



HeartWise Youth Heart Health Observatory

ACT — Canada 2026

*From Evidence to Action: Policy Directions for Youth Cardiovascular Health in
Canada*

A Policy Companion to UNDERSTAND

HeartWise Foundation

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About: 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.

Disclaimer: This publication makes policy recommendations based on a completed evidence review. It is not legal, clinical, or financial advice, and it does not represent the position of any government, health authority, or Indigenous governing body. Where this document verifies current policy or program status, that verification reflects publicly available information as of the date stated and should be independently confirmed before any operational reliance.

From UNDERSTAND to ACT

Understand: The HeartWise Youth Heart Health Observatory, Canada 2026 Pilot¹ asked a single question: what does Canada actually know about the cardiovascular health of its young people, and where does that knowledge run out. It found a country with real cardiovascular expertise, genuine pockets of strong practice, and a set of surveillance and data systems that were mostly built one condition, one program, or one province at a time. The result was not a demonstrated health crisis. It was a measurement and integration gap: a country that can describe adult heart disease in detail but struggles to produce a coherent, current, youth-specific picture of its own.

ACT starts from that gap and asks a different question: given what UNDERSTAND actually established, what should happen next, and who is positioned to make it happen. This is a narrower question than it might first appear. UNDERSTAND documented six findings and six data gaps with real, if uneven, evidentiary weight behind them. Not every one of those findings or gaps translates cleanly into a policy recommendation. Some point toward specific, nameable institutions with a specific, nameable next step. Others point mainly toward the limits of what any external nonprofit can responsibly propose, particularly where the missing evidence belongs to a population that has its own governance authority over how it is measured.

ACT is deliberately more restrained than it could be. Four headline policy priorities are proposed: two ACT NOW and two BUILD THE CONDITIONS. A further two items are treated separately, not as headline recommendations, because the evidence and the institutional landscape do not yet support treating them that way. A further list of plausible-sounding policy ideas is explicitly declined, with reasons given. The purpose of ACT is not to convert every finding into a recommendation. It is to say, as precisely as UNDERSTAND said what Canada does not yet know, what Canada's evidence currently supports doing about it.

Letter from HeartWise

When we published UNDERSTAND, we said we were not going to manufacture urgency the evidence did not support. Writing ACT tested that commitment in a different way. It is one thing to describe a data gap honestly. It is another to sit with that description and ask, seriously, whether HeartWise has any business recommending what should be done about it, and to conclude, in more than one case, that the honest answer is a narrower recommendation than we might have preferred to make, or in one case, no recommendation about the substance at all.

This document proposes four headline policy priorities, two ACT NOW and two BUILD THE CONDITIONS, that we believe the evidence in UNDERSTAND can actually support: a feasibility assessment for a recurring youth cardiovascular reporting framework, built from data Canada already collects; a real measure of whether young people with congenital heart disease actually make it into adult care, not just guidance recommending that they should; a shared definition for comparing specialty access before anyone builds a benchmark on top of it; and transparent verification of whether specified school AED requirements have actually been implemented, where jurisdictions already have such requirements in place. None of the four depends, as currently framed, on HeartWise proposing new legislation. None of them requires HeartWise to build, own, or operate anything. Each one asks an institution that already has real authority in this space to do something specific and measurable.

We also decided what we would not do. UNDERSTAND could not establish a coherent picture of cardiovascular health for First Nations, Inuit, or Métis youth, and it was explicit that closing that gap is not ours to define. Writing that sentence in an evidence report is one thing. Living by it while drafting a policy document is another, because the natural instinct when you find a gap is to propose filling it. We have written a governance commitment instead of a recommendation for this specific reason, and we mean it as a real constraint on what HeartWise will do, not a placeholder.

We are publishing ACT as a policy companion, not a final word. Where it identifies an open question, we expect that question to stay open until an institution with the standing to answer it does so. Where it identifies something HeartWise can do without overstepping, we intend to do it and report honestly on what happened.

Misha Panesar

Founder & President, HeartWise Foundation

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Executive Policy Brief

UNDERSTAND found that Canada's youth cardiovascular evidence is real but fragmented, and that several of its most consequential gaps are not gaps in expertise but gaps in whether existing systems talk to each other. ACT tested six candidate policy directions against that evidence and against the current institutional landscape, verified as of September 6, 2026. Four headline policy priorities emerge: two ACT NOW and two BUILD THE CONDITIONS. Two further items are treated separately because the underlying institutional picture is not yet settled enough to support a headline recommendation, and a further set of superficially reasonable ideas is explicitly declined.

Policy Priority 01 asks the Public Health Agency of Canada and Statistics Canada to assess the feasibility of a recurring youth cardiovascular reporting framework, built from data Canada already collects, without assuming that existing surveys can simply be merged and without producing a single composite score.

Policy Priority 02 asks the Canadian Adult Congenital Heart Network and the Canadian Cardiovascular Society to lead development of a nationally consistent measure of whether young people with congenital heart disease actually transfer into adult cardiac care, using a clinically appropriate transition window rather than a fixed eighteenth-birthday cutoff.

Policy Priority 03 asks that Canada develop a shared definition for pediatric cardiology and adult congenital heart disease referral-to-assessment time, and pilot comparable reporting against that definition, before anyone proposes a national wait-time benchmark.

