

### **Canadian eHealth Initiatives (1990s-Present)**

- Late 1990s Early Vision: Canada's health sector began recognizing fragmented patient information as a critical issue. In 1999, an Ontario commission's action plan envisioned "an integrated health information network with an electronic consumer record at its core," recommending creation of a central agency to lead eHealth development 1. Similar awareness grew across provinces that silos in hospitals, clinics, labs, and pharmacies hindered care.
- 2000–2002 National Push: In September 2000, federal and provincial health ministers collectively committed to develop electronic health records (EHRs) with common standards across all jurisdictions <sup>2</sup>. This led to the 2001 establishment of Canada Health Infoway, a federally funded, not-for-profit corporation reporting to all deputy ministers of health <sup>3</sup>. Infoway's mandate was to accelerate EHR implementation nationwide; it set ambitious goals (50% of Canadians with an EHR by 2010, 100% by 2016) <sup>4</sup>. Major federal investments followed over \$1.6 billion was granted to Infoway from 2001–2009 <sup>5</sup> with an expectation that provinces/territories co-fund projects. One early estimate pegged the cost of pan-Canadian EHR implementation at ~\$10 billion (with potential annual savings of ~\$6 billion through efficiencies) <sup>6</sup>.
- Infoway's Role and Platforms: Infoway acted as a strategic investor in provincial health IT projects, co-financing up to 75% of costs 7 8 . Rather than build one system, Infoway promoted a "pan-Canadian" interoperable approach - developing core EHR components (registries, drug information systems, lab systems, diagnostic imaging repositories, etc.) that each jurisdiction could deploy in a compatible way 9 10. By the 2010s this resulted in significant progress: for example, drug information systems (like BC's PharmaNet) were rolled out in most provinces, allowing any pharmacy to access a patient's medication profile and flag interactions (BC's system logged 2.5 million potential drug interactions in 47 million prescriptions in 2007) 11. Diagnostic imaging became largely filmless - over 70% of X-rays and scans were digitized and accessible in connected archives by around 2010 12. Laboratory results repositories and client demographic registries were established to enable sharing of test results and patient identifiers across facilities 13. Infoway's funding also targeted Electronic Medical Records (EMRs) in physician offices (raising primary care EMR adoption from ~20% in 2006 to ~62% by 2013) and telehealth and consumer health solutions 14 15. Notably, by the early 2010s, observers noted that "a utopian view of the EHR is now available in Alberta and PEI," which had made especially strong progress toward fully integrated health records (12).
- **Provincial EHR Initiatives Successes and Struggles:** Health is provincially delivered in Canada, so each province built its own electronic health information systems albeit with Infoway coordination and some common standards. **Alberta** was an early leader: it launched the **Alberta Netcare** portal in the mid-2000s, giving authorized providers province-wide access to patient records (medications, labs, imaging, etc.). By 2010, Alberta was often cited as having one of the most advanced EHR infrastructures <sup>15</sup>. **British Columbia** leveraged legacy systems like its 1995 PharmaNet (a province-wide pharmacy network) as a foundation <sup>11</sup>, and implemented interoperable lab and imaging systems; BC also pioneered giving patients access to lab results online in the early 2010s as part of a

"consumer health" push 16. **Ontario**, Canada's largest province, took a more winding path – it created the Smart Systems for Health Agency (SSHA) in 2002 to build a secure health network 17. SSHA focused on networking and identity management, but by 2007 Ontario lagged behind other provinces in deploying actual EHR repositories 18. In 2008, Ontario formed eHealth Ontario (merging SSHA with the Health Ministry's eHealth program) with a mandate of one EHR per patient by 2015 19 . However, eHealth Ontario became infamous for a 2009 scandal: extensive use of no-bid consultant contracts and spending mismanagement meant hundreds of millions were spent with little progress. (Ontario's Auditor General later noted the prior agency had run through ~\$600 million "with hardly anything to show for it" in terms of EHR deliverables 20 .) This led to resignations of the CEO and the Minister 21 22, and stalled Ontario's efforts for a time. Other provinces had their own stories: Quebec developed the Dossier Santé Québec (DSQ) EHR viewer, though rollout was slower than planned; Manitoba launched eChart Manitoba; Saskatchewan set up the provincial eHealth agency and Viewer; Nova Scotia and New Brunswick invested in core systems (e.g., drug and lab systems) and later patient portals. Prince Edward Island, being small, achieved an early fully integrated EHR with Infoway's help (often cited alongside Alberta as a success) 12. The Territories (Yukon, Nunavut, NWT) adopted scaled-down solutions or partnered with larger provinces for certain services.

- **Public Health Systems Panorama:** A notable national eHealth initiative was **Panorama**, an electronic public health surveillance and immunization system developed after the 2003 SARS outbreak. Canada Health Infoway sponsored Panorama's build as a pan-Canadian system for tracking communicable diseases, immunizations, and outbreaks <sup>23</sup>. **IBM** was contracted to develop it, with BC as a lead province. Panorama, however, faced major delays and issues: it was delivered almost three years late (initial due 2007, delivered ~2010) and riddled with defects the first release had ~1,200 known bugs, and thousands more emerged in use <sup>24</sup> <sup>25</sup>. The **national project cost ballooned to at least \$66 million** (Infoway contributed \$44.5M; provinces paid an extra \$21.5M to fix defects) <sup>26</sup>. Provinces then had to implement it individually **British Columbia** alone spent \$113 million (over 4× the budget) by 2015 and still hadn't fully implemented all modules <sup>27</sup>. Panorama is now used (to varying extents) in several provinces (e.g., BC, SK, MB, Yukon) primarily for immunization and disease case management, but some provinces (like Ontario) opted out or pursued other systems. The Panorama experience is often cited as a "dream delayed" a case where pan-Canadian integration proved very challenging <sup>23</sup> <sup>28</sup>.
- Modern Era Patient Access ("MyHealth" portals): In the 2010s and especially the 2020s, there
  has been a shift toward providing patients direct electronic access to their health information.
  Many provinces introduced "My Health" branded online portals for citizens:
- **Alberta's MyHealth Records** (launched 2019) gives residents secure access to their lab test results, medication history, immunizations, and more, drawn from the provincial EHR databases.
- Saskatchewan's MySaskHealthRecord offers similar features (e.g., COVID-19 test results, lab results, immunization status). New Brunswick's MyHealthNB and Nova Scotia's MyHealthNS/MyChart are other examples, each tied into provincial systems for test results and reports.
- Ontario does not have a single province-wide patient portal for all health data, but various regional
  or hospital portals (e.g., *MyChart* at certain hospitals) and apps provide partial access; in 2022
  Ontario also launched a proof-of-concept for patients to access clinical records through a centralized
  system (Connected Health Gateway).

