THE LINUX FOUNDATION | Research

An Open Architecture for Health Data Interoperability

How Open Source Can Help the Healthcare Sector Overcome the "Information Dark Ages"

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Foreword by
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October 2024

An Open Architecture for Health Data Interoperability

Healthcare is a unique and complex sector that is **highly regulated**, is **risk averse**, and must consider a **diverse set of stakeholders.**

Health data is siloed and its exchange hamstrung by entrenched incumbent record systems that **lack interoperability.**

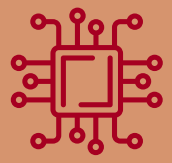
The European Health Data Space and the **Trusted Exchange Framework & Common Agreement** are two examples of initiatives working to enhance health data exchange.

Common misperceptions of open source, such as **a lack of technical & legal support and commercial inviability**, also exist in the digital health sector.

Open source digital health solutions can **increase health equity, de-risk innovation, and remove vendor lock-in.**

Open source solutions are gaining traction in Europe and developing countries, embracing efficiency and agility in regions that prioritize collaboration and cost savings.

Two examples of open source solutions are **DHIS2**, used for data management in over 100 countries, and **SORMAS**, used for outbreak monitoring in over 15 countries.



Artificial intelligence holds significant promise in healthcare, and its data needs may catalyze the development of more effective data exchange infrastructure.

A precompetitive digital health architecture would standardize the components of the system and allow for the development of applications that are portable, sustainable, and interoperable.

To build lifelong records, data must be **semantically standardized and patient centric**, separating the data from the applications and using a common data store.

Innovative and agile solutions can work around incumbent platforms, allowing for **bottom-up development** and an opening up of the digital health market.

A neutral foundation is necessary to create **a center of gravity for open source health solutions** to collaborate, learn, and standardize around a precompetitive layer.

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Foreword

The proliferation of digital health data has led to siloed systems, making it difficult for stakeholders to access and share information, which ultimately limits research and patient care. The healthcare sector faces significant hurdles in data interoperability due to the nonstandardized nature of electronic health records (EHRs), which complicates access to and sharing of health data. The unique characteristics of healthcare, such as unpredictable demand, ethical obligations, and strict regulations, contribute to the complexity of managing health systems and hinder effective digitalization. Effective governance is critical but often overlooked in health technology projects. Poor governance can impede the success of digital health initiatives and lead to ineffective implementations.

As this report from the Linux Foundation illustrates, open source solutions offer a promising avenue for enhancing healthcare data management by promoting collaboration, transparency, and cost-effectiveness, although adoption faces resistance due to misperceptions. Proprietary EHR systems create vendor lock-in, limiting flexibility and the ability to customize solutions to meet specific healthcare needs, which can negatively impact patient care. Open source projects benefit from community involvement, which can provide ongoing support, reduce dependency on single vendors, and enhance the sustainability of healthcare solutions. The ethical dimension of healthcare aligns well with open source principles, emphasizing the need for transparency and shared knowledge to improve patient outcomes and public health.

The practice of using encryption for protecting intellectual property (IP) dates back to Galileo in 1610 and has roots in ancient civilizations, highlighting the long-standing need for safeguarding valuable information. The modern open science movement aims to democratize access to scientific knowledge, addressing historical inequities and promoting transparency, accessibility, and inclusivity in research and innovation. Key milestones, such as the Budapest Open Access Initiative and UNESCO's 2021 Recommendation on Open Science, underscore efforts to make science more equitable and accessible. The COVID-19 pandemic demonstrated the potential of open science for rapid data sharing and collaboration, highlighting the importance of equitable access in global health responses..

But despite its ideals, open science faces challenges, including structural inequalities and entrenched systemic practices that hinder equitable access to knowledge and material resources. Open science does not unfold in a vacuum but in an ecosystem besieged with power dynamics and knowledge hierarchies, marginalizing certain groups and countries and affecting their credibility and access to scientific discourse and engagement. The dominance of the Global North in scientific endeavors creates disparities, with actors including innovators from low- and middle-income countries often facing barriers to collaboration. A radical reimagination of open science is necessary, advocating for the inclusion of marginalized voices and addressing existing power imbalances in the technological community. Ultimately, the impact of open science, just like any other disruptive innovation, hinges on who sets the agenda and who controls the movement.

At this moment of reimagination, important change can start within the open source community. We hope that this report inspires readers to initiate the next wave of development, collaboration, and innovation for the health technology sector.

LEO ANTHONY CELI
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Executive summary

This Linux Foundation research report reviews the adoption, perceptions, and potential of open source in health data infrastructure. It starts with an overview of the unique characteristics of the healthcare sector and how this impacts innovation and digitization. It then focuses on the primary problem statement of this research, namely the lack of interoperability between data systems and how this hinders data sharing. It addresses a number of reasons why there is a lack of interoperability, including the market power of incumbent electronic health record (EHR) systems. Turning to open source, the research discusses the perceptions of and challenges to open source adoption in the health tech sector and how the sector's interoperability challenges make it a relevant application for open source. After addressing the way that artificial intelligence (AI) could potentially catalyze a transformation of health data collection practices, the report concludes with recommendations on how to move forward, including the development of an architecture of standards and technologies to increase innovation and data sharing.

The state of the health tech sector

The digital transformation of healthcare has led to the exponential growth of data stores useful for providers, researchers, institutions, and companies to improve care for patients. A significant aspect of this digital transformation was the introduction of EHRs around the world, which are digital systems used to capture and manage health data, primarily in a hospital setting[1]. Despite widespread adoption of EHRs, accessing this data remains difficult, as these systems do not interoperate well with each other. For any individual engaging in healthcare systems around the world—as a patient, a provider, a researcher, an administrator, or an IT manager—it is clear that the sector suffers from poor portability of data.[2] This problem stems from technological, regulatory, cultural, and operational particularities that, in combination, make this sector uniquely challenging to effectively digitalize.

Open source communities have driven major new technological shifts, from the digitization of vehicles to 5G telecommunications to AI, by building the shared infrastructure for those transformations. Health data systems are in need of a similar transformation that prioritizes collaboration, transparency, and interoperability. These facets are fundamental to the open source value proposition, and yet major stakeholders in healthcare are absent from open source communities. LF Research undertook this research study to understand open source adoption in this space, what challenges exist, and how the LF could play a role in accelerating interoperable, digital healthcare systems. From the perspective of open source technologists, this report captures the reasons for the lack of data interoperability in the healthcare sector and the impact that this has on care and research, highlighting the obstacles to open source adoption as well as the ways in which a health-specific open source architecture of standards and technologies could address this issue.

Healthcare as a unique and complex sector

The healthcare sector has a number of particular characteristics that, combined, make it unique. From a market perspective, healthcare is not a typical industry sector due to a number of factors:[3]

The irregular, non-fungible, and lifetime demand for healthcare: When a patient demands healthcare, this typically comes at unpredictable times and often becomes urgent. Arun Kumbhat, Director of GoToMarket, HR, and PR Services for Libra Social Research Foundation, called health "a non-fungible subject," which, when combined with its nonlinearity and urgency, makes it "completely different from consumer goods, direct-to-consumer businesses, banking, finance, and insurance." He also explained how a patient may require follow-up or preemptive treatments throughout the progression of a disease, which necessitates a "continuous personal health record."

The ethical and moral expectation placed on physicians: Unlike most other markets, the relationship between the patient and the provider rests on trust that the provider has the best interests of the patient in mind during treatment. This trust layer is significant due to the risk on the line for the provider, where their decisions could mean the difference between life and death.[4] This places a moral and social obligation at the center of this market, which according to a professor at a European university of technology, makes it "a very specific sector... It's public or social purpose driven."

The strict and complex regulatory landscape: Healthcare is a highly regulated sector.[4] As Alex Scammon, Head of Open Source Development at G-Research, explained, the regulatory characteristics of the market introduce significant financial considerations for those developing healthcare products and services. He noted that the high-risk nature of a healthcare product increases the time and cost it takes to get approval, and, as such, "it takes a huge amount of resources to get things past the regulatory hurdles ... That does seem more unique [in healthcare] than in big tech, for example." Although these regulations are important from a safety perspective, some were written without the internet in mind or before smartphones, such as HIPAA, making them less relevant and potentially obstructive in the current context.