Policy Priority 04 asks jurisdictions that already require school AEDs to establish a transparent way of verifying that those requirements are actually being met, without treating the existence of a policy as proof that it is working, and without demanding a public school-by-school ranking.

Two further items do not rise to the level of a headline recommendation. Indigenous youth cardiovascular measurement is addressed through a governance commitment describing what HeartWise will not do, not a recommendation describing what someone else should do. Pan-Canadian congenital heart disease data infrastructure is tracked as a system-building watchlist item, because the two Canadian research networks working in this space have different and only partly confirmed current capacities, and recommending a specific next step for either one would outrun what this review could verify.

ACT also states plainly what it is not recommending: universal ECG screening, mandatory blanket athlete ECG screening, a provincial cardiac-readiness ranking, treating unconfirmed jurisdictions as unprepared, a single national youth sudden-cardiac-arrest rate, HeartWise-designed Indigenous cardiovascular targets, and a general claim that geography produces inequitable cardiac care for all Canadian youth. Each of these is plausible on its face and each is declined for a specific, evidence-based reason.

The Four Policy Priorities at a Glance

Priority	Status	Responsible Actor(s)	Action
01. A current view of youth cardiovascular health	ACT NOW	Public Health Agency of Canada; Statistics Canada	Assess feasibility of a recurring youth-specific reporting framework using existing data sources.
02. Measure whether CHD transition actually happens	ACT NOW	Canadian Adult Congenital Heart Network; Canadian Cardiovascular Society	Develop a nationally consistent transition/transfer measure.
03. Make specialty access comparable	BUILD THE CONDITIONS	Canadian Institute for Health Information; cardiology and pediatric cardiology bodies; provincial/territorial partners	Common definition and pilot reporting for referral-to-assessment time; benchmark only later.
04. Verify school cardiac-emergency implementation	BUILD THE CONDITIONS	Relevant ministry or school-system authority in each jurisdiction with a requirement	Transparent verification and reporting of implementation, not just policy presence.

Not a headline priority: Indigenous youth cardiovascular measurement (governed by the HeartWise Governance Commitment) and pan-Canadian congenital heart disease data infrastructure (tracked on the System-Building Watchlist).

How ACT Determines When Evidence Supports Action

Not every finding or data gap in UNDERSTAND is a policy recommendation waiting to be written down. ACT applies a consistent test before treating any candidate as ready for this document.

First, the underlying UNDERSTAND evidence has to actually establish the problem, not merely gesture at it. A data gap labelled NOT COMPARABLE or NOT IDENTIFIED in UNDERSTAND is real evidence of a measurement problem; it is not evidence of what the missing measurement would show, and ACT does not treat it that way.

Second, a real institution has to exist that could plausibly act on the recommendation. ACT does not recommend action to "government" in the abstract. Each priority names the specific federal, provincial, clinical-network, or research body whose actual mandate covers the action proposed, based on the policy verification conducted as of September 6, 2026.

Third, the proposed action has to be something that body could do without new legislation, unless legislation is genuinely what is missing. Most of what ACT recommends is a reporting decision, a shared definition, or a measurement commitment, not a new law. Where an existing legal or regulatory structure already covers the area, as with several provinces' AED legislation, ACT works within it rather than proposing to duplicate or override it.

Fourth, ACT distinguishes between evidence that a problem exists and evidence that a particular solution works. UNDERSTAND's transition chapter is the clearest case where both exist: a documented problem and a Canadian randomized trial showing a specific intervention improved a specific outcome. Most of the rest of UNDERSTAND documents a problem without a correspondingly tested solution, and ACT's recommendations in those cases are narrower: measure first, benchmark later; assess feasibility before building a new product; verify before ranking.

Finally, where the evidence describes a population whose data governance authority is not HeartWise's to exercise, ACT does not propose a measurement solution at all, regardless of how clear the underlying gap is. This is the basis for treating Indigenous youth cardiovascular data as a governance question rather than a fifth policy priority.

Where a candidate did not clear this test, ACT does not force it into the four headline priorities. Two candidates are addressed instead as a governance commitment and a watchlist item, and a further set of ideas is directly declined.

Policy Priority 01: A Current View of Youth Cardiovascular Health

Status: ACT NOW

Assess the feasibility of a recurring youth cardiovascular reporting framework

What UNDERSTAND established

UNDERSTAND's Observatory Finding 01 found that Canada's routine cardiovascular surveillance systems do not currently combine into a single, coherent, youth-specific picture across roughly ages 12 to 29, even though useful pediatric and condition-specific data exist in separate systems built around different age bands, provinces, and conditions.^{1,2} Observatory Finding 06 found that the strongest national index of youth cardiovascular health identified in the review is based on data collected in 2009 and 2010, with no more recent comparable national measure identified.^{1,3} Data Gap 01 made the specific, narrower claim underlying both findings: UNDERSTAND did not identify a routinely published, integrated youth-specific cardiovascular surveillance product, even though custom analyses using existing data sources are technically possible and have been conducted for specific research questions.¹

The policy gap

The issue is not simply that Canada lacks another report on youth cardiovascular health. The sources reviewed did not identify a routine national reporting product that can answer a straightforward question: is youth cardiovascular health in this country getting better, getting worse, or staying about the same. That is a narrower and more solvable problem than it might first appear. UNDERSTAND does not establish that youth cardiovascular health has worsened since 2009 and 2010; it establishes that this review did not identify a current national measure capable of answering that question.

