Canadian Sudden Cardiac Arrest Network, drawing on emergency medical services records across a multi-province Canadian catchment area; source descriptions of the exact number of participating provinces are not fully consistent, so this report describes it as multi-province rather than asserting a specific count.[9] The study identified 339 sports-related events among 18,769 total sudden cardiac arrests in that dataset, an incidence of roughly 1.2 per 100,000 person-years, with a mean age of 58 and the large majority of cases occurring in men. This is valuable, methodologically careful Canadian evidence, but it describes sports-related sudden cardiac arrest across an adult age range of 18 to 85, skewing toward middle-aged recreational athletes, not young people specifically. It should not be read as a youth sudden cardiac arrest statistic.

The layer of Canadian preparedness that is specifically relevant to young people is what happens in the environments they occupy: schools, and youth sport settings. Here, the picture is not a single national standard but a patchwork of provincial and territorial approaches, and it is one where this Observatory places particular emphasis on the difference between legislation, funding commitments, implementation deadlines, and documented on-the-ground readiness, because these are frequently conflated in public discussion.

Some provinces have enacted specific legislation addressing public-access defibrillators, in some cases naming schools among covered locations.[24,25,26] British Columbia's approach has taken the form of a ministerial order and supporting Ministry of Education and Child Care policy rather than standalone legislation: its "Response to Unexpected Health Emergencies" policy requires every board of education to have a policy ensuring AEDs and naloxone kits are accessible in every school, with AEDs and naloxone expected to be in place in all secondary schools by December 31, 2025, and the same expectation extended to elementary and middle schools by September 8, 2026.[27] As of this Observatory's evidence cutoff of August 31, 2026, the elementary and middle school target date had not yet arrived, and this review did not identify authoritative evidence confirming completed implementation ahead of that date; it should therefore be treated as an upcoming requirement, not a completed one. British Columbia has also implemented a mandatory Grade 10 CPR and AED curriculum component as part of its Physical and Health Education curriculum. Prince Edward Island has adopted a comparable mandatory CPR and AED curriculum requirement at the secondary level.[28] Other provinces and territories have taken different approaches, ranging from dedicated public-access-defibrillator legislation to funding programs supporting AED placement in schools and recreation centres to voluntary adoption without a specific legislative or funded mandate, and for several jurisdictions, this review could not identify a clear, current, government-sourced statement of policy at all.

Because these approaches differ in kind, not just in degree, this report presents them using categorical labels rather than a numerical score or ranked list. A jurisdiction with strong legislation is not necessarily a jurisdiction where every school currently has a working, accessible, well-maintained defibrillator; conversely, the absence of a legislative mandate does not mean a jurisdiction's schools have none. Legislation, funding, implementation deadlines, and verified on-the-ground readiness are four different things, and this review generally had reliable evidence only for the first two or three of these across most jurisdictions, not the fourth.

Canadian Cardiac Emergency Readiness Policy, by Jurisdiction

Categorical status only. PRESENT indicates confirmed legislation, regulation, or official mandate; PARTIAL indicates a funding program, non-binding policy, or requirement covering only part of the relevant schools or age range; NOT IDENTIFIED indicates this review could not locate a clear, current, official source, which reflects a limit of this review rather than confirmation that no policy exists; UNCLEAR indicates conflicting or ambiguous information. Each of Canada's thirteen provinces and territories is listed separately; none are grouped. This matrix reflects the most recent identified official source as of the evidence cutoff of August 31, 2026, and should be independently reverified before any operational use. No numerical score or provincial ranking is implied or provided, and a PRESENT rating describes a formal policy requirement only, not confirmed on-the-ground implementation.