These unique aspects of the healthcare market contribute to the complexity of health systems management, where many different stakeholders in highly dynamic settings with strict governance mechanisms accomplish numerous and diverse tasks and decision processes.[5][6] As Dr. Tony Shannon, Head of Digital Services at the Office of the Government Chief Information Officer within the government of Ireland, argued, "hospitals probably are the most complex organizational unit on the planet—there is so much going on in a typical hospital." Any transformations, technological or otherwise, in a healthcare system must consider a significant number of stakeholders and their interests, the regulations and risks in place, and the unique trust relationship between patient and provider.[4]

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Head of Digital Services
Government Chief Information Officer
Government of Ireland

The people and processes behind digital health transformation

Given the complexity of the health sector, its digital transformation has been a slow and fragmented process. The transition from paper to digital charts is a clear example of this. A senior consultant at a global consulting firm, explained that the implementation of digital records for the most part "didn't bring the tool, the technology, into the process of what the doctor is doing. And so it's an extra step, instead of being integrated into what they're doing." She went on to say, "if the technology isn't following their pathway, they're not going to use it." This usability issue is well summed up in the fact that there is an entire industry of medical scribes to put health data into the digital system. "What other industry would tolerate an industry of scribes working alongside professionals to feed the information beast?" Shannon lamented.

Shannon's own interpretation of the challenge with digital transformation is due to the fact that it comes down to a complex convergence of people, process, and technology, with human resources all siloed within three domains: "The medical professionals are trained in the clinical domain but don't understand technology; the technologists are trained in the technical domain but don't understand the clinical domain; and the management administrators are trained in management science but don't understand either the clinical process or the technical stack." Despite this complexity, he argued that all clinical domains contain generic patterns in their processes, which are key to more effectively managing health data. Identifying these generic patterns helps institutions align and interoperate IT infrastructure across healthcare environments, but without this alignment, the problem remains complex and siloed.[7] [8]

This convergence of technology, people, and process echoed across the interviews. Dr. Pankaj Gupta, Non-Executive Director of Libra Social Research Foundation, made a similar comment, arguing that "in healthcare IT, you need the business processes that are semantically standardized, you need physical and IT infrastructure that is well developed, you need the human resources that have crossover skills between healthcare and technology." A professor at a European university of technology explained the difficulty in ensuring that all these different facets work well together. "My medical colleagues, it's not their business to deal with data or technology, you know, they don't have time. So, you need new positions or interested parties who can do that. But it's very difficult to connect and trust other partners who might be proficient in technology or data analytics." From a health research perspective, David Buckeridge, Professor at McGill University, concurred: "The challenge is, you need a lot of perspectives to make sense of this, right? You need the research ethics board perspective, you need a substantive analytical research perspective, and you need the IT security perspective. They all have to come together and look at this issue and make a sort of determination about it. And it's challenging to get those people together, period, but also to get them together and have a discussion around issues like this." Similarly, Jared Keller, an independent data sharing researcher and consultant, pointed out that the proper management of a health technology requires technical people, lawyers, and businesspeople: "They're never all the same person, and it's hard to get them to talk to each other."

Understanding these different perspectives is important to have well-functioning, effectively governed, and sustainable projects. Limiting the focus of the project to defining the technology infrastructure ignores the potential institutional or social obstacles, which are just as important to consider.[9] Keller made the point that, in his experience, governance is always the last thing to undergo consideration. "There is a temptation to start with the tech, but that can lead people astray." Buckeridge

agreed that governance is one of the most significant obstacles to implementing digital health projects, but he pointed out that it is also one of the hardest elements to get right. "With everything I've built in terms of data analytics infrastructure, the governance is the hardest part. And if you don't figure it out ahead of time, it's a real headache, but at the same time, if you wait to figure it out, you may not get anything done."

Putting governance considerations on the same level as technical ones is particularly challenging in a sector where resources are not always well financed or well allocated. As a senior consultant at a global consulting firm explained, "the fact that [the Canadian] healthcare system is—I won't say bankrupt, but the belts are being tightened—the risk with that is, when you're doing a big project, the budgets get cut. And often the budgets get cut in the nontechnical streams, which is change management, clinical adoption, training, communication, and so on. And that's where this industry needs it the most. And so, I think the tightening of budgets is hampering the success of implementations." Without these governance and change management mechanisms in place, digital innovations in the health sector may not have the ability to really take off.

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Innovation in digital health

The unique aspects of the healthcare market make it a challenging area for innovation. First, being social purpose driven means that it is not as much of a profit-driven sector. A professor at a European university of technology sees digital health investments falling around the world, tying it to the way that healthcare represents a public good: "There is a limit to the profits you can yield from digital healthcare solutions." Peter Lee, Head of Microsoft Research, agreed with this sentiment, suggesting that there is a fundamental ethical difference between big tech and healthcare. As he explained, investors in big tech companies such as Microsoft demand significant revenue growth, which no healthcare business is capable of doing, reducing the motivation to invest in this sector. This leaves big tech companies to go through a cycle of investing in healthcare and then giving up, according to Lee.

Ian McNicoll, CEO of freshEHR, and a professor at a European university of technology both put the blame on the competencies of tech companies. As The professor stated, "healthcare is too far from their core competence. They jumped into the healthcare value chain without the medical competence." McNicoll pointed out that this cycle happens "because [big tech] is all driven by data analysis and not by direct care … They have a lot of experience in data analysis, but it's downstream from the frontline stuff. And frankly, because the frontline stuff is just too damn hard, they don't want to get involved in that." This leads to restricted investments in healthcare innovations, with concerns about what it will take for true digital transformation in this sector.[10]

On the other side of the spectrum, startups also have difficulties entering the market, as they provide a product or service that is very specific to a particular problem in the health market. A professor at a European university of technology pointed out that when the market is as big as it is, and the product only fits a specific need, "if you do not get into the bigger offerings, you might simply not be useful." As a result, the sector suffers from "pilotitis," where innovative interventions have seen success only in niche and restricted contexts, lacking the ability to scale up beyond their pilot stage.[9], [11] As McNicoll argued, without an ability to plug their offering into other areas of the market, "it's a real drag on innovation—the new little startups who come in, they're having to rebuild the whole infrastructure themselves." The startup's particular product or service is also subject to compliance requirements, which can be very costly and time consuming, such as the HiTrust certification in the U.S.[12]

Second, the slow pace of innovation is in part due to the higher risks in healthcare. Gawande (2012) notes how slowly new processes and medicines trickle down in medicine compared with other consumer areas, where the gap in discovery and implementation is "appallingly" large.[13] The "fail fast and iterate" concept that moves most consumer innovations along is not possible in a sector where the risks are too high to tolerate flaws.[4] From the procurement side, investment in innovative technologies is limited, and instead, hospitals and clinics tend to procure products from vendors. As Buckeridge posited, this procurement strategy "is seen as a way to mitigate risk and decrease requirements for skilled personnel at some level." Niraj Dalmia, Partner in Omnia AI at Deloitte Canada, explained the risk-aversion from a public sector perspective, stating, "In the private sector, there is some more appetite to take risk, especially in non-healthcare sectors due to the 'fail fast and iterate' benefits … The public sector, I would say, is looking for precedent and looking for a little bit more surety that it's been successful, it's been done. And I think, fair enough—

the public sector is spending tax dollars on these softwares, and they want to absolutely make sure it's going to be successful … It's a fine balance that's tricky to achieve, but it has to be obtained to counter the productivity paradox in the healthcare sector that comes with digital and information system implementations." There are also important risks to consider from a data privacy perspective. As a senior consultant at a global consulting firm explained, her work in risk advisory for her clients is "around the privacy and cyber within a technology platform, which is obviously very important for technology implementations where there's health information included in it." The stringent regulations around protecting data make for risk-averse technology implementations.

The unique characteristics of the healthcare market, in combination with the complexity of the various stakeholders and their relationships to one another, has made digital transformation of the sector challenging and restricted.