What ACT recommends

The Public Health Agency of Canada and Statistics Canada should assess the feasibility of establishing a recurring youth cardiovascular reporting framework using existing national data sources where methodologically valid, while preserving each source's actual age bands, definitions, data years, and limitations. This is not a recommendation to merge the Canadian Health Measures Survey, the Canadian Chronic Disease Surveillance System, and the Health Behaviour in School-aged Children study into a single dataset. Those three systems differ in method, periodicity, and population coverage, and combining them without addressing those differences would risk manufacturing false comparability, which is exactly the kind of error UNDERSTAND was built to avoid. Nor is this a recommendation to produce a single composite "youth heart health score." The immediate action is feasibility assessment and framework design, not publication of a finished product.

Who can act

The Public Health Agency of Canada, as custodian of the Canadian Chronic Disease Surveillance System and Canada's chronic disease indicator products, and Statistics Canada, as custodian of the Canadian Health Measures Survey, are the two bodies with the mandate and the data access to conduct this assessment. The September 6, 2026 verification did not identify a

youth-specific cardiovascular product published by either body. PHAC has stated that youth and child surveillance frameworks are under development in an adjacent domain, mental health, which suggests the institutional capacity for this kind of work already exists, even though it has not yet been applied here.

Why this action is proportionate

A feasibility assessment is narrower in scope than commissioning new national data collection, since it works from data these two bodies already hold. HeartWise has not assessed the specific analytic, staffing, or resourcing requirements such an assessment would take inside PHAC or Statistics Canada, and neither should be assumed to be minor. What can be said is that the ask is bounded: a determination of whether a youth-specific view can be responsibly constructed from existing sources, not a new survey or a new collection instrument.

What success would look like

A published feasibility assessment, within a reasonable planning horizon, that states clearly whether a youth-specific cardiovascular reporting framework can be built from existing sources, what its methodological limitations would be, and what, if anything, would need to change about current data collection to make it more useful. Success does not require that the assessment conclude a full framework should be built. A rigorous conclusion that it cannot be done responsibly with current data would itself be a useful and honest outcome.

What would change this recommendation

If PHAC or Statistics Canada indicate that a youth cardiovascular framework is already under internal development, this recommendation should be withdrawn and replaced with a request to track that existing work rather than propose a new one. If a feasibility assessment concludes that the underlying data sources cannot be responsibly combined, ACT's next step would be to ask what, specifically, would need to be added to Canada's existing survey infrastructure to make a youth-specific view possible, rather than continuing to press for a product from data that cannot support one.

Policy Priority 02: Measure Whether CHD Transition Actually Happens

Status: ACT NOW

Develop a nationally consistent measure of pediatric-to-adult congenital cardiac transfer

What UNDERSTAND established

UNDERSTAND's Observatory Finding 03 is the report's clearest case of a documented problem paired with tested intervention evidence. A Quebec population-based cohort found that a substantial share of people born with congenital heart disease had not received cardiology follow-up in the years after their eighteenth birthday, and that even among those with the most severe lesions, a meaningful minority had not been seen by a cardiologist after turning 18.^{1,4} International pooled evidence and a separate country-level meta-analysis found loss to follow-up varies significantly by geography, with a Canada-specific estimate distinct from both the United States and Europe.^{1,5,6} Separately, a Canadian randomized controlled trial, the CHAPTER 2 study, found that adolescents who received a structured, nurse-led transition 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 participants' knowledge of their condition and self-management skills.^{1,7}

The policy gap

Canada already has professional guidance recommending structured transition support, through the Canadian Adult Congenital Heart Network and the Canadian Cardiovascular Society's clinical guidelines,⁸ and a 2019 paper explicitly called for strategic national implementation of transition programming.⁹ A guideline recommending transition support is not the same thing as knowing whether a young person actually made it into adult cardiac care. The September 6, 2026 verification did not identify a measurable, reported national indicator of whether that transfer actually happens. A frequently cited figure describing successful transfer to adult care, 47 percent, comes from Reid et al., published in *Pediatrics* in 2004, a cohort study across Canada's specialized adult congenital heart disease centres that defined successful transfer as attendance for at least one follow-up appointment before age 22.¹⁰ This figure is sometimes attributed to Mackie et al.'s 2019 paper; that paper is a call for strategic implementation and should be cited separately from the Reid finding it references.^{9,10} The 47 percent figure describes that specific cohort and should not be presented as a current, real-time national transfer rate.

What ACT recommends

The Canadian Adult Congenital Heart Network and the Canadian Cardiovascular Society should lead development of a nationally consistent measure of pediatric-to-adult congenital cardiac transition or transfer, anchored to a clinically appropriate transition window rather than a rigid eighteenth-birthday cutoff. Canadian transition literature does not use a single fixed age: Reid's cohort measured attendance before age 22, and the Quebec cohort's transition window spanned ages 18 to 22.^{4,10} A national measure should preserve this flexibility rather than imposing a single artificial cutoff. It also matters that several related but distinct concepts stay separate when this measure is designed: transition education (preparing a patient for the move to adult care), transfer (the discrete event of moving), first adult appointment (a specific, time-bound milestone,

which is what the CHAPTER 2 trial measured), continuity (ongoing engagement with adult care over time), and loss to follow-up (patients who disengage from cardiology care specifically, while often remaining connected to the broader health system). A single indicator that conflates these concepts risks measuring the wrong thing.