Uptake: Patient demand for access is strong - in 2023, 4 in 5 Canadians expressed interest in

**viewing their health records electronically**, though only about 2 in 5 have actually done so to date  $^{29}$ . The trend is upward (in 2021 only ~32% had ever accessed online, rising to ~39% by 2023)  $^{30}$ . Those who do access records report feeling more informed and able to manage their care (in one survey, 81% of patients felt better equipped to manage their health after seeing their electronic records)  $^{31}$ , and a significant number avoided unnecessary healthcare visits because information was available online (e.g. 34% avoided an ER trip)  $^{32}$ .

- Major Recent Investment Alberta's Connect Care: A groundbreaking provincial initiative is Connect Care in Alberta. Launched in waves from 2019 to 2024, Connect Care is a single, integrated clinical information system (built on Epic software) for Alberta Health Services the province's health authority. It replaces numerous disparate hospital and clinic systems with one platform, aiming for "one patient, one record" across all AHS facilities. This initiative required significant investment (~\$1.4 billion over 5 years) 33 34. As of late 2024, the ninth and final implementation wave was completed, bringing all AHS hospitals and many clinics onto Connect Care 35. This means, for example, that a medication or test result entered at one hospital is instantly available to any other AHS site in the province a major stride in integration. Connect Care co-exists with Alberta Netcare (which still links community providers and external systems), but over time Connect Care will handle the bulk of clinical documentation within AHS. Other provinces are also consolidating systems e.g., Nova Scotia has been working on a "One Person One Record" project for its hospitals, and Quebec is streamlining its many hospital systems but Alberta's effort is among the most comprehensive so far.
- · Interprovincial Integration: Connecting health data across provinces remains limited. There is no single national EHR for individuals that spans provinces. If a person moves or visits another province, often their records do not follow automatically. There are some cross-jurisdiction successes - for example, all provinces do share federal immunization exchange data (notably during COVID-19, vaccination registries had to interoperate), and diagnostic images have been shared regionally. But generally, EHR integration stops at provincial borders. The federal government (through Infoway and Health Canada) provides pan-Canadian standards (e.g., HL7 messaging standards, terminologies, and more recently FHIR APIs), and in 2022 a Shared Pan-Canadian Interoperability Roadmap was announced to push common data standards nationwide 36. This is meant to ensure systems developed in each province can "speak" to each other in the future. The need is illustrated by surveys: over 80% of Canadians want their health information to be shareable with any provider who needs it 37, and providers themselves cite lack of technical interoperability as the top barrier to information exchange 38. Efforts like Infoway's national Patient Summaries project (for sharing a core summary dataset) and inter-provincial e-prescribing (e.g., PrescribeIT) are ongoing attempts to bridge gaps. However, as of 2024, true real-time health record integration across all of Canada is still more aspiration than reality - prompting interest in new approaches, such as engaging patients themselves as a key part of the solution.

# Position A: Client-as-Gateway (Patient Aggregation of Data)

• Concept: Client-as-Gateway refers to a distributed model where the patient (client) acts as the point of integration for their health information. Instead of providers or health authorities

pushing data to each other through central systems, each provider gives the patient access to their own records, and the **patient aggregates their data** (for example, via personal apps or simply by collecting printouts and files). The patient then controls who else gets to see that consolidated record. In essence, the individual becomes the "hub" connecting different care points.

#### Potential Benefits/Pros:

- Empowerment and Complete View: Patients would have a **comprehensive**, **unified view** of their health history across all providers. This can be empowering especially for those with chronic conditions or complex care involving many specialists. A patient who gathers their own data can ensure that **no single provider's silo is missing something important**. For instance, a patient in Saskatchewan described having to personally request records from two separate specialists and deliver them so each was aware of the other's findings <sup>39</sup> a burden today that a client-as-gateway model would formalize into a more efficient process (potentially via digital tools rather than paper).
- Bypassing System Fragmentation: This model offers a pragmatic workaround to slow healthcare IT integration. Rather than waiting years for institutional systems to seamlessly talk to each other, the patient can immediately bridge the gap by obtaining information from one source and sharing it with another. It's a form of "person-mediated health information exchange." For example, if hospital records aren't automatically sent to family doctors, a patient could access their hospital discharge summary through a portal and then show or send it to their GP. The fragmentation is addressed at the point of care by the patient's proactive involvement, potentially improving coordination in the near term.
- Personal Data Use: When patients have their own copy of data, they can use it **for their own purposes** whether that's uploading results into a fitness/wellness app, seeking second opinions more easily, or contributing their data for research. It encourages a sense of ownership of one's health information. Patients could also catch errors and prompt corrections (since they see all their data). In some cases, patients maintaining personal health records have noticed discrepancies (e.g., medication lists) and informed providers, leading to improved safety.

#### Drawbacks/Cons:

- **Burden on Patients:** This model shifts the onus of data management from professionals and institutions to patients. Not everyone is prepared or capable to shoulder this responsibility. It requires **digital literacy**, **time**, **and initiative** from patients to regularly gather and update their records. Those who are elderly, cognitively impaired, low-income (with limited technology access), or simply not tech-savvy could be disadvantaged. There's a risk that the **"digital divide"** in healthcare could widen engaged, resourceful patients benefit, while others fall further behind.
- Potential to Replicate Fragmentation: Using patients as go-betweens might not truly solve the root problem of siloed systems. It's essentially a manual patch on a broken system. Each provider still maintains their own silo; the integration happens only in the patient's hands or device. If every patient has to independently gather data from each portal or office, it's a fragmented experience by another name. In other words, this could replicate fragmentation at the individual level instead of one integrated network, you have thousands of micro-integrations (one per patient). Without common data standards or formats, patients may end up with a jumble of records that don't easily merge (one clinic's printout might not line up with another's data file, etc.). Lack of interoperability