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Partner in Omnia AI
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Nonstandardized data exchange infrastructure

In this complex regulatory, financial, technical, and governance environment, an important aspect of the health system suffers—health data. As the sector has digitized, and the data available in digital formats has grown exponentially, these different factors have locked data into silos that become challenging or even impossible to access and share. As a senior consultant at a global consulting firm plainly stated, "it's really hard to bring data together to provide value for either the patient or the clinician." Researchers also struggle with accessing data and, as a result, face limitations in their ability to produce outcomes from real-world evidence.[14] "We don't have enough data to do what we want to do. We would like 100 times more, 1,000 times more than what we have," explained Scammon in reference to his work on an open source diagnostic model for hip dysplasia.

This siloed context makes it very challenging to track data across a patient's journey. McNicoll referenced a cancer patient's journey as an example: As they move from symptoms to diagnosis to surgery to treatment, "there's a lot of handover of information at every step … and it's a real challenge to follow the patient through their data." What's more, the health data itself is "uniquely complex, wide, messy, and fractal," McNicoll pointed out. He explained, "it's never actually been mapped. It's all what's in clinicians' heads, it's all in bits of paper. There's lots of confusion and differences of meaning; context is very, very important." Noah Harlan, Senior Advisor at Findhelp, explained how this complexity gets worse when incorporating social determinants of health (SDOH) systems: "There are too many interlocking ecosystems as the notion of care expands outward. And there are too many places where different pieces and combinations of the information need to move." Different data, even data that some may consider adjacent to care, need to be able to come together to build an adequate picture of the patient—and this relies on standards.

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Health data standards and interoperability

Health data is defined using various standards that are meant to make it "computable, understandable, replicable, reusable, and interoperable" across health systems.[15] There are a number of standards developed for different stages of the health data lifecycle: content standards for data creation, code systems for data formatting, information standards for data analysis, exchange standards for data flow, and privacy standards for data protection.[15] Some more popular standards are Fast Healthcare Interoperability Resources (FHIR), SNOMED Clinical Terms (CT), Logical Observation Identifiers Names and Codes (LOINC), and the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM). Many of these are global standards, but there are also regional efforts to standardize health data. For example, a professor at a European university of technology describes how each European country has its own national healthcare record platform, and the European Union is working to build standards to join these platforms together and connect them as a single market.

FOUR COMMON HEALTH DATA STANDARDS

FHIR: Used to standardize medical data in exchange by defining the structure for the core information set that is common to most applications, regardless of how the data is stored.[16]

OMOP CDM: Used to standardize data in rest and for analysis by defining the structure and content of data using a core vocabulary of medical terms.[17]

SNOMED CT: Clinical terminology providing a standardized way to represent clinical phrases captured by the clinician, defining the representation of and the relationship between components of the clinical process.[18]

LOINC: Universal medical terminology of code names and identifiers for laboratory tests and observations.[19]

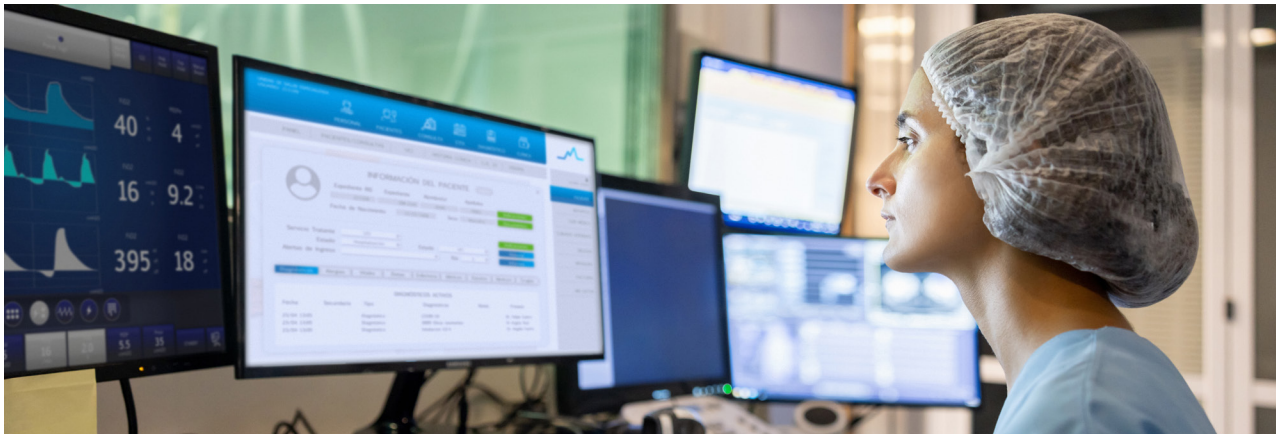
Despite progress in adoption and implementation, these standards have not solved the interoperability issue. The interviewees pointed out that these standards are not adequate to provide real, sustainable interoperability between different health systems. A senior consultant at a global consulting firm explained the issue from a governance and implementation perspective. In Canada, where healthcare is a provincial jurisdiction, the federal government "can put standards up there, but the provinces don't have to follow it. They can do their own thing." This impacts intra- as well as cross-provincial data sharing, where each system can use its own standard. Harlan also commented on this from the American perspective: "[Interoperability] is very hard. The social care programs have different rules, the rules vary from state to state, plus you've got federal rules."

McNicoll gave a similar reasoning from the perspective of the clinician's role and dynamic within the U.K. health system: "It's hard to standardize clinicians to get them to collect data in the same way. They wield more power than somebody in a different profession, you know, a lawyer, for instance, or somebody who's within IBM … where there will be company-wide standards. That's hard to do in health because of the power of clinicians." A senior consultant at a global consulting firm agreed. "When you look at [Canadian] clinicians, they're sole proprietors, for the most part … They can do their own thing a little bit more … so a lot of our time is spent in getting them to agree to a protocol or a pathway or something, across the hospitals, or even within a hospital."

To properly implement these standards requires authority. Janice Spence, Senior Standards Specialist, and Linda Parisien, Certified Terminology Standards Specialist, both at Canada Health Infoway, explained how the Canadian government is currently driving the adoption of SNOMED CT. However, they pointed to the fact that different EHR providers are not wholly compliant and often have limited capacity to fully implement terminology standards. "There is some functionality that is available, but [it's] not maximized," Parisien commented. Spence explained the problem from a governance perspective: "There needs to be drivers in place to say to the EHR vendors or digital health solution providers that they are required to adopt and support approved pan-Canadian and international terminology and data exchange standards, to comply with the standards, and to maintain those standards. Right now, across the country, we have that gap there … We're looking to see where we can have some levers in place to ensure that a compliance framework is actually put in place and maintained."

This leads to vendors who say they are using a standard without being wholly compliant or interoperable, according to an architect at a U.S. health department: "All vendors claim their product is interoperable. And that's 100% not true … The problem with all of the standards is that every vendor can implement them slightly differently, which means there is in fact no interoperability." Described from his data standardization perspective, McNicoll pointed out that there is standardization at the data exchange level, using a standard such as FHIR, but there is not standardization at the data store level. "When we exchange data, we exchange data in this agreed format. And then you can import the agreed format into your system … But the systems still store and manage data in their own internal database formats." Instead, he argued that the standard should be "inside" the data, creating a common format for data, and then the applications can work directly on top of that data.

The lack of interoperability is also the outcome of many different solutions being developed for different purposes in different contexts. Gupta and others pointed to the piecemeal development of health data systems, where "there's no way you can triangulate all these data points, because all these vertical [health] systems built their IT systems at different points in time, in different technologies. And the majority of them do not talk to each other, because they were never designed to do so," Gupta explained. However, the answer is not necessarily to have one uniform software—as a senior consultant at a global consulting firm commented, "interoperability is the answer, not homogeneous technology." A professor at a European university of technology also argued that "one giant solution is not possible in innovation … The way countries are moving is interoperability of diverse platforms." Despite this understanding, we see global EHR markets consolidating around a handful of giant providers.