Jurisdiction	Public-access AED policy	School AED / CPR-AED curriculum
British Columbia	PARTIAL (ministerial order and ministry policy, not standalone legislation; secondary school target date passed, elementary/middle target not yet due as of evidence cutoff) [27]	PRESENT (mandatory Grade 10 curriculum component) [27]
Alberta	UNCLEAR (this review found indications of a public-access defibrillation funding program but could not trace it to a citable, current official source)	UNCLEAR
Saskatchewan	UNCLEAR	UNCLEAR (this review found indications of a school-focused cardiac-readiness initiative but could not trace it to a citable, current official source)
Manitoba	PRESENT (Defibrillator Public Access Act) [24]	PARTIAL (schools among designated public locations) [24]
Ontario	PARTIAL (Defibrillator Registration and Public Access Act enacted; staged implementation) [25]	UNCLEAR
Quebec	NOT IDENTIFIED (no public-access legislation located)	UNCLEAR (this review found indications of a school AED installation initiative but could not trace it to a citable, current official source)
New Brunswick	NOT IDENTIFIED	NOT IDENTIFIED
Nova Scotia	PRESENT (Defibrillators Act) [26]	UNCLEAR (this review found indications of school AED funding but could not trace it to a citable, current official source)
Prince Edward Island	NOT IDENTIFIED (no public-access legislation located)	PRESENT (mandatory secondary curriculum component) [28]
Newfoundland and Labrador	NOT IDENTIFIED	NOT IDENTIFIED
Yukon	NOT IDENTIFIED	NOT IDENTIFIED
Northwest Territories	NOT IDENTIFIED	NOT IDENTIFIED
Nunavut	NOT IDENTIFIED	NOT IDENTIFIED

For the three territories and Newfoundland and Labrador, this review's searches did not surface a clear, current, government-sourced policy statement on either public-access AED requirements or school CPR/AED curriculum; this NOT IDENTIFIED rating reflects the limits of this review's search, not a finding that no such policy exists. Confirming the actual position in these four jurisdictions is a candidate priority for the next Observatory cycle.

Chapter conclusion

Canada does not have one national standard for how prepared a school or youth sport setting is to respond to sudden cardiac arrest. It has several provincial and territorial approaches, unevenly documented, that this review could categorize but could not rank meaningfully or reduce to a single readiness score, and it could not verify actual implementation on the ground for most jurisdictions. This is the basis for Observatory Finding 05, and it is treated here with particular caution given how easily a policy matrix like this one can be misread as a scorecard, which it is not intended to be.

07

OBSERVATORY INVESTIGATION

PRACTICES WORTH WATCHING

Where Canada already has something worth building on

This Observatory did not set out to find only problems, and it did not. Across the six investigations above, several Canadian programs, registries, and models stood out as genuinely promising, even where the evidence for their effectiveness is still developing. None of these are labelled a "best practice" here, because that term implies comparative evidence of superiority that, in most cases, does not yet exist. They are labelled, more accurately, as practices worth watching.

PRACTICE WORTH WATCHING

The Quebec Congenital Heart Disease Registry.

WHAT IT IS an automated, multi-source population registry drawing on hundreds of thousands of echocardiography reports and other clinical records to track congenital heart disease across the province without relying on manual case entry.[3]

WHY IT MATTERS it is the closest thing to a model this review found for how a province-scale congenital heart disease data infrastructure could work, and much of the strongest Canadian evidence cited throughout this report, including the lifetime prevalence estimate and the transition cohort findings, exists because this registry does.[3,19]

WHAT THE EVIDENCE SUPPORTS published methodology describing the registry's automated construction and its use across multiple peer-reviewed studies.

WHAT REMAINS UNKNOWN whether a comparable model would be feasible or cost-effective to replicate in other provinces, which have different clinical data infrastructure.

PRACTICE WORTH WATCHING

The Hearts in Rhythm Organization (HiRO) registry.

WHAT IT IS a national research registry and biobank connecting thirteen Canadian centres focused on inherited arrhythmia and cardiomyopathy conditions, many of which are directly relevant to sudden cardiac events in young people.[5]

WHY IT MATTERS it represents meaningful national coordination for a category of rare, genetically linked conditions that would otherwise be studied only in fragments at individual centres.

WHAT THE EVIDENCE SUPPORTS an active, multi-centre registry structure with defined participating sites.

WHAT REMAINS UNKNOWN how representative registry participants are of everyone in Canada living with these conditions, including those never referred to a participating centre.

PRACTICE WORTH WATCHING

C-SCAN, the multi-province sudden cardiac arrest surveillance network.