- **standards remains an issue** in this model 38 the fragmentation is just managed case-by-case by patients rather than systematically by the health system.
- Data Fidelity and Trust: Health providers may question the accuracy or completeness of patient-aggregated records. If a patient brings a consolidated file (e.g., a USB drive or an app on their phone with their history), a clinician might be uncertain: Are these all the latest results? Could anything have been modified (intentionally or unintentionally)? There can be medico-legal concerns about relying on patient-curated data. Providers typically trust information coming directly from another clinical system more than from a patient's possession due to concerns about tampering or error. This trust gap could limit the usefulness of the model unless there are verification mechanisms (for example, digital signatures on documents or a way for providers to confirm authenticity).
- Logistical Challenges: On a practical level, expecting every patient to act as an *information courier* can be inefficient. Imagine an elderly patient with six specialists they would need to constantly obtain and carry updates from each to each. Many already do something like this with paper files, but it's cumbersome. If done digitally, it might involve managing multiple portal logins and downloads. Without extremely user-friendly tools, this could frustrate patients and providers alike (e.g., "Did you remember to bring your latest bloodwork from Clinic X?" "Oh, I didn't know how to download it."). In short, it could introduce new failure points if patients, for whatever reason, don't or can't serve as a reliable gateway.
- Does it solve or perpetuate fragmentation? It provides a partial fix. The client-as-gateway approach mitigates fragmentation by leveraging the one stakeholder present at all points of care the patient - to connect the dots that the system isn't connecting. In the short term, this can improve information flow (as long as patients actively participate). For example, prior to digital records, patients often carried physical copies of their charts or imaging on CD when referred to specialists; this often was the only way information traveled. The digital client-gateway is a more scalable analogue of that – it can indeed help ensure each provider sees a more complete picture. However, it doesn't address fragmentation at its source. The fact that Brenda (the Saskatchewan patient advocate) had to sign multiple forms, pay fees, and wait weeks for paper copies to share 39 exemplifies that without systemic integration, the burden falls on individuals. If every patient has to do this, the system is still fragmented - the fragmentation is just being worked around on a case-bycase basis. In a worst-case scenario, health organizations might even become complacent, thinking "the patient will tell us anything we need to know," which could reduce pressure to implement true interoperability. Thus, while client-as-gateway can ameliorate the symptoms of fragmentation (missed information, repeated tests, etc.) for those who use it, it doesn't cure the disease - and could inadvertently entrench the siloed status quo if not accompanied by broader integration efforts.

# Position B: Data Literacy + Autonomy (AI Copilots with Personal Health Data)

• Concept: This position explores giving intelligent agents (like a health-focused *Copilot* based on ChatGPT or similar AI) access to a patient's structured personal health data, under the patient's direction. The idea is that an AI assistant can help interpret and make use of health information on the patient's behalf – enhancing the patient's understanding and autonomy in managing their health. Essentially, the patient wields an AI "coach" or "translator" that turns raw data into actionable

insights or guidance. This relies on the patient having or being able to access their data (as in Position A), and then the AI being permitted to analyze it.

#### Benefits/Opportunities:

- Personalized Insights and Education: An AI copilot could sift through a patient's records (labs, medications, doctor's notes) and **explain them in plain language**, answer the patient's questions 24/7, and even highlight significant trends. For example, it might notice that a patient's blood pressure readings have been creeping up over the last year and suggest this be discussed with a provider, or explain how a new prescription should be taken and what side effects to watch for. This kind of support **augments health literacy** patients can better understand their conditions and care plans, going beyond the limited time they get with physicians. It's like having a knowledgeable health tutor on demand.
- Data Synthesis and Convenience: Many patients, even if they have access to their data, find it overwhelming to interpret (e.g., a list of lab values or clinical reports with jargon). An AI agent can summarize and prioritize information. For instance, if a patient has 100 pages of medical history, the AI could summarize "the 5 key diagnoses and what has been done for each" or generate a history that the patient can share. This not only helps the patient; it could help providers by having a concise summary prepared (with the patient's consent). The AI could also perform checks like drug interaction reviews across all medications from different providers, acting as a safety net.
- Enhanced Patient Engagement: By giving patients a tool to navigate their own health data, we likely boost engagement. Patients who understand their data are more likely to follow through on treatments and ask informed questions. The AI might also motivate healthy behaviors for example, sending reminders based on the data (if blood sugar readings are high, it might gently coach on diet or prompt the patient to follow up). Essentially, it can be a **personal health coach** using the patient's actual data. There are echoes of this in existing technology e.g., smartphone health apps that monitor activity or heart rate and give feedback. The difference here is the AI could integrate clinical data as well, providing a more holistic coach.
- Precedents in Canada (patient-directed data access): Canada has already seen steps toward patient-directed health records:
  - Provincial patient portals (as noted) let individuals download or view their test results and reports. For example, Alberta's MyHealth Records portal allows users to not only view but also print or save a PDF of their lab results or immunizations, which they could share or input into another app.
  - In the late 2000s, recognizing the trend of personal health management, TELUS (a Canadian telecom and health IT company) launched TELUS Health Space a Personal Health Record (PHR) platform powered by Microsoft HealthVault. It was introduced as "Canada's first consumer e-health platform" for lifelong personal health records under the individual's control 40 41. The initiative had high-level support (even Ontario's Privacy Commissioner Ann Cavoukian praised it as empowering for patients) and was an early example of technology enabling Canadians to collect and manage their health data privately. Although standalone PHRs like HealthVault didn't gain mass adoption and HealthVault was later discontinued globally, these efforts showed an appetite for patient-held records.
  - Some healthcare organizations have piloted patient-centric records or data-sharing. For instance, cancer care agencies have given patients access to their treatment summaries; some primary care groups experimented with OpenNotes (sharing doctor's notes directly

- with patients). All these foster the idea that **the patient can be an informed steward of their own data**.
- The rise of mobile health apps and wearables has led many Canadians to track aspects of their health (exercise, diet, glucose levels via continuous monitors, etc.) on their own.
   Increasingly, patients bring these data to discussions with providers. While not the same as an AI reading an official medical chart, it shows that patients are willing to use tech for health insights. An AI copilot is a natural extension it could aggregate *both* clinical and self-tracked data.
- Overall, there is a precedent in policy and public opinion for patient-directed health information. Surveys by Canada Health Infoway consistently show Canadians support greater digital access and are interested in tools to help manage their health <sup>42</sup>. The use of an AI agent is a newer twist, but it builds on a trajectory of patient empowerment.
- Health System Complement: If many patients had AI copilots, this could even help the health system. For example, patients might resolve minor concerns via the AI's advice (within safe limits) rather than calling clinics as often. They might come to appointments better prepared (the AI could help them formulate questions or even compile a concise history to tell the doctor). In a way, this could make patient-physician interactions more efficient and focused. It's like each patient comes with a personal assistant that has organized their thoughts and data. Long-term, if such tools are widely used, some envision that it could offload certain educational or routine tasks from healthcare providers (who often repeat basic instructions) and allow them to focus on more complex decision-making.