EXAMPLES OF DATA EXCHANGE INITIATIVES

Several public and private initiatives and frameworks support health information exchange. One such example is the Trusted Exchange Framework and Common Agreement (TEFCA), which the U.S. Department of Health and Human Services Office of the National Coordinator for Health Information Technology introduced in January 2022. TEFCA aims to enhance the digital transfer of health information between participating entities, known as Qualified Health Information Networks (QHINs). Its goal is to establish universal governance, policy, and technical standards to achieve nationwide interoperability, thereby simplifying healthcare data sharing and exchange across organizations. Through its Common Agreement, TEFCA provides a governance framework with baseline legal and technical requirements that apply to all health information networks, ensuring consistent and standardized data exchange.[20]

The European Union recently approved a parallel initiative known as the European Health Data Space (EHDS). The Commission's approach emphasizes data rights, aiming to provide citizens with full control over their health data. This will be facilitated by a legal and policy framework designed to ensure the "free movement of health data," allowing health data to seamlessly follow individuals wherever they go. In practice, citizens will be able to access their health information in a standardized European format, free of charge, and regardless of their location within the E.U. Beyond enhancing personal access, the EHDS aims to foster benefits for research, scientific development, and industry by promoting a "genuine single market" for EHR systems. This standardization aims to simplify the market entry process for EHR providers across member states, promoting uniformity and interoperability. The EHDS is expected to result in substantial cost savings—over €5.5 billion over the next decade—through improved access to and exchange of health data. The initiative is scheduled for formal adoption in the autumn of 2024.[21]

EHR incumbent market power

Today, the developed world largely relies on a handful of major proprietary EHR platforms to handle hospital data. The two that primarily came up in interviews were Epic and Cerner—who collectively hold over 50% of market share in the U.S. and are some of the top EHR vendors in the U.K. and Canada.[22][23][24] Many interviewees brought up this consolidation and its impacts on data management. Buckeridge explained that historically, "most of the major academic health centers that had strong informatics programs in the U.S. would build and run their own electronic medical record, but almost all of those have been replaced in the U.S. now by Epic, for example." St. Michael's Hospital in Toronto exemplifies this: As Jamie Beverley, Director of Product Development for the Data Science and Advanced Analytics team at Unity Health Toronto, pointed out, it is replacing its current patient record system with Epic. A senior consultant at a global consulting firm also mentioned that most of her Canadian clients choose to implement Epic or Cerner. As an architect at a U.S. health department explained, "in the U.S., there's just one consolidation after another to make an increasing monopoly on healthcare networks."

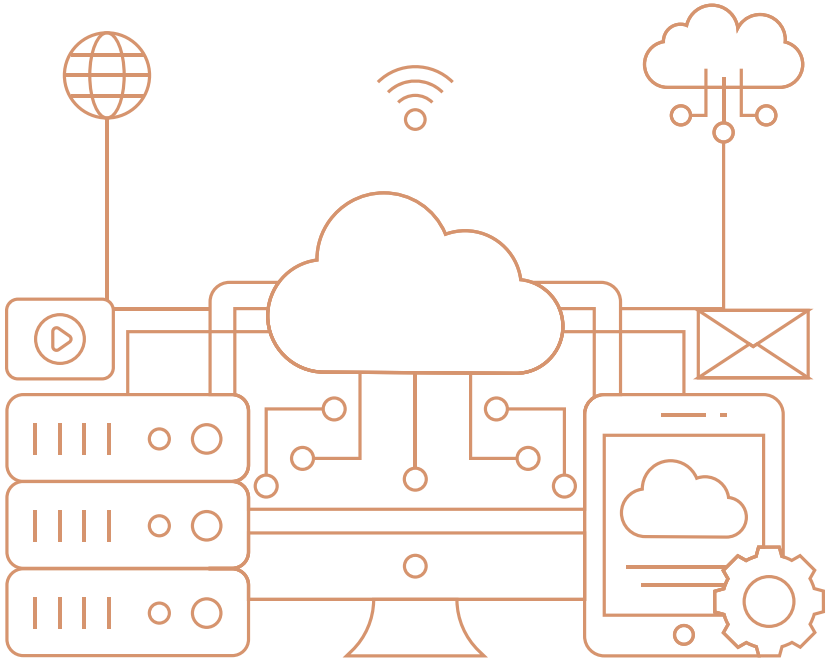
These incumbent EHR players are not oriented toward standardization. From an economic perspective, these players want to keep their users locked into their systems so that they will continue to pay the licensing fees. Standardizing their infrastructure could mean opening up the opportunity for clients to integrate their solutions with other standardized vendors. In a privately delivered system such as in the U.S., the hospital or clinic's interest in keeping its patient locked into its system compounds this. As an architect at a U.S. health department explained, "big healthcare networks want to lock their patients into their health network and keep the cash flow from that patient cohort. Similarly, EHR vendors want to have as many customers as possible paying license fees and so on for their platform." Neither of these parties has incentives to standardize in order to share data. Shannon agreed with this, stating, "there are active efforts to contain data, and not share it, that are built into the economic model of the healthcare systems that are there today."

Even in a publicly funded system, the motivation to make data portable is not always there. As Dalmia explains, "the motivation to share data across Canada [has been] limited," although he has seen growing interoperability initiatives across provinces in Canada. He argues that it requires "a culture and mindset change, and the appetite to do that." This lack of interoperability—particularly at a change management and governance level—requires resources and funding that publicly funded systems may not prioritize.

An important consideration in this consolidation around a few EHRs is that these systems do not cover all aspects of healthcare, and there is an "edge effect" that reduces the interoperability of a patient's data journey. When administrators purchase one chunk of software, thinking this will achieve interoperability, "this misses the point, because for example here in Quebec with Epic, it doesn't cover everything. It doesn't cover primary care. It's not going to cover public health," said Buckeridge. Harlan explained it from the SDOH perspective, where an individual who misses a food stamp registration may end up in the hospital because they're hungry, and everything up to the point of the hospital bill happens outside of Epic. "All of the negative externalities around that, all of the cost drivers around that, all of that process—Epic has no role to play in it."

Ultimately, the standardization and sustainability of health data records is crucial, as this sector needs records that are lifelong. Current systems are lacking the interoperability to produce lifelong records because of the absence of incentive, resources, and market competition to make them so. As a result of this lack of interoperability, "we're living in the information Dark Ages as far as healthcare is concerned at the moment," Shannon posited. "If you look at the U.S., if you look at many parts of the Western world, you see a healthcare system in crisis. And it's multifactorial, it's people, it's process, but it's in no small part down to the poor state of health IT today. It's killing people." He went on to say that "the health IT market … is full of vested interests at the moment. And they're resistant to that kind of advancement. The industry needs to be challenged; the monopolistic practices need to be challenged."

"There are active efforts to contain data, and not share it, that are built into the economic model of the healthcare systems that are there today."



Open source for health data management

Is open source the way to challenge this industry? Open source—and, in particular, open science—is a foundational tenet of healthcare. Shannon commented that "it's a medical, cultural thing that you publish what you learn and get peer review, or else you're hiding a secret, you know—it's not the moral thing to do." The moral obligations of the sector, according to Shannon, align well with the moral obligations of open source to encourage transparency and sharing. He gave an example of the medical family that hid its original forceps tool to protect its private practice, which, by the current standard of "publish or perish," is unfathomable to today's doctors. This collaboration is crucial to solve the universality of challenges that exist in this sector, making it a classic open source use case, according to Shannon: "We will only solve the wicked challenges in healthcare with a more open collaborative approach to the digital dimension."

"We will only solve the wicked challenges in healthcare with a more open collaborative approach to the digital dimension."

Dr. Tony Shannon
Head of Digital Services,
Government Chief Information Officer,
Government of Ireland

(Mis)perceptions of open source

Despite this natural connection, it became clear from interviews that many common (mis)conceptions of open source exist in this sector, and the adoption of open source experiences resistance because of real and perceived challenges. Despite many of these perceptions being overcome in other sectors, it appears they still exist in healthcare. The following are common beliefs and misperceptions that came up in the interviews.

Open source clashes with private sector interests

As mentioned above, interviewees felt that open source carries an ethical obligation that may go hand in hand with the ethics of healthcare. As Gupta argued, the Libra Social Research Foundation develops open source software projects where, as a developer, "you can build your own product and use it, and if you create anything new on top of the core, that is yours—but then if you modify the core, then you have to—you're sort of morally bound to—bring it back into the open source." Although this may not be the case in practice, open source is bound up with morality, at least for Gupta.