Who can act

The Canadian Adult Congenital Heart Network, administered through the Canadian Cardiovascular Society, connects the specialized adult congenital heart disease programs that would need to adopt a shared definition and report against it.⁸ The September 6, 2026 verification did not identify a measurable, reported national transition indicator published by either body; the CCS's national quality-reporting program covers atrial fibrillation, coronary artery disease, cardiac rehabilitation, and heart failure, but not congenital heart disease transition. Developing such an indicator is consistent with CACH and the CCS's existing guideline, quality-improvement, and network-coordination functions. It is not a new authority that would need to be created, though neither body should be assumed to have already prioritized it.

Why this action is proportionate

The CHAPTER 2 trial demonstrated that a structured transition intervention improved a specific process outcome: timely first engagement with adult cardiology care.⁷ This recommendation does not ask CACH or the CCS to invent a new clinical intervention. It asks them to measure whether patients are actually receiving the kind of support already shown, in this trial, to improve that specific process outcome. Nor does it claim that structured transition improves longer-term cardiovascular outcomes; the trial does not show that, and ACT does not treat it as showing that. The burden of building a shared indicator is real but bounded: defining a common measure and aligning reporting across roughly fifteen specialized programs is meaningful coordination work, not a new clinical service.

What success would look like

Adoption of a defined, named transition or transfer indicator, reported in aggregate across CACH-affiliated programs on a recurring basis, tracked as a national trend rather than a ranked comparison across individual programs, which vary in patient complexity and resourcing in ways a simple ranking would not capture fairly.

What would change this recommendation

If the Canadian Adult Congenital Heart Network or the Canadian Cardiovascular Society confirm they already have a comparable indicator in active development, this recommendation should shift from "develop" to "support and evaluate" the existing work. If newer Canadian transfer or loss-to-follow-up data emerge that supersede the Reid 2004 and Quebec 2009 cohorts, any future version of this document should cite that newer evidence as the baseline rather than continuing to rely on cohorts now two decades old.

Policy Priority 03: Make Specialty Access Comparable

Status: BUILD THE CONDITIONS

Develop a common definition and pilot comparable reporting before considering a benchmark

What UNDERSTAND established

UNDERSTAND's Investigation 3 found that specialized pediatric cardiology and adult congenital heart disease care in Canada is concentrated in a relatively small number of centres, and that one Canadian study identified a specific geographic mortality signal in infants with moderate-complexity congenital heart disease requiring early intervention.^{1,11} Data Gap 03 made the narrower, load-bearing claim: UNDERSTAND did not identify a nationally comparable dataset for pediatric cardiology or adult congenital heart disease referral or wait times built on shared definitions, and it explicitly declined to construct a comparison using incompatible existing measures, such as comparing one province's median wait to another's 90th-percentile wait.¹

The policy gap

The Canadian Institute for Health Information (CIHI), an independent, not-for-profit pan-Canadian health information organization, currently reports wait times for five priority areas established through a 2004 federal-provincial-territorial process: cancer treatment, cardiac care, diagnostic imaging, joint replacement, and sight restoration.¹² Within cardiac care, the only procedure reported is coronary artery bypass graft.¹² No pediatric cardiology or adult congenital heart disease referral-to-assessment measure appears in this CIHI framework, and the September 6, 2026 verification did not identify a comparable measure elsewhere in Canada's publicly available health-information infrastructure. Separately, a Canadian survey of all fifteen specialized adult congenital heart disease centres found wait times for non-urgent consults and interventions exceeding national recommendations, a capacity finding distinct from any formal wait-time benchmark.¹³ A wait-time number is only useful if everyone reporting it is measuring the same thing, from the same starting point to the same endpoint; right now, nothing guarantees that.

What ACT recommends

Canada should develop a common definition for pediatric cardiology and adult congenital heart disease referral-to-assessment time and pilot comparable reporting against that definition before considering a national benchmark. This is a deliberate three-step sequence, and the steps should not be collapsed: first, a shared definition of what is being measured and how; second, a pilot in which willing jurisdictions report against that definition to test whether it produces genuinely comparable data; and only then, if clinical consensus and evidence support it, a benchmark describing what an acceptable wait time should be. ACT does not propose a benchmark number here, because UNDERSTAND's evidence does not establish what an appropriate benchmark would be, and asserting one without that evidence would repeat the exact error UNDERSTAND was built to avoid.

Who can act

No single body should be read as able to decide this alone. The Canadian Institute for Health Information holds the pan-Canadian health-information methodology and reporting infrastructure that a common definition and pilot measurement would need to use, but it is not, on its own, positioned to set a clinical benchmark.¹² The relevant cardiology and pediatric cardiology professional bodies, including the Canadian Cardiovascular Society and the Canadian Pediatric Cardiology Association, hold the clinical authority needed to define and reach consensus on what should be measured and, eventually, what an appropriate benchmark would be.¹³ Provincial and territorial partners would need to contribute the underlying data and carry out any resulting reporting or implementation. The Canadian Cardiovascular Society has already proposed a national cardiac wait-time benchmarking initiative, beginning with heart failure, in a 2024 pre-budget submission; this is a proposal, not an operational program, and it does not currently include pediatric cardiology or adult congenital heart disease.¹⁴ A comparable Canadian precedent exists outside cardiology: a national wait-time benchmark for pediatric rheumatology (juvenile idiopathic arthritis) was set through professional consensus rather than new legislation, and offers a workable model for how a specialty-specific benchmark can be developed in Canada.¹⁵

Why this action is proportionate

Defining a shared measure and piloting it is analytically demanding but does not require new legislation, new funding programs, or a commitment to any specific benchmark number. It uses data infrastructure and inter-provincial relationships CIHI and the relevant clinical societies already have. Deferring the benchmark question until after a working, comparable measure exists avoids committing Canada's health system to a number that current evidence cannot support.