#### · Risks and Caveats:

- **Privacy and Data Security:** Allowing an AI (especially cloud-based services like ChatGPT) access to personal health data raises **serious privacy concerns**. Medical information is highly sensitive, and AI models might store or learn from that data beyond the patient's direct control. For instance, data given to a large language model could inadvertently become part of the model's training dataset <sup>43</sup>, which "can be disclosed to unintended audiences and used for various purposes without authorization" <sup>43</sup>. Unlike a hospital system, which is bound by health privacy laws, a general AI service might not fall under the same regulations (OpenAI, for example, is not a healthcare entity bound by HIPAA/PHIPA) <sup>44</sup>. If a patient uploads their medical record to a third-party AI, they may be **forfeiting some privacy protections**. There's also the risk of data breaches the more places data goes (e.g., from hospital to patient to AI cloud), the more opportunities for it to be intercepted or misused. This risk is not just hypothetical: it's a top concern of policymakers and researchers as AI penetrates health care <sup>45</sup> <sup>46</sup>. Mitigations could include using **local or on-device AI** (so data never leaves the patient's device), or AI models designed to purge memory of personal data, but these features are nascent. Without strong safeguards, the **trust of both patients and providers could be undermined** by fears of who else sees the data.
- Accuracy and Safety of AI Guidance: Current AI models like ChatGPT are not infallible they can generate incorrect or even absurd answers ("hallucinations") with a confident tone. In a health context, misinformation or misinterpretation can have real consequences. If an AI misreads a lab result or gives a wrong recommendation (e.g., "Your chest pain is likely nothing to worry about" when it could be serious), patients might be harmed by false reassurance or faulty advice. Even if the AI is mostly accurate, subtle errors could erode its credibility or, worse, lead a patient down a dangerous path. At present, AI is not a clinician, and it doesn't have judgment it might miss the nuance or unique aspects of a case. There is a risk that patients might over-rely on AI without consulting professionals, or misunderstand the AI's output. For example, an AI might summarize a pathology

report in a scary way, causing undue alarm, or conversely underplay something critical. Ensuring that AI copilots are **safe**, **calibrated**, **and transparent about their limits** will be crucial. Possibly, they should be seen as supplementary ("inform your discussions with your doctor") rather than diagnostic or prescriptive. Regulators in Canada (like Health Canada) would also have to consider whether such AI tools fall under medical device regulations if they start influencing care decisions.

- Digital Literacy and Equity (again): Using an AI copilot presupposes that patients can access and understand it. There's a risk that these advanced tools might primarily benefit the digitally savvy segment of the population, potentially leaving others out. If healthcare advice and interpretation start coming via AI, those without access (due to lack of technology or skills) might be further disadvantaged. Also, the quality of AI output depends on the quality of data input patients with incomplete records or less ability to articulate questions may get less useful help, potentially widening gaps in health outcomes.
- Consent and Ethical Issues: If patients do choose to share data with an AI, do they fully grasp what they are consenting to? There's an ethical duty to ensure informed consent users should know how the AI works, what happens to their data, and that it's not a substitute for professional care. Another aspect: if the AI identifies a serious issue (say it suspects a certain condition from the data), what should it do? There may need to be guidelines for escalating urgent findings (e.g., "Contact your doctor immediately"). Without integration to the health system, the AI might alert the patient, but if the patient ignores it, the system has no way of knowing. These scenarios need careful thought.
- Integration with Providers: Currently, many clinicians are unfamiliar or uneasy with AI interpretations that patients bring. A patient might say, "My health app says I'm at risk of X, doc." This can create extra work for providers to validate or explain. If the AI copilot becomes common, providers will need to adapt perhaps even have access to a physician-facing view of the AI's analysis. Otherwise, there's a risk of conflict ("The AI told me this new drug is dangerous, why are you prescribing it?"). Without alignment, the AI could inadvertently undermine professional advice or sow confusion. This is not an insurmountable issue, but it highlights that introducing AI to patient data flows will require clinician education and possibly endorsement (or provision of "approved" AI tools) to ensure everyone is on the same page.
- Examples/Precedent in Canada or Abroad: While the idea of a ChatGPT-like copilot for patients is very new, we can see precursors:
- The Canadian startup scene has some AI-driven health assistants (for example, chatbots for mental health or triage like *Ada*, *Babylon* in certain provinces for symptom checking). These show that people are willing to interact with chatbots about health questions, though these tools typically don't have access to the user's medical record. Marrying the chatbot with the record is the next step.
- Internationally, the concept of "Blue Button" in the US allowed patients to download their health data, and some third-party apps used that data to provide personalized advice or reminders. Apple's Health app now can integrate health records from connected hospitals (a few in Canada have started participating), and Apple provides some simple analytics on that data for users. We can think of the copilot as a more sophisticated version of these personal data aggregators combined with AI analytics.
- A specific precedent: In 2019, the **Mayo Clinic** partnered with an AI company to create an assistant for their patients (allowing queries on health info). And more recently (2023), some large US

providers have begun experimenting with GPT-4 for patient-facing tools (with guardrails). Canada's public system hasn't launched such a tool yet, but given global trends, it's likely in consideration.

• Summary of Position B: Giving patients an intelligent agent with access to their structured health data could *significantly enhance patient autonomy and understanding*. It leverages the growing availability of personal health data (from portals and PHRs) and the leaps in AI capabilities. The benefits are enticing – a more informed, proactive patient population and potentially more efficient healthcare utilization. However, there are serious **risks around privacy, accuracy, and equity** that must be managed. Precedents show a trajectory toward more patient control of data; the AI copilot could be a powerful realization of that, provided it's implemented responsibly.