This morality adds a dimension that may fit well with health technology goals, according to some interviewees—but not to all. Despite some interviewees arguing that financial opportunity has held back technological innovation, Scammon felt that financial gain is the root of what drives proprietary—and not open source—innovation. He argued that healthcare is adversarial to open source because "proprietary vendors are driven by money. That's the root of what is aggressive against open source, because there's a lot of money to be made in medical IP. And a lot of these vendors who are making a lot of money will see this as a threat … The very simple answer is that it's money." Shannon agreed with the idea that the sector is still very driven financially, arguing that "parts of the world where there's a lot of money will be slow to embrace open source and healthcare." However, he felt that in regions where there is less money in this sector, there will "emerge a set of tools that will disrupt the Western healthcare systems, whether they like it or not; it's just interestingly coming from a place where innovation is happening, because the current incumbents aren't there."

This argument played out in various other interviews as a tension between the private sector and open source. From an open data perspective, Keller described how much harder it is to incentivize the private sector to openly publish their data, as it is hard for companies to understand the financial value particularly when they are fearful of giving away a competitive advantage. Gupta explained briefly how this conflict between financial interests and open source played out in India. When the government of India established the open source mandate for digital health standards, "there were reservations from the private sector because they had to balance their other interests." He went on to describe that although the mandate "sent shockwaves into the private sector … some of them realized that the government is doing it for the greater good."

An architect at a U.S. health department argued that the arguments against open source are unfounded because of the commercial interest behind them. "Clearly they are managers, they're nontechnical people. They don't care about innovation, they don't care about data." He went on to describe the lobbying culture in the U.S. and how it hindered the adoption of the Veterans' Affairs open source Veterans Health Information Systems and Technology Architecture (VistA) platform. "This religion, effectively, that commercial by definition is better … That's nothing but pure misinformation on behalf

of vendors and contractors that want to sell the government their commercial products." He went on to say that today, "unless you have a national healthcare system, [open source] in healthcare is not a very good fit. Because there are so many other incentives in play—mainly money-driven ones, profit-seeking ones."

Open source lacks support compared with proprietary

The lack of proprietary backing for open source software concerned some of the interviewees. Buckeridge linked this hesitation for open source procurement to a lack of IT resources to manage this kind of environment, where, despite a policy in Quebec to favor open source, he sees a trend away from needing in-house, local expertise to manage the software. In reference to his hospital's development group, he said: "We use virtualization, and for that, we don't use open source, we use VMware—mainly because our system administrator is not so comfortable with that, and his skillset doesn't really extend to creating an open source environment for that." He explained this as a conflation between open source software and a locally developed application, the latter of which can be detrimental to a hospital if it is poorly managed and the person who builds it moves on, "and nobody really quite knows what to do with it."

Beverley also pointed to the issue of resourcing, explaining how when their group tried to open source and share their models with other hospitals, they realized that the hospitals "didn't have the teams and the infrastructure to run those models, and then, to retrain them after they started drifting and to monitor them as they started drifting … Hosting maintenance, ML Ops, monitoring—that's been a gap in adoption of our open source efforts." Dalmia also reflected on this, where projects do not "have the skills that are required in understanding, managing, and developing open source tools, so they just go with application packages … [This] does create a little bit of that comfort that it's already been developed, tested, and tried and that you're not building from scratch."

Some interviewees linked the trend to vendor-backed software as a response to liability concerns. Chinmay Singh, Founder of iWish and TeleVox Healthcare, argued, "If I take an open source product, then the requirements around liability are not addressed, right. Like, if this software malfunctions, who do I go and see? I need to see somebody." He goes on to clarify, "Now, that's not an insurmountable problem, because a lot of open source is being used in health IT … But the liability issue is the primary deterrent." Jason Clark, DevOps Engineering Manager at CarrumHealth, brought up the same issue, articulating that from his perspective with academic medical institutions, "they want to have someone to call, they want a support agreement." An architect at a U.S. health department also noted that "anybody, such as a hospital or a business, will want to have a vendor with 24/7 support for their software need. They need support 24/7, they need a real company behind it."

Open source is commercially inviable

The concern around the sustainability of open source software also came up in the context of its commercial viability. McNicoll expressed a concern with sustainability, stating that "philosophically," he agreed with advocating for open source in healthcare, but he felt that "practically, it's very hard to sustain." In his work in Jamaica, for example, they initially worked with open source systems but didn't ultimately choose them because "they were hard to support." He argued that this comes down to commercial viability of open source, where most of the viable open source projects "tend to have a big IT sponsor

or government sponsorship," without which open source projects have a hard time making something work commercially.

Open source is only used for smaller projects

A number of interviewees expressed, either directly or subconsciously, that open source is best suited for smaller projects. A professor at a European university of technology commented, "at a smaller scale, developers love to use open source solutions to come up with certain modules for a platform. But it has its own limits, right?" A senior consultant at a global consulting firm mentioned, "I don't necessarily work a lot with open source projects, because at Deloitte, we often have very large projects." She also stated, "I don't know anyone in the public health space who would use open source for the [healthcare] back office." It was clear from some comments that there is a perception that open source is not a viable option for larger health information projects. This also points to a common preoccupation of open source at the application layer instead of considering its use at the protocol layer.

These various challenges and perceptions of open source hinder its adoption in the healthcare sector, whether these perceptions are valid or are based on a lack of knowledge of open source. The following section reviews the common benefits of open source and how they apply in this sector to disrupt misconceptions and identify avenues for adoption.

Benefits of open source

For those in the open source community, the usual benefits seen across industry verticals and technology horizontals also apply to the healthcare sector.

Open source encourages health equity by reducing costs

Affording proprietary solutions can be challenging, particularly for developing countries. As Scammon commented, his work on the open source hip dysplasia model "needs to exist for the world, because millions of infants need to get treated every year. And if it only exists in a proprietary form, it will only be used in places that have money. And that's not fair." He described how their open source model is available for free, with the scanning instrument as the only cost. Health systems that require certain tooling can therefore rely on open source alternatives to save on the expense of subscription and licensing fees.

Similarly, Gupta explained the financial incentive for adopting open data standards in India: "While writing the metadata and data standards for health, the directive given to us from the Ministry of Health was very clear: You need to have open standards. Don't go and start proposing proprietary standards or value sets for which India will have to pay. Imagine, for 1.4 billion people, if India had to pay per transaction—it's going to be a nightmare, it's just unaffordable. So that was a very clear direction that it has to be open source." Kumbhat argued that "national-level transformations in healthcare, particularly in [developing countries], are only possible with open source. Because it needs crowdsourced innovations, you want to avoid vendor lock-ins, you want to avoid obsolescence. And ultimately, it would reflect in the cost of delivering healthcare to the bottom of the pyramid. And [developing countries] can't really afford proprietary systems in that sense."

The ethical characteristic of healthcare makes it a good application area for open source as a way to reduce costs. An architect at a U.S. health department made the case that this is a sector that should be putting the public before profits. He said, "for public healthcare systems that are taxpayer funded … we should be giving that money back to the public for services and not just helping shareholders benefit on the backs of taxpayers. That's just fundamentally wrong, especially for something as basic as healthcare."

"National-level transformations in healthcare, particularly in [developing countries], are only possible with open source. Because it needs crowdsourced innovations, you want to avoid vendor lock-ins, you want to avoid obsolescence."

Arun Kumbhat
Director of GoToMarket, HR, and PR Services for Libra Social Research Foundation

Open source building blocks de-risk innovation

An important outcome of reducing costs through open source is that, according to Kumbhat, it "de-risks" innovation. He described this through his experience with various startups, where "a lot of time and money is spent in designing a product that is relevant to the market," and this design cost is high without being able to build on the expertise of others who have open sourced their solutions. India's work developing and open sourcing its healthcare tooling means that innovators can benefit from and build on top of that. "Innovation needs to be crowdsourced, it needs to be inexpensive. It needs to be de-risked if you're going to provide effective healthcare to a large population, right?" When a software is open sourced, Kumbhat explained, "the risk of standards and interoperability is removed, because that's already part of the minimum viable product. That's a very significant risk reduction." When this de-risking happens, vendors can instead focus on the money-making aspects of the industry, according to Scammon: "In reality, there's still a lot of money to be made on more advanced problems if we let OSS take care of the basics."