What success would look like

Publication of a shared definition for pediatric cardiology or adult congenital heart disease referral-to-assessment time, and voluntary reporting against that definition by at least a subset of provinces, sufficient to demonstrate whether the measure produces genuinely comparable results across differing referral and scheduling systems.

What would change this recommendation

If the Canadian Cardiovascular Society's proposed wait-time initiative receives funding and is confirmed to include pediatric cardiology or adult congenital heart disease in a later phase, this recommendation should be revised to support and align with that initiative rather than propose a parallel effort. If a pilot measurement effort finds that referral-to-assessment cannot be defined consistently enough across provinces to produce comparable data, ACT's next step would be to identify what structural differences, in referral systems, for instance, make comparison difficult, rather than proceeding to a benchmark on data known to be incomparable.

Recommended sequence: Define → Pilot → Consider benchmark.

Policy Priority 04: Verify School Cardiac-Emergency Implementation

Status: BUILD THE CONDITIONS

Verify and report implementation, without treating policy adoption as proof of readiness

What UNDERSTAND established

UNDERSTAND's Observatory Finding 05 found that legislative, regulatory, and educational approaches to public-access defibrillation and school CPR/AED curriculum vary meaningfully across Canadian provinces and territories.^{1,16,17,18,19,20,21} UNDERSTAND was explicit that this finding concerns policy variation itself, and that the review did not have nationwide implementation data needed to say how that variation translates into actual, on-the-ground emergency readiness. Data Gap 06 named this directly: UNDERSTAND did not identify a consolidated Canadian dataset confirming actual school-level AED presence, maintenance, or readiness, distinct from policy commitments or legislation.¹

The policy gap

A policy requiring AED access in schools and a functioning defibrillator that staff can actually find and use in an emergency are not the same thing, and UNDERSTAND's own jurisdiction-by-jurisdiction matrix was explicit that a "NOT IDENTIFIED" rating reflects the limits of that review's search, not confirmation that no policy exists.¹ The September 6, 2026 policy verification found that existing Canadian AED registries, including Ontario's registry under the Defibrillator Registration and Public Access Act, are designed to support 911 dispatch by making device locations known to emergency services.^{17,18} That verification did not identify a registry functioning as a public school-compliance reporting mechanism showing which schools have a working, maintained device or which staff have completed training. British Columbia's policy requires AEDs and naloxone kits to be accessible in all secondary schools, with elementary and middle schools following by September 8, 2026.²⁰ As of the September 6, 2026 policy verification date, that deadline has not yet arrived, and this report does not attempt to say whether it was met.

What ACT recommends

Jurisdictions that already require school AEDs should establish a transparent method for verifying and reporting implementation, rather than treating the existence of a policy as evidence that it is being met. Verification should cover the implementation elements that jurisdiction's own policy or legislation actually requires, which may include device availability, functional maintenance, staff training, or other requirements, depending on what that jurisdiction has adopted; this recommendation does not assume every jurisdiction must verify all three regardless of what its own policy covers. ACT does not specify whether verification should happen at the school, board, or provincial-aggregate level; that choice should be left to each jurisdiction's own administrative structure and its capacity to collect the data without creating disproportionate burden, particularly for smaller and more remote schools. What matters is that some verification exists and is made public in a way that distinguishes policy from implementation, not that every jurisdiction adopts an identical reporting format. This recommendation does not call for a public

school-by-school ranking; UNDERSTAND's own caution against misleading rankings built on incomparable data applies with equal force here.

Who can act

The relevant ministry or school-system authority in each jurisdiction that already has a school AED requirement holds primary responsibility for verifying its own policy, together with any existing registry or health-system partner that jurisdiction already relies on. Existing AED registry operators, such as the AED Foundation of Ontario, are a plausible extension point if any jurisdiction wishes to build on infrastructure that already exists rather than create something new, though no registry has been confirmed to have the school-specific data depth this recommendation envisions.¹⁸

Why this action is proportionate

This recommendation does not ask any jurisdiction to adopt new AED legislation where none exists, and it does not ask jurisdictions with legislation to expand it. It asks for verification of what is already required, scoped to what that jurisdiction's own policy actually covers. The administrative burden of implementation reporting is real; unfunded reporting mandates can fall disproportionately on smaller or rural school boards, and any jurisdiction adopting this recommendation should weigh that burden against the value of knowing whether an existing policy is working.

What success would look like

At least one additional Canadian jurisdiction, beyond current registry arrangements, publishing some form of school-level or aggregate implementation data that distinguishes device presence, functional maintenance status, and training completion from mere policy existence. British Columbia's September 8, 2026 deadline offers a natural, near-term point at which a future edition of this document could examine whether implementation data have started to appear.