# Position C: Alternative to API-First Integration (User-Led Data Management vs. System Interoperability)

- Concept: Traditional health IT integration focuses on connecting systems via standardized APIs and messaging standards (like HL7 v2, and now HL7 FHIR) essentially an "API-first" approach where institutions exchange data directly computer-to-computer. Position C posits an alternative: user-led health data management as a complement or even replacement to building complex cross-system interfaces. Instead of investing solely in making every hospital, clinic, and lab system interoperable in real-time (a slow and expensive endeavor), the health system could enable patients to pull their data from each source and carry it with them (digitally), using tools (like the Copilot) to integrate it for their personal use. In short, it's shifting from system-centric interoperability to patient-mediated interoperability.
- Implications for Data Standards: In an API-driven integration, much effort is spent on agreeing on data schemas, coding systems, and transaction protocols so that when data travels from point A to B automatically, it's correctly understood (e.g., ensuring one system's "CBC" lab test maps to another's "Complete Blood Count"). If each user is the integrator, one might think formal standards become less important - after all, a human or their personal app can interpret the different reports. However, in practice, standards are still critical for user-led exchange to be effective. For example, if a patient downloads their immunization record from Province A to show a provider in Province B, a standard like Pan-Canadian HL7 FHIR immunization profile or even a simple common PDF format ensures the data is usable. Without standards, the patient might have data that no one else can read or trust. So, while user-led management bypasses some need for system-to-system messaging, it still benefits from common data definitions. In fact, to truly empower patients, systems should output records in machine-readable, standardized formats (like FHIR JSON or CDA documents) that personal health apps (or AI copilots) can ingest. Canada's interoperability roadmap emphasizes common standards to "enable seamless flow of health information among... patients and providers" 47 - notably including patients in the loop. So, the alternative approach doesn't eliminate the need for standards; it shifts the implementation focus. Instead of building many complex realtime interfaces, the priority could be to ensure every provider can give the patient a standard digital copy of their data. This is arguably simpler (one data-sharing touchpoint per provider-to-patient,

rather than many provider-to-provider). The bottom line: **Data standards remain foundational** – the approach changes how they're applied (patient pull vs system push).

- Data Safety and Quality: One advantage often cited for direct system integration is that it reduces human error – for instance, e-prescribing via integrated systems can prevent transcription mistakes. In a user-mediated model, there's a risk of errors creeping in during manual handling. A patient might download the wrong document, or mix files from different dates, etc. There's also the issue of partial or outdated information: a provider might update their record, but if the patient doesn't fetch the new data, they carry an old version. By contrast, an API-linked system could update continuously. This could have safety implications. For example, consider allergies: if a patient's allergy list is updated in one system but they haven't updated their personal record and show an outdated list to another provider, a medication error could occur. To mitigate this, the onus would be on patients to regularly refresh their data from each source – which is not trivial. Some technological help can be provided (apps could automate fetching new records if portals allow it via APIs). Nonetheless, the lack of automatic, real-time data syncing is a safety concern. Any user-led approach needs fail-safes (perhaps alerts like "your data from Clinic X is 6 months old, consider updating it"). It introduces a new category of quality assurance problems - essentially, personal health record reconciliation – that currently is handled by the health system (through standards and interfaces) in an API-first model.
- · Adoption and Workflow: Relying on every patient to manage their data is a very decentralized approach. Its success depends on widespread adoption by patients and acceptance by providers. One challenge: uneven adoption - some patients will enthusiastically maintain pristine records, others will not engage at all. This could lead to inconsistency in care. Providers might face a scenario where for some patients they get a well-organized data package from the patient, and for others they still have to hunt through faxes and call other offices. This patchwork could be frustrating; many clinicians would prefer a single reliable system. In contrast, API-first integration aims to eventually ensure everyone's data is connected behind the scenes (though it's been slow). With user-led, there might always be a portion of patients who, for various reasons, don't manage their data - those patients' info remains siloed unless the traditional integration is also pursued. **Provider adoption** is another aspect: Will clinicians trust and use patient-presented data? To illustrate, Manitoba has a system called eChart that clinicians use 48, but a physician quoted that after a hospital visit they often lack a discharge summary and must rely on the patient's memory 48. In a user-mediated world, ideally the patient would hand over the discharge summary themselves. Some doctors would welcome that (better than nothing), but others might hesitate to rely on a document that isn't coming through official channels. For it to work, providers must be willing to treat patientsupplied digital records as part of the clinical workflow. That might require policies or even legislation clarifying things like liability (if a doctor acts on a patient's data that turns out to be incomplete, who is responsible?).
- Comparative Speed and Innovation: It's worth noting that a user-led approach could move faster in some respects. Setting up inter-system APIs often involves lengthy agreements, IT development, and testing cycles, especially across organizations and provinces. By empowering users, changes can happen at the speed of consumer tech adoption. For example, if tomorrow a great personal health app comes out, any patient can start using it to aggregate data (provided they can get the data). We've seen analogous patterns in other sectors: sometimes user-driven solutions (like personal finance apps aggregating bank info) leap ahead of industry-wide interoperability. User-led models

can also spur competition and innovation in the marketplace of health apps, potentially leading to better tools than a monolithic government system might build. However, **the caveat** is that health data isn't like other data – mistakes can be life-threatening, and equitable access is a core value, so a purely laissez-faire approach could create risks and disparities. Still, the **agility of a patient-centric model** is attractive given the sluggishness of many top-down IT projects.