The open sourcing of software projects creates a roster of "building blocks," as a few of the interviewees described them. These building blocks become very useful in contexts where work is consistently being duplicated, such as the example Scammon provided. He spoke about Pharmaverse, an open source clinical trial platform that all pharmaceutical companies can use and contribute to.[25] He said, "Right now, every single pharmaceutical company has to build their own clinical trial platform, and every one of those needs to get approved by the Food and Drug Administration (FDA). And that's a huge amount of time and effort for each one of the companies. And it's a huge amount of time and effort for the FDA. If we just had one shared one that everyone contributed to … we're saving everybody time, saving tons of money, and allowing them to focus on their core business."

Dalmia commented that moving away from vendor entrenchment means a more productive environment for building solutions. Instead, using open source software "allows a little bit of flexibility with almost Lego bricks, as opposed to these monolithic applications." He qualified that this approach requires maintaining the right in-house or contracted skillsets to keep these projects working, but despite this need, open source is an important consideration for his clients' procurement decisions. He gave a specific example where one of his clients wanted to convert a chunk of their codebase into open source "because they liked the flexibility; they have the skills; they did think that it's a more modern way of doing it."

Open source removes vendor lock-in

Interviewees discussed concerns over the persistence and preservation of health data when using proprietary systems and how open source removes the risk of losing data if a company decides to remove its solution. As Singh argued, open source means procurers are not beholden to the whim of a single provider, who may decide to kill a product or service: "The use of open source takes you away from these proprietary systems, which is a good thing—it is less whimsical." He mentioned the VistA open source EHR solution, arguing that VistA would never be able to say, "'from today, no support'—it would not happen. But that does happen in healthcare all the time. And these companies, the way they develop the technology solution, they're trying to hold on to that data because that creates a vendor lock-in, and with open source, that's not an issue. You can clearly see that with VistA."

Buckeridge commented that avoiding vendor lock-in is the rationale for open source adoption in his lab: "We're right now architecting our analytics stack, as we're going to be rebuilding that in the next year or two, and thinking about what we want it to look like when we have Epic come, which is a behemoth of the system. Our main strategy is to get data out into an open source stack quickly so that we don't have lock-in to a particular vendor or product." Beverley also expressed a concern with vendor lock-in in terms of his ability to customize a software to a hospital's specific needs. He commented, "I've grown scared of vendor lock-in, and I think lots of groups are [scared]—the idea of committing to commercial products and being in a place where you can no longer customize those things to the needs of an environment, to patients, or to healthcare staff." His use of open source tooling has allowed him to develop solutions for St. Michael's Hospital in Toronto that are tailored to his specific context.

This kind of sustainability is crucial for a sector such as healthcare that requires lifelong records. Instead of relying on a proprietary vendor whose financial interests may conflict with building out sustainable health records, an open source platform is the better fit. An architect at a U.S. health department contrasted open source with proprietary vendors, where if you want to change vendors, "your data is trapped in the previous vendor's database, and you'll never get your data back." He felt that because of this, "there's more argument for [open source] in organizations that care about data governance."

Open source is trustworthy

Not only do open source projects have the long-term benefit of removing vendor lock-in, but they are also more sustainable due to the fact that they are perceived as more trustworthy. An architect at a U.S. health department argued that developers are more likely to trust open source code. "If you want adoption of your software, and you want trust—in other words, you want a lot of developers developing on your platform—the only way you get trust is by open sourcing your code and saying, 'Look, we're open source.' And then you get developers who are interested: 'Okay, I can play with this, I can use this, I can learn about this without having to pay anything.'" If developers trust the code, they will want to continue to use and contribute to it, making it a more sustainable project. He also extended the importance of trust to users of the product or service, stating, "You wouldn't trust your data in anything but something open source—something that has a governance model that isn't about monetizing your data."

Clark also discussed the trust placed in open source. He framed it within his work with AI models, where the democracy of decision-making, the transparency of the code and algorithms, and the ability for developers to improve the model themselves without appealing to a business are all crucial to building successful models. This inherent trust, from the governance structure down to the very code, makes open source an attractive option for healthcare providers who need to build lifelong records.

Open source has a community around it

Another important aspect of open source is the community that surrounds it. McNicoll spoke to this as the power of having crowdsourced governance: "The way that we manage these little components [of OpenEHR]—which is absolutely open source, crowdsourced, crowd managed—every archetype is its own little governance space. That is the genius thing, we have to let this stuff evolve. It's on a fast, agile turnaround." This means that the projects can adapt and be flexible to the community managing them and be as effective as possible.

This community also provides an important support system for those who implement open source software. Beverley explained that, in their procurement choices, they look for software with strong community support. "In five years, are there still going to be people on the job market who know this tool and are developing it and updating it, giving it security patches and all that. And that's been—we've had really positive experiences with open source tooling … In an emergency situation, we can reach out and get help." He also pointed to the community to describe how open source software outpaces proprietary offerings: "There's a lot of really great tooling out there, and I don't think the proprietary stuff really keeps up a lot of the time with some of the open source tools. I'd say it's pretty infrequent that we hit a point where what is open source and battle tested over 20 years of communities using this software—it's pretty rare that we find that that doesn't fit our needs."

This community reduces the need for local expertise in a hospital setting. In Buckeridge's example of virtualization software, there are open source alternatives to VMWare that have reliable organizations behind them, such as Mirantis, Docker, IBM, and Red Hat. It also means that there are various options to use when seeking out a support agreement.

Despite Singh's and Clark's concerns about this aspect, open source reduces the reliance on one vendor, where a software such as the Linux operating system has the support of multiple vendors, such as Red Hat, Oracle, IBM, and Canonical, who can sign an agreement.

developers trust the code, they will want to continue to Overall, these benefits demonstrate the different ways that healthcare is a fit for open source, and some actually run counter to the perceptions of the previous section—where removing vendor lock-in, de-risking innovation, and reducing costs demonstrate commercial viability and sustainability, and the level of perceived support depends on how you choose to define the community and resources around your software stack.

Open source healthcare solutions around the world

There are a few regions and projects around the world that have realized the benefits of open source for healthcare, adopting solutions and adapting them to their specific contexts. Interviewees gave examples of these projects and the context as to what conditions allow them to take hold.

Open source has seen greater traction in healthcare systems in Europe than in the U.S. and Canada. As a professor at a European university of technology explained, the coordination between E.U. member states leads to greater standardization and collaboration, two concepts that go hand in hand with open source: "In Europe, we have national health records in member states, and now we have cross-border solutions, and hopefully at a certain point we can have European health records that become a base or common ground for all other digital solutions in general." McNicoll referenced an uptake of open source–based projects in Europe, pointing to how the regionalization in Europe creates hubs for open source innovation where integrated and standardized systems can grow without the drag of prioritizing purely proprietary interests. He described developments in Catalonia, Karolinska, and London, where governments are adopting the open standards solution OpenEHR as a way to address the growing appreciation to separate the open standard data layer from the proprietary application layer.

In India, digital health became the government's key mandate because of the cost of healthcare on the household in a country where "a large percentage of the population falls below the poverty line every year," explained Gupta, who led the taskforce that developed open standards in India. He described the work of the National Digital Health Mission, which developed the open source "minimum viable product definitions and building blocks" for the country to develop its digital health ecosystem, following "a very clear directive from the government that we do not want anything proprietary." One significant outcome of this development was the Ayushman Bharat Health Account, a national digital health identifier that is used to build a longitudinal health record through all the health data that has been linked with that identifier.[26] Kumbhat made the point that these open source solutions can be of benefit outside of India, as well: "Considering that India is a country of more than 1.4 billion people, there's a great amount of diversity in terms of maturity, technology levels, populations, and healthcare systems, and therefore any kind of challenge that you will see in [developing countries] or even in the West is probably going to be a subset of what we face here."

More generally, Shannon pointed to open source adoption taking place in the developing world, where he has seen "a huge amount of movement around OpenMRS, an open source medical healthcare system." He described it as "the leading open source healthcare system internationally … It's all over the world, you know, it's in 80 countries … This tells you that this movement around open source is already ongoing."

These regional developments show a growing interest in implementing open source for greater standardization, reducing costs, and improving sustainability. The following textboxes are examples of two open source projects that are in use today: VistA and OpenEHR.