What would change this recommendation

If any province publishes credible, verified school-level or aggregate compliance data before this recommendation is acted on elsewhere, that jurisdiction's approach should be documented as a working model for others rather than treated as a hypothetical. If verification proves administratively infeasible without dedicated funding, this recommendation should be revised to address funding directly, rather than continuing to ask for reporting that jurisdictions cannot practically deliver.

Implementation sequence: Policy → Implementation → Verification → Accountability.

HeartWise Governance Commitment: Indigenous Data

This is not a fifth policy recommendation directed at another institution. It is a commitment describing what HeartWise itself will and will not do, and it exists because UNDERSTAND's evidence about Indigenous youth cardiovascular health cannot responsibly be converted into a recommendation the way the four policy priorities above can.

UNDERSTAND's Observatory Finding 04 found that no suitable youth-specific cardiovascular outcome estimates for First Nations, Inuit, and Métis populations emerged from the review that could support a coherent national picture. Available evidence is generally adult-focused, risk-factor-based rather than outcome-based, and affected by incompatible age bands and geographic coverage across the surveys that do exist.¹ UNDERSTAND was explicit that closing this gap is not a task for HeartWise to define unilaterally, and that it requires Indigenous leadership, ownership, and governance of any future data work.¹

Having identified a real gap does not give HeartWise standing to design its solution. Accordingly, HeartWise commits to the following:

1. HeartWise will not independently design Indigenous youth cardiovascular measurement, screening, or intervention frameworks. Identifying that a data gap exists is not the same as having a legitimate role in closing it, and HeartWise does not treat it as one.
2. First Nations, Inuit, and Métis governance will remain distinct in any future HeartWise communication or consideration of this space. First Nations, Inuit, and Métis are distinct peoples with distinct governance and data-governance structures, and treating them as a single "Indigenous" category, even inadvertently, repeats an error UNDERSTAND specifically avoided.
3. HeartWise will not treat OCAP®, the First Nations principles of ownership, control, access, and possession, as a framework that governs Inuit or Métis data. OCAP® is a First Nations-specific framework, stewarded by the First Nations Information Governance Centre.²² Inuit and Métis governance structures are separate and should be referenced on their own terms, not assumed to be interchangeable with OCAP®. Inuit-led health research and data governance is exercised through Inuit Tapiriit Kanatami's own strategy and survey infrastructure;^{23,24} Métis-specific health research and data governance principles have been articulated separately and should be consulted on their own terms.²⁵
4. Before considering any engagement in this space, HeartWise will seek appropriate protocol guidance rather than proceeding on its own judgment about what respectful engagement looks like.
5. HeartWise will participate in or support Indigenous youth cardiovascular data work only where a First Nations, Inuit, or Métis governing or data-governance body invites it, and only where HeartWise has a legitimate, clearly defined role to play, such as funding or technical support offered on terms the inviting body sets.
6. Indigenous organizations have no obligation to review, endorse, or respond to this document or any future HeartWise work. Silence or a decline is a complete and acceptable outcome, not a problem for HeartWise to solve by trying again with a different approach.

Consistent with this commitment, ACT's twelve-month action agenda does not include unsolicited outreach to the First Nations Information Governance Centre, Inuit Tapiriit Kanatami, or Métis governing organizations as a default action. If HeartWise's work becomes known to any of these bodies through other channels and they choose to initiate contact, HeartWise will respond thoughtfully and on their terms. HeartWise will not initiate that contact itself as a matter of routine practice.

System-Building Watchlist: Pan-Canadian CHD Data

Status: INVESTIGATE FIRST

This item is tracked separately from the four headline policy priorities because the current institutional picture is genuinely unsettled, and treating it as a headline recommendation would require more certainty than this review can currently provide.

What is known

UNDERSTAND's Data Gap 02 did not identify a pan-Canadian congenital heart disease registry beyond the Quebec model, and the strongest available Canadian registry evidence, describing prevalence and the adult share of the CHD population, comes from a single province.¹ UNDERSTAND identified the Quebec Congenital Heart Disease Registry as a genuine model, an automated system drawing on existing clinical records without manual case entry, and noted that its authors describe it as a blueprint for potential national expansion.^{1,26} The September 6, 2026 verification left this picture unsettled. It identified the Quebec registry as a Quebec-only pilot and did not identify a confirmed expansion beyond Quebec.²⁶ A second, separate research network, the Canadian Research Network for ACHD Interventions, is active across seven provinces and has proposed a national adult congenital heart disease intervention registry known as C-ACHDiR.²⁷ Whether that proposed registry is currently operational could not be confirmed: the network's own materials describe it as incorporating patient-reported data, while its public clinical-trial registration record has not been updated in several years and describes the registry as not yet recruiting.^{27,28} These two descriptions do not align, and ACT does not attempt to resolve that discrepancy on its own authority.

Why ACT is not making a recommendation yet

Given this uncertainty, ACT does not recommend that HeartWise fund, build, or operate any part of a pan-Canadian congenital heart disease registry. HeartWise is not a research institution and has no comparative advantage in the technical, privacy, and inter-institutional work that linking clinical and administrative data across provinces requires. What ACT does recommend is more modest: HeartWise should support the general principle that interoperable, pan-Canadian congenital heart disease data infrastructure is valuable, recognize the Quebec registry and the ACHD-focused research network as real existing Canadian work rather than proposing something new, and revisit this item once either network's current operational status and expansion plans, if any, become clearer. This is a watchlist item precisely because the right next step depends on facts this review could not fully confirm, not because the underlying goal is unimportant.