WHAT IT IS a research collaboration tracking sudden cardiac arrest, including sports-related events, across several Canadian jurisdictions, producing some of the more methodologically careful recent Canadian evidence on this topic.[9]

WHY IT MATTERS it is building exactly the kind of comparable, multi-province surveillance infrastructure this report repeatedly identifies as missing elsewhere.

WHAT THE EVIDENCE SUPPORTS peer-reviewed publication using this dataset, including the 2025 sports-related sudden cardiac arrest study discussed in Investigation 6.[9]

WHAT REMAINS UNKNOWN whether this network's scope will extend to producing youth-specific sudden cardiac arrest estimates, which do not yet exist within it.

PRACTICE WORTH WATCHING

Structured, nurse-led congenital heart disease transition programming.

WHAT IT IS a defined educational intervention, tested in a Canadian randomized controlled trial, designed to prepare adolescents with congenital heart disease for the move into adult cardiology care.[22]

WHY IT MATTERS of everything reviewed in this Observatory, this is the clearest example of a specific, testable Canadian intervention with evidence that it improves a concrete outcome, timeliness of adult congenital heart disease follow-up.

WHAT THE EVIDENCE SUPPORTS a randomized trial in which participants who received the intervention were 1.8 times more likely than those who received usual care to have their first adult cardiology appointment within one month of the clinically recommended time, with sustained gains in condition knowledge and self-management skills.[22]

WHAT REMAINS UNKNOWN how widely this specific model has been adopted outside the trial setting, and whether its effect holds at larger scale and over longer follow-up periods.

PRACTICE WORTH WATCHING

Telecardiology and eConsult programs.

WHAT IT IS electronic and remote consultation arrangements, including cardiology outreach clinics connected to major pediatric centres and eConsult services used in Nunavut, that let primary care providers access specialist input without requiring an in-person referral and travel.[12]

WHY IT MATTERS these programs directly address the geographic concentration of specialty cardiac care discussed in Investigation 3.

WHAT THE EVIDENCE SUPPORTS documented rapid specialist response times in at least one evaluated Nunavut eConsult program.[12]

WHAT REMAINS UNKNOWN the effect of these programs on downstream clinical outcomes, as opposed to speed of specialist response.

PRACTICE WORTH WATCHING

"With Every Step, We Grow Stronger" and other Indigenous-led community health initiatives.

WHAT IT IS a community-based, Indigenous-led healthy lifestyle intervention developed with Lytton First Nation, incorporating culturally grounded programming.[18]

WHY IT MATTERS it demonstrates what non-extractive, community-governed cardiovascular health work can look like, in direct contrast to the external, deficit-framed data collection this report critiques in Investigation 4.

WHAT THE EVIDENCE SUPPORTS a published evaluation showing measured improvements in participants' aerobic fitness and resting blood pressure.[18] A second example, a community-led arts-based sharing-circle project in the James and Hudson Bay region, shows a comparable model applied to qualitative, strengths-based knowledge translation rather than fitness metrics.[16]

WHAT REMAINS UNKNOWN how either model would translate to other communities, which is, by design, a decision for those communities to make, not something for this report to prescribe.

THE OBSERVATORY'S SIGNATURE ACCOUNTING OF UNCERTAINTY

HeartWise Observatory Data Gaps Register

A Data Gap, in this report, is a specific question this Observatory attempted to answer, together with what evidence would be needed to answer it, what was actually found, and why that evidence is insufficient. None of the statements below claim that Canada collects no information whatsoever on these topics; several describe evidence that is partial, fragmented, or not comparable, rather than entirely absent.

DATA GAP 01

A routinely published, integrated youth-specific national cardiovascular surveillance product

QUESTION

Does Canada routinely publish a current, integrated cardiovascular picture, using consistent age bands, for the Observatory's approximate 12-to-29 population?

WHAT WE LOOKED FOR

A standing national surveillance product, comparable to the detail the Canadian Chronic Disease Surveillance System provides for adults, that isolates cardiovascular outcomes within this age range as an ongoing reporting category.[1]

WHAT WE FOUND

All-age and broad-age-band mortality and hospitalization data exist through Statistics Canada and the Canadian Institute for Health Information, and cardiovascular disease can be identified as a cause within them.[2,4] Custom analyses of these same data sources, isolating a youth-specific age band, are plausible and have in fact been done for specific research questions, including the hospitalization study and the youth cardiovascular health index cited elsewhere in this report.[4,6] What this review did not identify is a routinely published national surveillance product that already provides a current, integrated cardiovascular picture for this age range on an ongoing basis, without requiring a custom research analysis each time the question is asked.