- Data Standards vs. User Empowerment a Balance: It's not necessarily an either/or. Even in a client-centric model, using modern APIs (like FHIR) can actually empower users. For instance, some jurisdictions might expose FHIR endpoints for patients to retrieve their records. That's both API-driven and user-driven: the API is there, but it's the user (or their app) calling it rather than another hospital. This "open API for patients" approach could be a sweet spot it uses standards (ensuring consistency and safety) but keeps the patient in control of when and where data moves. The difference from traditional integration is that the patient is the instigator of the data exchange, rather than the health systems doing it automatically.
- Safety and Regulatory Considerations: If user-led management becomes a major pathway, regulators might need to set guidelines for personal health record systems to ensure safety. For example, certification for apps that handle patient data (to make sure they implement updates, security, and standards correctly). Just as electronic medical record systems used by doctors in Canada often go through certification (e.g., by provincial EMR programs), perhaps personal health apps would, too, if they are effectively becoming part of health information exchange. This would bolster trust among providers that data coming from a certified patient app is reliable.
- Adoption Issues Rural and Underserved Populations: A user-led approach could face adoption hurdles in rural, remote, and underserved communities. Those areas often have less robust health IT in the clinics to begin with (some still rely on paper or fax, making digital patient access moot), and patients may have connectivity challenges. The model risks exacerbating the urban-rural digital health gap. On the other hand, if implemented thoughtfully, it *could* help certain remote scenarios e.g., an Indigenous patient in a remote community who often travels for care could keep a personal digital record that any new provider can use, overcoming lack of a shared system. But to realize that, support and training must reach those communities, and the tools must function in low-bandwidth or offline scenarios too. We must ask: will this model work for a patient who has no internet at home or who isn't fluent in English/French? If not, complementary solutions are needed for those cases (such as community health representatives helping manage data, or keeping "copilot kiosks" in clinics where patients can download and print their records to carry).
- Summary of Position C: A user-led health data integration model offers an alternative pathway to the promised land of connected health records. It can be seen as an expedient shortcut leveraging patients' rights to access their data to achieve interoperability from the bottom-up, potentially faster than top-down system integration. It emphasizes patient agency and flexibility over centralized control. However, it introduces challenges in maintaining data standards, quality, and equity of access. It likely isn't a full replacement for API-based system interoperability, but rather a parallel strategy. Over time, the two approaches (patient-mediated exchange and system-to-system exchange) might converge for instance, if patient-driven data sharing becomes common, health systems might build lighter-weight APIs to accommodate it, effectively meeting in the middle. The key issues to address are ensuring that data remains standardized and secure, and that providers and patients can trust the information exchanged through this user-centric route.

#### **Additional Considerations**

- Privacy and Consent (Client as Integrator): When the patient is in control of aggregating and sharing data, the paradigm of consent changes. On one hand, it's very straightforward - the patient decides when to share their info with a provider or an app (consent is explicit and direct). This can be empowering, and aligns with privacy laws that treat the patient as the ultimate owner of their information. However, once the data leaves a health institution's secure environment and is in the patient's hands or devices, it may fall outside the protection of health privacy legislation. For example, if a patient in Ontario downloads their medical file and uploads it to a personal cloud service or AI app, that service is not a "health information custodian" under Ontario's PHIPA law meaning the strong privacy safeguards and oversight that apply to hospitals no longer apply to that copy of the data. Patients might unwittingly expose themselves to privacy risks if they don't vet the tools they use. This raises the need for clear guidance and possibly new regulations to protect patient data even when the patient is the one moving it. Concepts like data ownership, portability, and the "right to be forgotten" become important – if a patient revokes consent, can they truly delete their data from an app? In the user-led model, ensuring patients are educated about these issues is critical. Consent must be informed: patients should know, for instance, that emailing their lab results or storing unencrypted files on their phone could have privacy implications. On the positive side, a patient integrator model could simplify consent in inter-provider exchange: rather than multiple hospitals figuring out legal data-sharing agreements, the patient can just say "I consent to give Dr. X this record" – a model sometimes called "consumer-mediated exchange". This can cut through red tape, but again, relies on patient vigilance. In summary, privacy by design should extend to patientfacing tech: ideally, personal health apps will use encryption, local data storage, and transparent policies so that patients acting as integrators do not inadvertently compromise confidentiality. Policymakers may consider certification or trust marks for apps handling health data, to signal to patients which ones meet high privacy standards.
- Implications for Rural, Indigenous, or Underserved Populations: A recurring theme is the digital divide. Populations in rural or remote areas (including many Indigenous communities) often face infrastructure barriers - spotty internet, less access to devices - and may have lower levels of digital literacy due to fewer opportunities or resources. There's also linguistic and cultural accessibility to consider (many health apps and portals are only in English/French and assume a certain literacy level). If the future of eHealth pivots to a client-centric copilot model, there's a risk these communities could be left even further behind. For example, if discharge instructions at an urban hospital assume the patient will go home and use an app to follow up, but an Indigenous elder from a remote community has no reliable internet, they lose out on critical info. Moreover, trust in technology varies – some Indigenous communities might understandably be wary of digital tools, given historical and ongoing concerns about data sovereignty and misuse. It's crucial that any patient-centric solution is co-designed with these communities, taking their needs into account. Perhaps community health workers can act as proxies or guides for the copilot in areas where individual use is low; perhaps solutions like paper-based or offline digital records (smart cards, USB drives with encryption) need to supplement the high-tech approach. On the flip side, one could argue that a patient-held record is actually beneficial to transient or underserved populations – e.g., a person who travels for specialty care could carry their info back to their local provider. In Northern communities, patients often travel south for treatment; a personal digital record could help local nurses and doctors know what was done. To truly realize that benefit, investment must be made to

build **capacity in those communities** – training, tech infrastructure, and ensuring the tools are culturally safe and user-friendly. Special attention is needed so that eHealth advancements do not inadvertently widen health inequities but instead help close them.

• When Clients Maintain Better Records Than Providers: We are approaching a reality where a diligent patient might have a more complete health record on their phone than any single provider has in their EMR. This flips the traditional information hierarchy. There are already cases: for instance, parents of children with complex illnesses often keep binders with every report, and they sometimes educate a new specialist on the history more thoroughly than the referral info provides. If digital copilots make it easier, more patients will do this. Pros: Care can improve - if a patient can show all their test results, allergies, and medications to every provider, mistakes due to missing information (which are unfortunately common) could decrease. Patients with "better records" can also catch discrepancies: e.g., "Doctor, I see you wrote I had X last year, but actually it was Y, and here's the report". In that sense, it's like having a second set of eyes, potentially improving accuracy. **Cons:** This situation can challenge professional roles. Some clinicians might feel undermined or defensive if patients have data they don't. There could be confusion over which information is the source of truth. For example, a provider's record says the patient is on 3 medications, the patient's says 5 (because two were prescribed by another doctor and not updated in provider A's chart). Whose list is considered current? Ideally, this prompts providers to update their records accordingly (with the patient's help), effectively using the patient's record to reconcile - a process known as **medication** reconciliation, which could be greatly aided by patient input. However, it requires a culture shift where patient-contributed information is valued and verified rather than dismissed. Another concern: if a patient's record is better and something goes wrong because a provider ignored it, liability could become an issue ("the patient told you they had an allergy, but you didn't note it"). Conversely, if a provider relies on the patient's data and it was incomplete, that's also problematic. Clear quidelines will be needed on how to incorporate patient-maintained records into clinical decision-making. Some healthcare systems in other countries have started to formally accept patient-generated data (e.g., home blood pressure readings, patient-reported outcomes) into the medical record. We may see similar with patient-aggregated records – maybe even a function in EHR systems to upload the patient's file and have it systematically match against the clinic's records to identify discrepancies. Ultimately, if patients end up maintaining the most comprehensive record of their health, the health system should leverage that, not fight it - by developing trust frameworks and technical means to merge that data for safer care.