Where ACT Does Not Recommend Policy Change

Restraint is not a gap in this document. It is a deliberate output of applying the same evidentiary standard to plausible-sounding ideas that ACT applies to the recommendations it does make. Each of the following is declined for a specific reason, not general caution.

Universal ECG screening of Canadian youth.

UNDERSTAND's Observatory Finding 02 found that Canadian cardiology guidance considered and declined blanket ECG screening even for the narrower population of competitive athletes, based on concerns about false positives and the absence of evidence that expanded screening reduces population-level sudden cardiac death.^{1,29} Extending screening to the general youth population has even less evidentiary support in this review.

Mandatory blanket ECG screening of student athletes.

This is the specific policy UNDERSTAND's Finding 02 addresses directly. Canadian guidance already considered this approach and adopted a tiered history-and-physical model instead.²⁹ The international debate between that approach and first-line ECG screening remains genuinely unresolved, not settled in either direction, and ACT does not attempt to settle it here.

Provincial cardiac-readiness rankings.

UNDERSTAND explicitly declined to construct a numerical ranking of provinces because the underlying data are not comparable: legislation, funding, implementation deadlines, and verified on-the-ground readiness are four different things, and most jurisdictions have reliable evidence for only the first two or three.¹ Producing a ranking now would manufacture a precision the evidence does not support.

Treating jurisdictions rated NOT IDENTIFIED as unprepared.

UNDERSTAND was explicit that a NOT IDENTIFIED rating reflects the limits of that review's own search, not a finding that no policy exists.¹ Several jurisdictions, including the three territories and Newfoundland and Labrador, fall into this category, and their absence from UNDERSTAND's search results should not be read as evidence of anything about their actual readiness.

A single national youth sudden-cardiac-arrest rate.

UNDERSTAND's Data Gap 05 is explicit that the review did not identify a youth-specific national rate.¹ Available Canadian evidence either spans an age range extending well past what most people mean by youth or has a mean age in the late fifties.^{30,31} Neither isolates a youth-specific figure, and no combination of these sources should be presented as one.

HeartWise-designed Indigenous cardiovascular targets or interventions.

This is addressed fully in the HeartWise Governance Commitment. UNDERSTAND is explicit that this is not a task for HeartWise to define unilaterally, and ACT treats that as a binding constraint on its own recommendations, not a gap to be filled elsewhere in this section.

Broad claims that geography produces inequitable cardiac care for all Canadian youth.

UNDERSTAND's geographic finding concerns a specific population, infants with moderate-complexity congenital heart disease requiring intervention in the first year of life, in a study that excluded Quebec.^{1,11} UNDERSTAND explicitly declined to generalize this finding to describe geographic inequity across all Canadian youth cardiovascular care, and ACT preserves that boundary. Declining to recommend action in these seven areas is not the same as declaring them unimportant. Several, particularly the absence of a comparable youth SCA rate and the broader question of geographic access, are precisely the kind of gaps that Policy Priorities 01 and 03 are designed to eventually make answerable. Restraint here is what makes the four recommendations this document does make credible.

Who Can Act: Responsibility Map

Actor	Primary Role	Priority	Limit / Boundary
Public Health Agency of Canada; Statistics Canada	Hold the mandate and data relevant to Priority 01	01	—
Canadian Institute for Health Information	Holds wait-time reporting infrastructure for methodology and reporting	03	Not positioned to set clinical benchmarks on its own
Ministries of education	Hold direct authority over school policy questions, where a requirement exists	04	—
Ministries of health	Hold authority over public-access defibrillation legislation in most provinces where it exists	04	—
Canadian Adult Congenital Heart Network; Canadian Cardiovascular Society	Hold professional authority; individual programs are the actual data-collection sites	02	Supporting role only in Priority 03, alongside the Canadian Pediatric Cardiology Association
Canadian Congenital and Pediatric Cardiology Research Network; Canadian Research Network for ACHD Interventions	Relevant research bodies for the System-Building Watchlist item	Watchlist	Neither is asked to act by a headline priority
First Nations Information Governance Centre; Inuit Tapiriit Kanatami; Métis National Council-affiliated bodies	Hold distinct authority over their own populations' health data	—	None is assigned an action by this document; HeartWise's posture is restraint, not assignment
HeartWise Foundation	Can brief, convene, request information, publish analysis, request meetings, explore partnerships, track responses	All	Cannot legislate, regulate, set clinical standards, compel reporting, operate surveillance, or speak for any Indigenous government