STATUS · **PARTIALLY AVAILABLE.**

WHY IT MATTERS

Without a standing, routinely updated product, tracking whether youth cardiovascular health in Canada is improving, worsening, or holding steady depends on occasional, one-off research studies rather than routine, ongoing reporting, and each new question requires a fresh custom analysis rather than consulting an existing public report.

DATA GAP 02

A pan-Canadian congenital heart disease registry

QUESTION

What is the current national prevalence, distribution, and outcome profile of congenital heart disease among Canadians, including youth, across all provinces and territories?

WHAT WE LOOKED FOR

A national congenital heart disease registry comparable in coverage to the Quebec Congenital Heart Disease Registry.

WHAT WE FOUND

The Quebec registry itself, providing detailed provincial data,[3] and a national hospital discharge analysis providing hospitalization counts but not a full prevalence or outcome registry.[4]

STATUS · **PARTIALLY AVAILABLE.**

WHY IT MATTERS

The strongest Canadian congenital heart disease evidence in this entire report describes one province. Without comparable data elsewhere, it is not possible to know whether Quebec's findings, including the transition follow-up gap in Investigation 5, hold true nationally or reflect something specific to that province's health system.

DATA GAP 03

Comparable pediatric cardiology and adult congenital heart disease specialty access and wait-time measures

QUESTION

How does wait time and access to pediatric cardiology and adult congenital heart disease specialty care compare across Canadian provinces and territories, using a shared, comparable definition?

WHAT WE LOOKED FOR

Provincial or national wait-time data specific to pediatric cardiology or adult congenital heart disease referral, using consistent metrics such as median or a defined percentile wait.

WHAT WE FOUND

Fragmented, jurisdiction-specific information not built on shared definitions, making direct comparison unreliable. Structural evidence, such as the concentration of specialized programs,[10] and one geographic outcome signal in a specific infant population,[11] but no comparable national wait-time measure.

STATUS · **NOT COMPARABLE.**

WHY IT MATTERS

Investigation 3 identifies a real geographic access question that this data gap prevents from being answered at a national level. This is one of the more consequential gaps in this review, because it blocks a straightforward and important comparison that families, clinicians, and policymakers would reasonably want to make.

DATA GAP 04

Youth-specific cardiovascular outcomes for First Nations, Inuit, and Métis populations

QUESTION

What is the current, measured cardiovascular health status of First Nations, Inuit, and Métis youth in Canada, disaggregated by population and reasonably representative of on-reserve, off-reserve, urban, rural, remote, and northern communities?

WHAT WE LOOKED FOR

Youth-specific, measured (not self-reported risk-factor-only) cardiovascular outcome data, comparable across First Nations, Inuit, and Métis populations.

WHAT WE FOUND

Risk-factor survey data (overweight, obesity, smoking) for youth in each of the three populations, generally in the 12-to-17 or 12-to-24 range with some coverage exclusions;[13,14] one regional measured blood pressure survey for Inuit adults 16 and older in Nunavik, not youth-disaggregated;[15] adult-level First Nations cardiovascular risk estimates, not youth-specific.[16]

STATUS · **NOT IDENTIFIED.**

WHY IT MATTERS

This is the most significant data gap identified in this Observatory review. Addressing it responsibly requires Indigenous leadership and governance of any future data work, consistent with frameworks such as OCAP®,[17] not simply more external data collection about Indigenous communities.

DATA GAP 05

Youth-specific sudden cardiac arrest incidence and survival

QUESTION

What is the current incidence and survival rate of sudden cardiac arrest specifically among Canadians under 30, across all settings, not only competitive sport?

WHAT WE LOOKED FOR

National or multi-province sudden cardiac arrest data disaggregated for a youth-specific age band.

