The leapfrog opportunity: Relational health data governance as the key to improving cancer control in under-resourced nations

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Comprehensive cancer control is impossible without knowing who develops cancer, who dies from it, and who is being left behind. Yet only about 15% of the world's population, and roughly 1% of Africa's population, is covered by population-based cancer registries. Drawing cautionary lessons from wealthy health systems that have built data fragmentation of their own making, this article argues that relational data governance is the foundation on which all functional digital health services including cancer control stand. Digital health is recognized as a sociotechnical discipline, yet historically nations like Canada have focused on technical considerations while neglecting the human relationships that are foundational to high-functioning health data systems. The result is an expensive and complex health data mess that has broken public trust. A young or underserviced health data environment can leapfrog high-resource ecosystems by first investing in relational data governance that will pay long-term dividends in the form of a broad suite of solutions, including high-function cancer registries that support healthier populations. This will enhance public trust, allowing a country at any resource level to bypass the accumulated complexity of well-resourced nations and build in a few years what others have not achieved in decades.

You cannot control what you cannot count

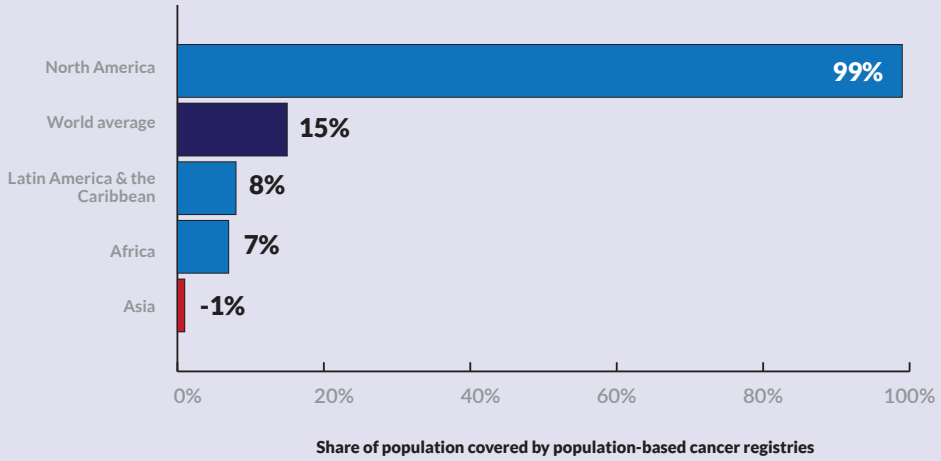
Ask a minister of health what cancer control requires and the response is quick: vaccinations, tobacco control, screening programmes, timely diagnosis, modern treatment, palliative care, and, increasingly, artificial intelligence (AI). All these factors serve as the upper floors of a cancer-control building according to our analogy. For these floors to function beneath them must be a foundation that rarely gets mentioned in political speeches: population-based data that identifies who develops cancer, what exposures and activities put people at risk, who dies from it, and who is being left behind.

The World Health Organization's (WHO) definition of cancer control is explicit on this point: comprehensive service aims to reduce the incidence and mortality of cancer to enhance the quality of life of those affected, through an integrated approach spanning prevention, early detection, treatment, rehabilitation and palliation *(1)*. The definition is population-based for a reason: incidence and mortality are population measures. A cancer control programme cannot reduce what it cannot measure. Gathering population-level data is crucial and will guide informed action.

Unfortunately, the global cancer data foundation is deficient. Only around 15% of the world's population is covered by population-based cancer registries: coverage approaches 100% in North America but falls to roughly 8% in Latin America and the Caribbean, 7% in Asia and 1% in Africa *(2, 3)* (see Figure 1). The map of cancer data is, almost exactly, an inverted map of cancer need, with around 70% of cancer deaths now occurring in low- and middle-income countries *(4)*. Further the inversion is set to deepen; WHO projects that annual cancer cases will rise from an estimated 20.6 million today to nearly 35 million by 2050, with growth concentrated in lower-income countries, where survival is lowest and, as in Africa, registry coverage is thinnest *(5)*. In other words, the burden is growing most rapidly precisely where it is measured the least.