HeartWise 12-Month Action Agenda

- 1. Brief the Public Health Agency of Canada and Statistics Canada on Policy Priority 01.** Objective: make UNDERSTAND's Finding 01, Finding 06, and Data Gap 01 directly visible to the bodies positioned to act on them. Deliverable: a written briefing referencing the relevant UNDERSTAND findings. A brief acknowledgment that it was received is not itself a measure of success. Real progress would look like a meeting, a written clarification of where the relevant program stands, referral to the right team, or the start of a feasibility discussion.
- 2. Request clarification from jurisdictions where UNDERSTAND's policy matrix could not confirm a current position.** Objective: close the specific "limits of this review's search" gap UNDERSTAND named for itself. Deliverable: a direct, specific written inquiry to each relevant ministry. Any authoritative response, including "no such policy exists," would improve on UNDERSTAND's current rating.
- 3. Request a meeting with the Canadian Adult Congenital Heart Network regarding Policy Priority 02.** Objective: understand whether CACH or the Canadian Cardiovascular Society already have, or are developing, a transition measurement approach, before HeartWise continues to frame this as a new ask. Deliverable: a meeting request and briefing referencing UNDERSTAND's Finding 03 and the CHAPTER 2 trial.
- 4. Explore whether CIHI or the relevant clinical societies have any current interest in Policy Priority 03.** Objective: determine whether HeartWise's recommendation would be additive or redundant given the Canadian Cardiovascular Society's existing wait-time proposal. Deliverable: exploratory contact only; no partnership assumed or announced.
- 5. Publish an annual ACT progress update.** Objective: maintain honest public accountability for whether any of the four policy priorities in this document actually advanced. Deliverable: a short annual document tracking status against each priority, including honest reporting of priorities that did not advance.
- 6. Maintain a transparent policy-response tracker.** Objective: record which bodies responded to HeartWise's outreach and how, without characterizing silence as either agreement or disagreement. Deliverable: a simple, regularly updated public log.

Consistent with the HeartWise Governance Commitment, this agenda does not include unsolicited outreach to First Nations, Inuit, or Métis governing or data-governance organizations. If any of the six actions above generates unexpected interest from an Indigenous-led organization, HeartWise will respond according to that commitment, not according to this agenda.

What Progress Would Look Like by the Next Observatory

Priority	What Would Count as Progress
01	a published feasibility assessment from PHAC or Statistics Canada, even a cautious or negative one, would represent real progress beyond the current absence of a published assessment.
02	a named, adopted transition indicator reported across even a subset of CACH-affiliated programs would represent progress; continued informal encouragement to provide transition support, without measurement, would not.
03	a published shared definition for referral-to-assessment time, tested in at least one province, would represent progress; a benchmark number proposed without that groundwork would represent a step ACT does not recommend taking yet.
04	any jurisdiction publishing school-level or aggregate implementation data, distinct from policy text, would represent progress, and British Columbia's September 8, 2026 deadline offers a natural point to check whether that has started to happen anywhere.

Equally important, genuine progress on the governance commitment and the watchlist item would look like continued restraint, not activity. If HeartWise has not initiated unsolicited contact with Indigenous governance bodies, and if any future contact originated from those bodies rather than from HeartWise, that would represent the commitment working as intended. If the pan-Canadian CHD data infrastructure watchlist item remains unresolved because the relevant networks have not clarified their status, that is an honest outcome to report, not a failure of this document.

Limitations

This document inherits every limitation documented in UNDERSTAND, and adds several specific to policy translation. The four policy priorities recommend action by institutions HeartWise does not control and cannot compel; nothing here should be read as a commitment by PHAC, Statistics Canada, CIHI, the Canadian Adult Congenital Heart Network, the Canadian Cardiovascular Society, or any provincial ministry to do anything described in it. The September 6, 2026 policy verification underlying this document reflects publicly available information as of that date and can change. In particular, the operational status of the C-ACHDiR registry could not be confirmed from public sources, and treating it as a watchlist item rather than a settled fact reflects that uncertainty rather than resolving it.^{27,28} The 47 percent transfer figure and the CHAPTER 2 trial result are both real, specific, and precisely dated; neither should be read as a current, real-time description of Canadian practice.^{7,10} ACT does not, and cannot, verify whether British Columbia's September 8, 2026 school AED deadline was met, because that date had not yet arrived as of this document's policy verification cutoff.²⁰ Finally, the restraint in the Indigenous governance section is a commitment about HeartWise's own conduct. It is not, and does not claim to be, a resolution of the underlying data gap UNDERSTAND identified, which

remains open and belongs to Indigenous governance bodies to address on their own terms, if and when they choose to.

Conclusion

UNDERSTAND asked what Canada knows about youth cardiovascular health and found a country with real strengths sitting alongside a genuine measurement problem. ACT asked a narrower question: given that evidence, what should happen next, and who is positioned to make it happen. The answer is four headline policy priorities, two ACT NOW and two BUILD THE CONDITIONS, not a program of reform. Each one asks an institution that already has real authority in its space to do something concrete and measurable, using infrastructure that in most cases already exists. None of the four depends, as currently framed, on HeartWise proposing new legislation.

Equally deliberately, ACT does not convert every finding in UNDERSTAND into a recommendation. Where the evidence describes a population whose data governance is not HeartWise's to exercise, this document commits to restraint rather than proposing a solution. Where the institutional picture remains genuinely unsettled, it tracks the question rather than forcing a premature recommendation. Where a policy idea sounds reasonable but the evidence does not support it, it says so directly.

HeartWise intends to report honestly on what happens to these four priorities, including if the answer, a year from now, is that little has changed. An Observatory's value comes from being trusted to describe things as they actually are, whether that description is encouraging or not, and ACT is written to be held to that same standard.

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A note on dates. Two distinct cutoffs apply throughout this document and should not be conflated. UNDERSTAND's evidence cutoff remains August 31, 2026, and is not altered by anything in ACT. Policy and institutional status claims specific to ACT are labelled "policy status verified as of September 6, 2026" and reflect a separate, later verification exercise conducted specifically for this document.