#### **Conclusion and Recommendation**

• Viability of a Client-Centric Copilot Model: A patient-centric "Copilot" approach – where individuals aggregate their health data and use AI assistants to interpret and share it – represents a **bold shift** in eHealth thinking. It is not a panacea for Canada's health information woes, but it *could be a viable pivot point* that accelerates progress. The Canadian eHealth journey over the past decades has yielded infrastructure (digital records, portals, standards) but still struggles with siloed information and slow integration. Empowering patients as active data stewards offers a way to **inject energy and new perspectives** into the system, aligning with modern expectations of user empowerment in the digital age. It effectively adds a "bottom-up" strategy to complement the long-running top-down efforts. Many benefits are evident – improved patient engagement, a potential reduction in information gaps, and perhaps even system cost savings (as patients help coordinate their care,

avoiding duplicate tests or adverse drug events through better information sharing <sup>32</sup> ). Moreover, Canadians appear ready for more digital health empowerment, as evidenced by high interest in accessing records and digital tools <sup>42</sup> . **However, for this model to succeed, several conditions must be true:** 

- Universal Digital Access: Patients must be able to easily obtain complete, up-to-date electronic copies of their health information from all points of care. This requires every provider from large hospitals to small clinics to have some mechanism of patient data access (be it a portal, download link, or even standardized email/fax by request). Gaps in availability of data will quickly erode the usefulness of any personal health copilot. In practice, this means continuing to invest in digital health records at lagging institutions and implementing the Pan-Canadian Interoperability Roadmap commitment that patients have online access to their health info 36. Common standards (like FHIR APIs for patient access) should be mandated as part of system funding so that, for example, labs in every province expose results to patients in a consistent way. Without near-universal coverage, the copilot will only have partial information and its utility and uptake will suffer.
- Data Standards and Quality Assurance: Building on the above, the data that patients obtain should be in consistent, machine-readable formats to maximize the copilot's effectiveness. Achieving this calls for adherence to standards (clinical terminology, data models) when organizations implement patient data access. It also means the data should be comprehensive and accurate if a hospital's system is prone to errors or missing info, giving that to patients doesn't magically fix it. So data quality initiatives (ensuring, say, medication lists are reconciled, or diagnostic codes are correct) are important. The copilot model will highlight any data issues (patients will quickly spot if something looks off). A positive side effect is that this could pressure providers to improve their data quality. But initially, ensuring the copilot isn't analyzing garbage data requires attention to back-end data integrity on the health system side.
- Robust Privacy and Security Frameworks: To gain public trust, the use of personal health data with AI must have ironclad privacy protections. This might entail technical solutions (on-device AI processing so data isn't sent to the cloud; strong encryption of any data in transit; zero-trust architectures for apps) and/or regulatory measures. For instance, Canada could update privacy laws or guidance to explicitly cover patient-mediated data sharing making sure that third-party apps handling health info adhere to comparable standards as healthcare providers. Certification or accreditation of "Health AI Copilots" could be introduced, so patients know which tools are vetted. Open-source or government-endorsed AI models might be developed to keep trust high. Essentially, without clear privacy guarantees, both patients and providers will be hesitant. High-profile breaches or misuse could set the concept back significantly. Therefore, privacy by design is a non-negotiable condition the model must prove that it can safeguard sensitive data at least as well as the status quo. This includes obtaining informed consent in a user-friendly way. Canadians must remain in control of who sees their data and for what purpose at all times, even as the copilot automates some tasks. Recent experiences (like contact tracing apps during COVID) show that if privacy is well-addressed, many people will participate; if not, adoption stalls.
- **Digital Literacy and Patient Support:** A copilot is only as good as one's ability to use it. Widespread **digital literacy initiatives** will be needed so that all segments of the population can benefit. This could mean integrating digital health skills into patient education (e.g., hospitals teaching patients how to access and use their portal and AI tools upon discharge) or community programs (public

libraries and seniors' organizations helping people learn these tools). Special focus should go to marginalized groups – for example, providing multilingual support, adapting tools for those with disabilities (visual/hearing/cognitive impairments), and ensuring content is culturally appropriate. Additionally, some patients may prefer a **human intermediary** – for instance, a patient could authorize a family member or health navigator to use the copilot on their behalf. Policies should accommodate such delegation in a secure way (like caregiver access provisions). The success condition here is that **no one is left unable to use the new model due to lack of knowledge or assistance**. If significant portions of the population remain uncomfortable with technology, the healthcare system must continue to offer traditional means in parallel, or provide training wheels (maybe a simpler "dial-a-copilot" telephone service could even be envisioned for those without devices). In summary, *human support for the digital tool* is crucial during the transition.