This article makes three principal arguments. First, population-level data is not a luxury to be acquired after cancer treatment services are built. Health data is the lifeblood of all health programmes and services and is integral to any health system that learns. For cancer control to excel across the full scope of service, access to quality health data is essential; it is the foundation on which every other investment stands or falls.

Table 1: **The map of cancer data is an inverted map of cancer need**



Source: IARC Global Initiative for Cancer Registry Development (GICR); Omonisi et al., JCO Global Oncology 2020.

Second, wealth does not necessarily buy that foundation; most high-income nations have spent decades and billions building technology-rich, institution-centric information "islands", resulting in a self-imposed data complexity that has become an intractable barrier to essential population-based insight. Third, and most hopeful, countries that have not yet built health data systems are not necessarily behind. Unencumbered by the impediment of fragmented health information technology and by employing a set of principles based on lessons learned, they can build in a matter of years something that many of the well-resourced countries have failed to achieve in decades.

The costs of an invisible burden

In every health system, budget lines follow numbers, and cancer burdens often exist only as anecdotes: the surgeon's impression, the crowded ward, and the family's grief. These cannot compete with the treasury of diseases that are represented in hard data and statistics. Political invisibility is the first and most expensive consequence of missing population data. This is especially true in the age of AI whose success depends on vast quantities of high-quality data.

The second cost is poor planning. Without knowing which cancer a population has, screening programmes can be poorly targeted, drug procurement mismatched to caseloads, radiotherapy capacity guessed, and palliative care, the intervention most needed where patients present late, not planned at all because late-stage disease is never quantified. Without baseline data, programmes cannot demonstrate that they are working, budget cycles are founded on anecdote, and over time the case for investment grows weaker rather than stronger.

Ultimately, transparent population data creates accountability. A registry gives suffering a denominator. Once the burden of disease is counted, it can no longer be dismissed as anecdote. Someone in power must answer for the number, and the question of what will be done about it follows on its own. The absence of data does not make the burden disappear. It silently transfers the cost onto patients, families, communities, and nations, and it hands decision-making to whomever holds the data, whether a foreign donor, an industry, or often to no one at all.

A cautionary tale from well-resourced countries

It would be natural to assume that the remedy to this circumstance is money. We suggest that limited financial resources are not necessarily a constraint, and Canada offers some hard lessons in this regard. Canada has universal healthcare coverage, world-class cancer and discovery science, a robust clinical trials apparatus, among the highest per-capita healthcare spending in the world and has invested billions of dollars in health information technology solutions which date back decades. Yet, in 2026 Canada is host to an entrenched health data problem of its own making; a convoluted ecosystem of fragmented health data technologies across ten provincial and three territorial jurisdictions and thousands of institutions that do not, and often cannot, exchange digital data with one another.

Data fragmentation causes widespread harm, both clinical and financial. Picture a frail elderly cancer patient who requires transfer between three care settings in a single week, with each clinician working from an independent and partial clinical record. This is not an uncommon scenario in Canada, where adverse drug events account for up to 7% of acute care hospital admissions, and at least 58% of these are preventable, driven in part by incomplete medication information *(6)*. A

recent economic analysis for the Canadian Institute for Health Information estimated that connecting and properly using Canada's health data could unlock more than CA$ 9.4 billion in value annually *(7)*.

How did a wealthy country arrive at this state? Not through lack of technology: Canada bought plenty of it. The failure was one of sequence: technology first, governance and policy later. Institutions and jurisdictions procured health information technology systems to optimize their internal workflow, with no thought given to data interoperability with the other services with whom they share patients, or even recognition that interoperability was necessary for effective care. Incumbent IT vendors followed suit and profitably sold incompatibility. Over decades a service-centric or custodial model of data governance took root, in which institutions hold data and protect it, from each other, from researchers, and, functionally, from the patients the system is meant to serve. A recent Canadian report highlighted the root problem; no one oversees the strategic design and use of health data in Canada *(8)*. When no one is accountable for the data foundation, the system on the floors above breaks and no one fixes it. Deploying more technology on top of a weak data foundation makes matters worse.