VISTA

Veterans' Affairs doctors and technologists developed an open source EHR called VistA in the 1970s and 1980s.[27] This system was built ground-up by doctor-programmer teams who were decentralized throughout the organization but saw the benefit of building on common infrastructure. This system took into account what the clinicians needed from an information collection system, creating what Singh argued "is one of the best EHRs you will find." An architect at a U.S. health department explained that "it was the culture of innovation, of decentralized development, that allowed VistA to evolve." VistA took hold at the VA despite the top-down central office that slowly "chipped away at the VA's ability to innovate." VistA stands alone as one of very few open source implementations at the hospital level in the U.S.

OPENEHR

OpenEHR started in 2003 with the goal of establishing a new way of building lifelong health records based on open source licensed components and specifications.[28] It defines a set of open source blueprints for standards-based data stores (clinical data repositories) and a library of healthcare data model components, which facilitates the building of healthcare applications and systems and is not an out-of-the-box open source medical application/solution. The licensing deliberately allows for the building of both open and closed source applications and technology solutions around this open core. "OpenEHR is about that data layer," said McNicoll. He went on to explain, "It says nothing about applications or, indeed, about the database technology that the OpenEHR stack sits upon." This means that the software can be used interchangeably with any application that sits on top of it. Shannon explained that the philosophy behind OpenEHR was to avoid the deployment of a monolithic, singular solution in a particular setting and instead incorporate a "building block approach." The Ripple project adds several open source tiers to the core "data definitional" OpenEHR offering, including an open source UI framework and an open source clinical data repository store.[29] McNicoll pointed out that OpenEHR implementations have been growing recently. It has been picked up by commercial vendors, particularly in Europe and Australia, who felt that it responded to the challenges they were experiencing in "data management using traditional data stores … because their data is so complicated." As he pointed out, these vendors needed "a low-code data solution that would start to make them much more flexible as a way of competing with the Epics and Cerners of this world."

The slow but clear adoption of open source in healthcare systems in Europe, India, and other areas of the world signals a desire to move away from the "archaic" infrastructure that burdens the healthcare sector and instead to embrace an approach that encourages innovation, efficiency, and agility. Shannon felt optimistic about this transition, arguing that "what will happen over time is that as people increasingly see how dysfunctional the current proprietary nature of the healthcare IT market is, and as these other alternative approaches gain traction, you will see a shift. It's going to take years for that to happen at scale, but that shift is now ongoing because, simply put, the current approach is just not sustainable."

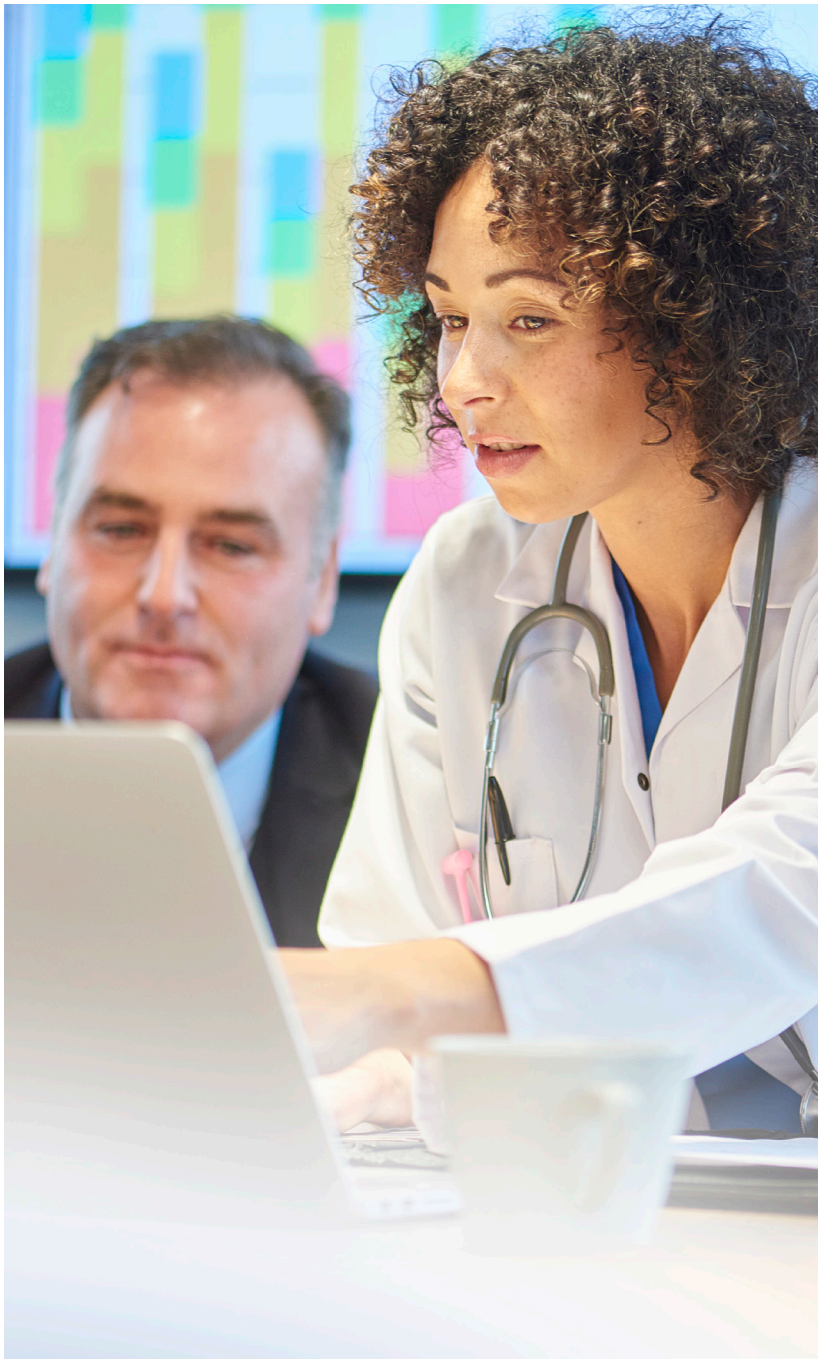
EXAMPLES OF GLOBAL HEALTH INFORMATION EXCHANGES

DHIS2

DHIS2 is an open source software platform for data collection, management, and analysis, widely used as a health information management system in over 100 countries, with national-scale implementations in more than 70 of them. The system supports multiple levels of data collection and analysis, including aggregate data (e.g., routine health facility data, staffing, equipment, infrastructure, and population estimates), event data (e.g., disease outbreaks, surveys, audits, and patient satisfaction surveys), and individual-level longitudinal data (e.g., vaccination records, lab sample collection, patient treatment and follow-up, and student progress). Due to its scalability and adaptability, DHIS2 has applications in sectors beyond health, functioning as an information management, reporting, and monitoring system at district or national levels in areas such as education and civil registration.[30]

Surveillance Outbreak Response Management and Analysis System

German and Nigerian public health and research institutions developed the Surveillance Outbreak Response Management and Analysis System (SORMAS) in response to the 2014–2015 Ebola epidemic in West Africa, and it became open source in 2016. The system focuses on disease surveillance, outbreak response, and management during epidemic and pandemic situations. SORMAS seeks to support the surveillance, management, and analysis of infectious diseases, providing public health agencies with tools to monitor infection rates, manage caseloads, and conduct contact tracing. More than 15 countries currently use SORMAS for outbreak monitoring and response efforts.[31]



AI the catalyst

As in other industries that have embraced open source, a disruptive factor may speed up this transition. For healthcare, AI could play that role, given its significant potential to solve problems and address constraints in healthcare. The opportunities for its application span activities of automation, detection, and prediction—often with more precision, and at much faster speeds, than healthcare providers.

Interviewees listed a number of different AI use cases. In terms of automation, Singh focused on AI activities that bring down the costs of operation, such as building nursing schedules, while Muhammad Mamdani, Vice President of Data Science and Advanced Analytics at Unity Health Toronto, similarly explained the assignment tool that his team implemented at St. Michael's Hospital to assign nurses to different zones in the emergency department. A senior consultant at a global consulting firm discussed AI support in completing forms, including flagging issues as information is added to an EHR system. Dalmia spoke about automating nurses' check-up calls after patient discharge: "We can have conversational AI have a chat with them, get the notes, and see if it needs to be escalated to a nurse. That will free up so much nurse capacity."