- · Healthcare Provider Buy-In and Workflow Integration: The health system must adapt its workflows to incorporate patient-generated or patient-curated data. This means developing trust and verification protocols for information coming from the patient's copilot. For example, a clinic might establish a process to rapidly review and import data a patient brings from their copilot (perhaps using a standard summary format). Professional bodies and regulators should provide quidance on medicolegal questions, clarifying that considering patient-provided health information is part of good care (just as considering a referral note is), while also advising how to document it. If physicians view the copilot as a threat or extra hassle, they may resist. But if they see it as a helpful aide (imagine a consult note auto-generated by the patient's copilot that the physician finds accurate and time-saving), they will embrace it. Early engagement of clinicians in designing these tools will help ensure the output is useful and presented in a familiar way (for instance, using standardized summary templates). Change management efforts – showing success stories, training providers on how to guide patients in using the tools appropriately - will be important. The condition for success is that using patient-mediated data becomes seamlessly integrated into care, not an awkward add-on. This might involve updating electronic health record systems to easily ingest patientsubmitted data, with appropriate annotations (so it's clear what came directly from a patient). Ultimately, a cultural shift is needed such that the health system values patients as partners in information management rather than seeing it as solely an IT department task.
- Equity and Inclusion: It must be ensured that this new model benefits all Canadians, not only the tech-enabled majority. As discussed, particular measures for rural, remote, and Indigenous communities are needed such as government investment in rural broadband (which is happening), provision of devices or digital health kiosks in underserviced areas, and designing the copilot with intercultural input. Perhaps partnerships with Indigenous health organizations to create culturally relevant interfaces or to store data in a way that respects Indigenous data sovereignty could be part of the plan. For low-income individuals, there could be subsidized access programs (similar to how some jurisdictions provided free internet or phones for virtual care access during the pandemic). An equity lens should be applied at every stage of implementation. Success will be measured not just by overall adoption, but by adoption across demographic groups if urban affluent uptake is 80% and remote uptake is 20%, the job isn't done. Policymakers should set targets to close these gaps. Inclusion is also about involving patients and diverse communities in the co-design of the copilot system from the start, so it truly meets people's needs.
- **Recommendation:** Embrace the client-centric copilot model as a **complementary strategy** to ongoing eHealth initiatives, rather than a wholesale replacement. Canada should pilot this approach

in a controlled manner - for example, select a region or a clinical area (like chronic disease management) to roll out a patient data access + AI copilot combo, and evaluate outcomes (e.g., patient satisfaction, health outcomes, provider feedback, system utilization changes). Early successes will build momentum and confidence. If pilots demonstrate improvements - say patients are avoiding duplicate tests, or managing medications better - then scale up quickly, because those are exactly the improvements the eHealth investments have long promised 6. That said, one must be clear-eyed about the challenges: this model will only succeed if the conditions above are met and if all stakeholders (patients, providers, government) collaborate in its development. It is viable indeed, likely inevitable – that patients play a greater role in managing health information. The question is whether we do it in a way that is organized, secure, and equitable. With Canada's strong public healthcare values and the technical groundwork laid over 20+ years (Infoway's standards, widespread EHR adoption, etc.), the country is well positioned to pivot to a more patient-centric digital health paradigm. The client-as-integrator with an AI copilot could very well be the catalyst needed to finally break through the interoperability logiam, provided we ensure no one is left behind and trust remains at the core. In conclusion, the recommendation is to proceed with cautious optimism: start integrating this model into national and provincial eHealth strategies - make the necessary policy and infrastructure adjustments – and treat patients not just as recipients of care, but as empowered partners in managing health data and driving better health outcomes for themselves and the population.

#### Sources:

- Office of the Auditor General of Ontario *Special Report on Electronic Health Records Initiative* (2009)
- Canada Health Infoway Richard Alvarez commentary in Health Innovation Forum (2011) 15 11 16
- Canada Health Infoway *Investment Highlights* (circa 2010) 9 14
- Auditor General of British Columbia Audit of Panorama Public Health System (2015) 26 27
- Canada Health Infoway / CIHI Digital Health Surveys (2023) 31 29 32
- CIHI Interoperability and Health Data Sharing Report (2024) 52 38
- Wikipedia eHealth Ontario (summarizing Ontario eHealth scandal and history) 20 21
- Digital Health Canada (archived) TELUS Health Space (HealthVault) Launch (2009) 40 41
- Alberta Health Services Connect Care Backgrounder (2020s) 33 34
- Journal of Medical Internet Research *Security Implications of AI Chatbots in Health Care* (Xu et al., 2023) 45 46
- Canadian Medical Association Journal (CMAJ) National disease surveillance "dream delayed" (2013) 28
- Canadian Institute for Health Information *Shared Health Priorities Data Access and Sharing* (2023) 36 39

1 2 3 4 6 17 18 49 50 51 Ontario's Electronic Health Records Initiative — Special Report, October 2009

 $https://auditor.on.ca/en/content/specialreports/specialreports/ehealth\_en.pdf$ 

5 Electronic Health Records in Canada—An Overview of Federal and Provincial Audit Reports—April 2010 https://www.assembly.pe.ca/sites/test.assembly.pe.ca/files/overview-electronic-health-records-in-Canada.pdf

## 7 8 9 10 11 12 13 14 15 16 What happened to the last billion dollars in health information technology? | Health Innovation Forum

https://www.healthinnovationforum.org/article/what-happened-to-the-last-billion-dollars-in-health-information-technology-2/

19 20 21 22 eHealth Ontario - Wikipedia

https://en.wikipedia.org/wiki/EHealth\_Ontario

#### 23 National electronic disease surveillance: a dream delayed - PMC

https://pmc.ncbi.nlm.nih.gov/articles/PMC3680568/

24 25 26 27 caaf-fcar.ca

https://www.caaf-fcar.ca/auditnews\_map/auditnews/documents/3868\_1\_OAGBC\_PanoramaReport\_FINAL.pdf

#### <sup>28</sup> [PDF] An Audit of the Panorama Public Health IT System

http://www.e-healthconference.com/wp-content/uploads/2016/07/CS48.02-Conference-presentation-Panorama\_FINAL.pdf

## 29 30 31 32 36 37 38 39 42 47 48 52 Canadians and health care providers want connected electronic health information systems | CIHI

https://www.cihi.ca/en/taking-the-pulse-measuring-shared-priorities-for-canadian-health-care-2024/canadians-and-health-care-providers-want-connected-electronic-health-information

#### 33 Connect Care launches Nov. 3; thousands of clinicians involved to ...

https://www.albertahealthservices.ca/news/releases/2019/Page15293.aspx

#### 34 Canadian health system signs \$459M deal for Epic EHR

https://www.beckershospitalreview.com/healthcare-information-technology/ehrs/canadian-health-system-signs-459m-deal-for-epic-ehr/

#### 35 Alberta expands Epic EHR across the province

https://www.canhealth.com/2024/11/06/alberta-expands-epic-ehr-across-the-province/

#### 40 41 Microsoft licenses HealthVault for Canada | Digital Health

https://www.digitalhealth.net/2009/05/microsoft-licenses-healthvault-for-canada/

43 44 45 46 Security Implications of AI Chatbots in Health Care - PMC

https://pmc.ncbi.nlm.nih.gov/articles/PMC10716748/