The lesson is not that rich countries have problems too, but that the failure to effectively leverage health data for public good is self-inflicted and unnecessary. It is the result of the blind deployment of costly technology as a solution to what is, in essence, a problem of human relationships. Digital health technologies do not magically interoperate harmoniously if the people deploying them do not establish a clear model of cooperation.

The Canadian experience reflects an avoidable failure of health data governance and literacy, not financial or technology constraint. Countries now building their data foundations are advised to study the Canadian situation, and health data failures in other developed nations, the way engineers study bridge collapses: the lessons are abundant and can easily inform a path to coherent health data optimization.

Mindset, skillset, toolset – in that order

What led Canada, despite a wealth of financial and knowledge resources, to doggedly pursue the deployment of fragmented digital health systems without recognizing the folly of the strategy? It has been observed that Canada's focus on deploying health information technology has historically not been accompanied by any substantive effort to modernize supporting governance or policy. A recent paper suggests that the Canadian techno-centric digital health focus arose from significant gaps in health data literacy among clinicians, policymakers, and the public. The authors conclude that "without a shared level of literacy across the public, healthcare providers, decision-makers, and researchers, even advanced systems may result in fragmented care, poor decisions, wasted resources, and reduced public trust" (9). This finding suggests that Canada has lacked the literacy, or skillset, to fully understand that investing solely in technology, or toolsets, was not a recipe for success.

Evidence supports this conclusion. Stanford's Digital Economy Lab found in a study of successful enterprise AI deployments, that every dollar of technology investment requires up to ten dollars of "invisible work" – process redesign, policy development, training and change management – before any gain materializes from the technology deployment *(10)*. This is born out in a 2026 study in Africa that found that investment in human factors, including policy and practice, training, active stakeholder participation in system design, and integration of digital tools into clinical workflows, are core determinants of successful health information technology projects *(11)*.

Ultimately, the techno-centric focus of Canadian digital health initiatives highlights the longstanding "love affair" we have had with the value of technology and our belief in its ability to solve health sector deficits relative to the depreciation of the role human relationships have in health data function. The American Medical Informatics Association has long described health informatics as a sociotechnical domain. In Canada's rush to adopt information technology, we neglected to consider that the matrix of human relationships, and the policy and governance that frames them, need to work harmoniously with the technology we adopt. This highlights the need to shift our mindset away from a singular focus on technology and include consideration of the human interoperability needed to support digital health solutions. Without this shift in our mindset, acquiring the skillset needed to be data literate will continue to be challenging, and the toolsets we adopt will continue to fail.

The leapfrog opportunity

When Africa lacked comprehensive copper telephone networks it did not attempt to catch up by installing landlines; it advanced straight to mobile network technology, and in doing so overtook traditional market structures in telephone access and innovation *(12,13)*. The same leap is available in health data system development. A jurisdiction without legacy analogue hospital systems has no vendor lock-in to escape, nor decades of incompatible records to reconcile, or entrenched custodians set on complying with antiquated, privacy-focused legislation. Starting from scratch is usually framed as a deficit. We believe it is an advantage and one that well-resourced countries would pay dearly to recover.

Leap-frogging does not mean launching a national electronic

health record megaproject. Rather, it should begin modestly, and purposely consider the full scope of both human and technical factors needed for a small data project to succeed. In this manner, opportunities to learn will be afforded as the scope of the initiative grows.

Consider a population-based cancer registry as a first, affordable, high-leverage data investment. It would be a registry limited to one defined population, a minimum data set, and standard classifications (ICD-11). Consider adopting free, purpose-built software (IARC's CanReg5) and technical support through the Global Initiative for Cancer Registry Development and its regional hubs *(14)*. The growth of registries across sub-Saharan Africa under the African Cancer Registry Network demonstrates that this is feasible in low-resource settings *(15)*. Pause and reflect on what the properties of the data in this registry will need to have to serve the needs of impacted cancer patients. The data will need to follow them across services in their care journey and serve secondary purposes like research and innovation. To do so the data will need to be expressed in a standard language and traverse different data platforms. This will help dictate the partners who will need to collaborate to bring this registry to life and suggest a supportive policy suite, technology standards, and an inclusive and cooperative governance model.