WHAT WE FOUND

Ontario evidence on sudden cardiac arrest during competitive sport spanning ages 12 to 45;[8] a more recent multi-province study of sports-related sudden cardiac arrest with a mean age of 58;[9] neither isolates a youth-specific rate.

STATUS · **PARTIALLY AVAILABLE.**

WHY IT MATTERS

Public concern about youth sudden cardiac arrest is real and understandable, but this review could not identify the specific national number that would let that concern be sized accurately against other risks young people face.

DATA GAP 06

National information on school AED presence, maintenance, and readiness

QUESTION

How many Canadian schools currently have a functioning, accessible, properly maintained automated external defibrillator, and how does this compare to policy commitments in each province and territory?

WHAT WE LOOKED FOR

A national or provincial dataset tracking actual AED presence and maintenance status in schools, as distinct from policy commitments or funding announcements.

WHAT WE FOUND

Provincial and territorial policy statements, legislation, and funding program descriptions, addressed in Investigation 6,[24,25,26,27,28] but no consolidated dataset confirming actual on-the-ground implementation.

STATUS · **NOT IDENTIFIED.**

WHY IT MATTERS

This is the clearest example in this review of the difference between policy and implementation. A jurisdiction can have strong legislation and still have gaps in actual school-level readiness, and this review found no way to verify which is closer to the truth in any given province.

What these gaps reveal together

Read individually, each of these gaps describes a specific missing dataset. Read together, they describe something more structural: Canada's cardiovascular information systems were largely built one condition, one program, or one province at a time, in response to specific clinical or research needs as they arose, rather than designed from the outset to answer a youth-specific national question. That is a reasonable way for health data infrastructure to develop, and it has produced real strengths documented throughout this report. It has also produced exactly the kind of fragmentation this Observatory set out to investigate.

FROM EVIDENCE TO ACTION

What the Evidence Suggests Next

This section is organized by evidence strength rather than presented as a flat list of recommendations, because the evidence reviewed in this Observatory supports different levels of confidence for different kinds of action.

Evidence-supported opportunities

Structured transition support for young people with congenital heart disease moving from pediatric to adult cardiology care has direct Canadian trial evidence behind it, with participants 1.8 times more likely to have their first adult cardiology appointment within one month of the clinically recommended time.[22] Expanding access to this kind of structured, nurse-led transition programming, building on the existing Canadian Adult Congenital Heart Network,[10] is the most directly evidence-supported opportunity identified in this review.

Promising directions requiring further evaluation

Telecardiology and eConsult access for remote and northern communities shows promise in the evidence available, particularly for reducing time to specialist input, but this review did not find outcome evidence beyond response speed,[12] and further evaluation of downstream clinical impact would strengthen the case for expansion. Similarly, the general model demonstrated by the Quebec Congenital Heart Disease Registry, an automated registry drawing on existing clinical data rather than requiring new manual reporting, is worth evaluating for feasibility in other provinces, though this review did not assess the technical or financial requirements of replication.[3]

Research and measurement priorities

The single highest-value research priority identified in this review is Indigenous-led development of youth-specific cardiovascular outcome measures for First Nations, Inuit, and Métis populations, governed and directed by Indigenous organizations.[17] A second priority is an updated, national measure of youth cardiovascular health comparable to the 2009-to-2010 index discussed in Investigation 1, given how much has changed for Canadian youth in the years since that measure was taken.[6] A third priority is development of a shared, comparable wait-time definition for pediatric cardiology and adult congenital heart disease referral, which would make Data Gap 03 addressable without requiring an entirely new data collection system, since it may be achievable by standardizing how provinces already report.

Areas where HeartWise should not recommend action yet

This Observatory does not recommend universal ECG screening for young Canadians, because the evidence reviewed here does not establish that such a policy would reduce population-level sudden cardiac death, and because Canadian cardiology guidance itself has considered and declined this approach for now.[7] It does not recommend a ranked provincial scorecard for cardiac emergency readiness, because the underlying data are not comparable enough to rank responsibly, and because policy presence does not reliably indicate implementation. It does not make claims or recommendations about Indigenous youth cardiovascular outcomes, because suitable evidence to support such claims was not identified, and because any resulting recommendations belong with Indigenous leadership rather than with this Observatory. It does not offer a broad, single-number estimate of youth sudden cardiac arrest incidence in Canada, because no evidence base identified in this review supports one at the youth-specific level.