Inevitably errors will be made; building a harmonized health data network is a demanding endeavour. But ultimately this is a sociotechnical effort; success is founded on the ability to forge cooperative relationships around the use of networked technology. The lessons learned from an initial small-scale project such as this can inform an approach to relational governance that is the foundation of much larger optimized health data system function.

Data governance as foundational sociotechnical architecture

Health data systems that work are distinguished from the fragmented majority less by their hardware or budgets than by how they are governed. In our experience, it is the human architecture that frames accountability for data. In our early report, Interoperability Saves Lives, we argued that most failures of health data are not technical but relational, arising from how institutions and providers relate to one another around a shared resource *(16)*. Data governance is the discipline that orders those relationships.

We describe data architecture as sociotechnical deliberately. A registry is never only a database; it is an agreement among people: clinicians, registrars, patients, communities and the state, to responsibly and safely collect, steward and use information about a population, employing technology but held together by trust. A jurisdiction that gets the agreement right can carry a population a long way on modest technology, while one that gets it wrong, as Canada did, will struggle to buy its way out.

Good governance begins with a single act: establish a data stewardship model. Operationally, this is a person or an organization with the authority and the accountability to foster data quality, access and use. From that centre of accountability other design commitments follow, and each is a facet of governance rather than a rival to it. Interoperability, the ability of data to be transmitted and mean the same thing wherever it goes, is as much a human agreement as a technical standard, since a shared minimum data set and a common coding language matter only when the people holding the data have agreed to share and work together. Data integrity, built from quality metrics and data provenance recorded from day one, is what makes the data worth trusting. Data security, kept proportionate to real risk rather than imported wholesale from a wealthy country's compliance apparatus, protects that trust with simple, enforced controls: role-based access, audit logs and encrypted storage. Confidentiality is the promise that makes a population willing to be counted, and it must serve patients rather than institutions. The failed Canadian custodial experiment shows how easily the language of privacy can be conscripted to defend the status quo. Lastly, data sovereignty recognizes that individuals, communities and nations retain rights over their own health information; where registries touch Indigenous and other rights-bearing communities, internationally recognized frameworks such as the CARE Principles for Indigenous Data Governance and the First Nations principles of OCAP® *(17,18)* turn data sharing from that of extraction into partnership, with terms, consent and benefits flowing both ways.

Held together by governance, interoperability and confidentiality do two things that money alone cannot buy. First, they build trust, and a trusted system is one in which people are willing participants in the use of their own health information. Second, they make leap-frogging achievable in practice. They are the reason a jurisdiction, starting today, can build in a few years what the well-resourced country failed to achieve in decades. Cooperative relational data governance is the foundation on which first class data systems are built, not the other way around.

Conclusion

Just as past generations built roads, railways and electrical grids as their public infrastructure, we are building data highways. In order for the data highway to function safely and effectively, it must be managed much like a road system that connects cities towns and countries, with a common set of standards (which side of the road one drives on, what the different colour of lights

mean, speed limits, etc.), integrated technology (roads arriving at the edge of a city or a border connect with each other), and clear accountability for who ensures the infrastructure is maintained and functions. Unfortunately, Canada has failed to set agreed upon "rules of the road" for our data highway. There are no common standards for data content and exchange, data from different services and regions do not connect, and it is unclear who is accountable for system oversight. At heart this is a governance failure; it is very challenging for a complex system to function safely and effectively if no one is in charge.

Understood this way, data governance is far more than a bureaucratic overhead imposed on a cancer registry: it is what makes the registry functional enough to be useful, trustworthy enough that a population consents to be counted, and it is what lets a young system sidestep the accumulated complexity of older ones. The experience of well-resourced countries teaches that a data governance foundation is very costly and difficult to build after the fact: it must be prioritized, and established deliberately and collectively, from the start.

This relational health data governance foundation is within reach of every nation and jurisdiction at every resource level, because the essential elements of good data governance: interoperability, sovereignty, integrity, security and confidentiality, are crafted from human relationships rather than purchasing power. A young or underserviced health data environment can leapfrog high-resource ecosystems by first investing in relational data governance that will pay long-term dividends in the form of a broad suite of solutions, including high-function cancer registries that support healthier populations. ■

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