LOOKING AHEAD

Research Priorities for the 2027 Observatory

Rather than repeating every Data Gap identified above, this section highlights the questions most likely to meaningfully change the picture this Observatory can offer next year.

Whether a Canada-wide, or at minimum multi-province, youth-specific cardiovascular health index can be constructed, updating and extending the 2009-to-2010 national index discussed in Investigation 1.[6] This is high value because it would directly address the oldest and most consequential data gap in this report, and because the methodology for the original index already exists as a starting point.

Whether First Nations, Inuit, and Métis-led organizations are pursuing, or would welcome partnership on, youth-specific cardiovascular data initiatives. This is high value because it is the only responsible way to make progress on Data Gap 04, and because the 2027 Observatory should report on whatever such partnerships or Indigenous-led initiatives exist, rather than attempting to fill this gap unilaterally.

Whether the Canadian Adult Congenital Heart Network or provincial health authorities have data on how widely structured transition programming, of the kind tested in the Canadian randomized trial discussed in Investigation 5, has actually been adopted.[10,22] This is high value

because it would clarify whether the most evidence-supported opportunity in this report is being acted on or remains largely confined to the original trial setting.

Whether provincial and territorial governments, including the three territories and Newfoundland and Labrador where this review could not identify a current policy source, can be engaged to confirm actual school-level AED implementation status, moving Data Gap 06 from policy description toward verified readiness data. This is high value because it is the gap most directly tied to a young person's safety in an emergency, and because British Columbia's September 2026 implementation deadline will have arrived by the time the next Observatory is prepared, offering a natural point to check documented progress.[27]

READ THIS BEFORE CITING ANY FINDING

Limitations

This Observatory review has real limitations, and this section is written to state them plainly rather than to minimize them.

This was a structured evidence review, not a formal systematic review with a pre-registered protocol and dual independent screening. A more formal systematic review of a narrower question, for example transition outcomes in Canadian congenital heart disease alone, would likely surface additional relevant studies this review did not capture.

Age bands across the sources used in this report are genuinely heterogeneous, ranging from 12 to 17 in some surveys[13,14] to 12 to 45 in the Ontario sudden cardiac arrest evidence[8] to 16 and older in the Nunavik survey.[15] This report has tried to preserve those bands accurately rather than force them into a single youth category, but the resulting picture is necessarily uneven, stronger for some age ranges than others.

Geographic variation limits several of this report's strongest findings. The congenital heart disease prevalence and transition follow-up evidence both come primarily from Quebec.[3,19] The infant remoteness study excluded Quebec entirely.[11] The Nunavik blood pressure survey describes one Inuit region, not Inuit Nunangat as a whole.[15] None of these should be read as automatically generalizable to the rest of the country, and this report has tried to flag that limitation each time these findings are used.

Several key statistics in this report are dated, most notably the 2009-to-2010 youth cardiovascular health index[6] and the Quebec transition cohort born in 1983.[19] This report treats that dating as a finding in itself, Observatory Finding 06, rather than presenting old data as though it were current.

Administrative data, including hospital discharge records, capture diagnosed and treated conditions, not undiagnosed disease in the community, and can be affected by changes in coding practice or ascertainment over time, a limitation directly relevant to the out-of-hospital cardiac arrest figures discussed in Investigation 6.[23]

Rare events, including youth sudden cardiac arrest and severe congenital heart disease outcomes, produce small numbers even in large studies, which makes precise incidence estimates harder to pin down and comparisons across smaller subgroups less statistically reliable.

Evidence specific to Indigenous youth cardiovascular health is the most significant gap in this entire report, discussed at length in Investigation 4 and Data Gap 04. This limitation is not incidental to the review; it is one of its central findings, and it should be read as such.

Policy information, particularly the cardiac emergency readiness matrix in Investigation 6, reflects the most recent official source this review could identify as of August 31, 2026,[24,25,26,27,28] but government policy pages and legislative status can change, and this review could not independently verify actual on-the-ground implementation in most jurisdictions. That matrix should be treated as provisional and reverified before any operational use.

Where this review relied on secondary reporting, for example a foundation report synthesizing registry data rather than the underlying registry publication itself,[23] that reliance is noted at the point of use, and such figures are generally treated with somewhat lower confidence than figures traced directly to a primary source.

Nearly all associations described in this report are correlational, not causal, and this report has tried to use language reflecting that throughout. Where a study's authors offered an interpretation beyond what their data directly established, such as the suggested role of universal insurance in the infant remoteness study,[11] this report presents that as the authors' interpretation, not as an established fact.

Finally, this report treats policy presence and implementation as distinct throughout, particularly in Investigation 6, and readers should not infer that a jurisdiction with strong legislation necessarily has strong real-world readiness, or that a jurisdiction without legislation necessarily lacks it.

CLOSING

Conclusion

This Observatory set out to answer a question that turned out to be harder than it looked: what does Canada actually know about the cardiovascular health of its young people. The honest answer is that Canada knows a considerable amount, spread across systems that were not built to speak to each other.

Canadian cardiology has real expertise in congenital heart disease, much of it documented through detailed work based in Quebec.[3] Canada has made a deliberate, evidence-informed choice about how to screen young athletes, sitting inside a genuine, unresolved international debate rather than outside it.[7] A national network connects specialized adult congenital heart disease programs across the country,[10] and a Canadian trial has already shown that structured support at the transition into that network measurably improves the timeliness of a young person's first adult cardiology appointment.[22] Multi-province surveillance of sudden cardiac arrest is now being built where it did not previously exist.[9] None of this describes a system with nothing working.

At the same time, this review could not produce a single, current, national picture of youth cardiovascular health, because the best available measure of that is now fifteen years old.[6] It could not establish, with data adequate to trust, whether where a young Canadian lives meaningfully changes their path to specialty cardiac care, beyond one specific and important signal in infants with moderate-complexity congenital heart disease.[11] It could not find comparable evidence about actual school-level emergency readiness across the country, despite finding real variation in the policies meant to produce it. And it could not, most significantly, identify youth-specific cardiovascular outcome evidence for First Nations, Inuit, or Métis young people that would let anyone, including HeartWise, speak responsibly to their current cardiovascular health.[13,14,15,16]

An Observatory's purpose is not to manufacture certainty where none exists. It is to make visible what is known, what is uncertain, what is working, and what Canada still cannot reliably see, and to do that honestly enough that the people who can act on it, health authorities, clinicians, researchers, school systems, and Indigenous-led organizations among them, have an accurate starting point rather than an inflated or a falsely reassuring one.

This pilot found a measurement and integration gap, not a crisis. That is a real finding, not a disappointing one. It points toward specific, addressable next steps, some of them already supported by tested Canadian evidence, rather than toward alarm.

It is worth saying plainly what this report has tried not to do. It has not searched only for bad news to justify its own existence, and it has not smoothed over genuinely positive or genuinely uncertain findings to manufacture a more dramatic conclusion. Where Canadian practice held up well against the evidence, as with the current approach to athlete screening, this report has said so. Where the evidence simply was not there, as with Indigenous youth cardiovascular outcomes, this report has said that too, without pretending otherwise and without filling the space with assumption.

A pilot Observatory is, by its nature, a first attempt. Some of the questions asked here will turn out to have been the wrong ones, or asked at the wrong level of detail, once more evidence becomes available or once partners with more direct knowledge of a given area, including Indigenous-led organizations, weigh in on what this report gets right and what it misses. HeartWise intends to treat that kind of correction as a normal and expected part of running an Observatory, not as a failure of the model. The value of doing this work publicly, rather than keeping it internal, is that it can be checked, challenged, and improved by the people who understand these systems better than any single review can capture on its own.

HeartWise intends to return to these questions in future Observatory cycles, revise this approach as it learns where the model works and where it does not, and continue reporting honestly on what the evidence does and does not yet show. The goal was never to arrive at a finished picture. It was to give Canada a more honest starting point than it had before, and to keep improving that starting point year over year.

VANCOUVER-STYLE, NUMBERED

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