For prediction, Mamdani discussed the CHARTwatch tool implemented in two hospitals in Toronto, which predicts whether a patient will die or go to the ICU to help prevent deaths by monitoring the patient and paging the medical team when needed.[32] Dalmia also discussed the opportunity to predict how many patients may enter a hospital over the course of a few weeks to better manage scheduling, with the overall goal of "helping the health system meet the demand that it is facing right now." From a diagnostic perspective, Singh also pointed out that AI can help "for instance, [with] radiology and those things. The problem is that the FDA comes into play," which makes adoption in diagnostic use cases slower and more hesitant.

Despite the promise of AI, interviewees also pointed out the current vulnerabilities of the technology and identified where bolstering is necessary to build sustainable AI infrastructure. Primarily, this technology has massive data requirements that many organizations cannot meet.[33] Kumbhat stated that "AI is likely to fail qualitatively unless there is a ground-up flow of real-time, authentic data available." Dalmia also highlighted this problem, saying that data is one of the biggest challenges for AI adoption. "There's a lot of bad quality data, expired datasets, even datasets that might not be digitized and in manual fax format or paper format. So, in that environment, there's a lot of foundational work that's required to be done even before we go into any AI work."

Privacy and governance concerns came up as well as a way to build "trustworthy AI," a term Dalmia used. This involves AI models that incorporate bias and ethics mechanisms, with governance structures that maintain transparency and privacy in an environment as sensitive as healthcare. [33] In terms of governance, A senior consultant at a global consulting firm brought up another challenge in that AI's incorporation into a hospital information system would require collaboration and agreement among doctors with varying needs and interests. "They would have to agree on whether this is a value to them as a group, not just individually, because you can't necessarily have AI for each clinician," she pointed out. As discussed above, this kind of collaboration is complicated in the healthcare setting.

The potential of this technology, and what it needs to move forward, creates an interesting liquidity moment, where AI could cause a wider and faster shift in the digital health sector. He commented that, as it stands, the current system is not set up for AI to be truly transformative for healthcare. Shannon concurred. "Healthcare is going to get disrupted by digital, whether it wants to or not. AI is coming now. And so, the role, the process, around the knowledge capture and control by the profession alone is now going to be challenged by AI … The disruptive forces on healthcare will continue to hit it until the change happens. It's inevitable. It's just a question of time, you know?" Dalmia made a similar comment: "I don't think there is an 'if,' it's a 'when,' … [But] how will it be rolled out? And how do we make sure that it's done in the best way, to benefit everyone?" Shannon's position was clear: "We want the AI model to be open source so that it can be peer-reviewed, so that I know how the decisions are being made. And there's no black box there."

"AI is likely to fail qualitatively unless there is a ground-up flow of real-time, authentic data available."

Arun Kumbhat
Director of GoToMarket, HR, and PR Services for Libra Social Research Foundation

Moving the sector forward: Recommendations from experts

Although at times expressed as an intractable problem, interviewees gave a few recommendations to untangle data collection and management from the systems that maintain entrenched interests and a lack of interoperability. The following section reviews these recommendations and some next steps for the digital health sector.

Building a digital health architecture

As McNicoll clearly stated, "we need to fundamentally change the way that we're architecting health systems." The digital health sector is lacking an architecture that defines and standardizes the different components, nodes, and technologies within the system and how they all fit together. No particular company owns this architecture, since it is community developed, and it provides the protocol on which proprietary applications can be built and interoperate. This is similar to the World Wide Web, where emails from different providers can be sent among themselves, and browsers from any vendor are able to access any website, because they are all based on a common set of standards and open source protocols. Other sectors, such as telecom and finance, have similar architectures: For example, the 5G Super Blueprint, which LF Networking developed, provides the instructions for pulling their sector's open source building blocks together and incorporates a landscape that shows where all telecommunications providers and cloud technologies plug in to this ecosystem.[34] The Apperta Foundation suggests the adoption of an open architecture: "[It is] vendor and technology neutral, eliminates lock-in, facilitates innovation, and forces vendors to compete on quality, value, and service."[6]

A number of interviewees supported the development of an architecture, using different terms to describe this concept, including "digital backbone" (Gupta), "protocol" (Harlan), and "reference model" (Shannon). Lee explained the value of the architecture for smaller vendors and startups, who can manage one "box," or area, of the larger picture, which can be applied in different systems across different jurisdictions that are using this architecture. In this case, the EHR would represent one "box" in the healthcare diagram, while other applications can individually support admissions, discharge, transfer management, after-visit summaries, and more instead of having to expand incumbent EHR systems to encompass more and more outside of their original intent. As McNicoll stated, building this open standardized architecture means that the startups do not have to "rebuild the whole infrastructure themselves" when they develop a solution in a specific corner of the sector.

Building on top of an open, precompetitive architecture means that applications can interoperate with a federated set of systems anywhere. At this point, Shannon explained, the solution provider is "competing on the service rather than on the architecture." Harlan made the same point, arguing that "where open source is at its best is when you've got protocol layer stuff, particularly around data exchange and information exchange, and trying to get all of those pipes working together … As you get closer and closer to the application layer, open source has less and less of a role to play. And that's really where organizations can build discrete products and compete in both the financial marketplace and the marketplace of ideas." This will give health organizations "the ability to swap in and out different components," explained Buckeridge.

CASE STUDY: PAYLOADS

Harlan provided a clear example of where an architecture can bring greater efficiency to the healthcare system and ultimately better care to patients: payloads. Described as a referral that an organization sends to another individual that contains notes, health records, or other documents, Harlan explained that moving these payloads around means that they must be interoperable for different types of platforms to consume them and that they need to protect the personally identifiable information in them. A protocol for these payloads would shape and standardize what the payload looks like, what the API endpoints are, and what permissioning looks like so that individuals can receive and participate securely in the process. It can also provide a map for application developers to provide tools that can plug into the system and participate in the protocol exchange. This approach would support greater interoperability within the health system but also address the "edge effect" described above, which is an important aspect of addressing SDOH, where health outcomes relate to processes outside of the traditional health system.

Without an architecture, innovators lack the ability to build an application that is sustainable, portable, adaptable, and interoperable for different health information systems. Buckeridge gave the example of the CODA infrastructure developed to share COVID-19 patient data in a federated way.[35] He explained that it was hard to scale the project beyond COVID-19 data in the hospitals "because we didn't have the same architecture being governed the same way within our environment." Despite this project being open source, the underlying variation in infrastructure and governance across hospitals did not support scaling the project.

Some floated OpenEHR, VistA, and other solutions as current systems that could be used as an architecture. An architect at a U.S. health department sees VistA "as a foundation for the next generation of EHRs in the United States … [where] the kernel is the interface layer and the database is the data management layer, as the foundation. Because the applications are very specific to your institution." He explained how different health services outside of the VA, including in New York, Jordan, and India, forked the VistA codebase and now all use this identical infrastructure, despite the fact that they have built their own specific applications on top of it. Shannon likewise advocated for the adoption of OpenEHR, which he described as a "future proof" architectural standard.

Standardizing data, semantically

A digital health architecture requires standardization, meaning that there is still a need for standards currently in use. "We still need the FHIR exchange, we need other standards such as OMOP … We need things like SNOMED. [The architecture] is only part of the solution," McNicoll stated. This includes standard data formats and standard APIs so that these applications can talk together. As the Apperta Foundation explains, building a "minimum viable" open platform that creates true portability and interoperability of health data and applications needs to be based on core standards, such as FHIR HL7, SNOMED CT, or OpenEHR.[6]

Harlan pointed out the need for standardized terminology, such as the definition of gross income, in order to harmonize fields across organizations' forms and remove ambiguity. In Europe, a professor at a European university of technology argued that standards are the critical piece to move data sharing forward. She said, "if we have standards and we have strategic support, that means resources to adjust the [national data] platforms … It's [the standards] actually connecting the technology but also data transmission data safety. Data sharing rules."

Advocating for the effective and widespread adoption of existing data standards, as Spence and Parisien are doing at Canada Health Infoway, is an important step in this process. Policy is a part of this; Dalmia argued that "as applications are modernized, there needs to be some good policy … that there's some data standards to adhere to that will allow us to share data." He pointed to efforts in Canada to build the "lowest common denominator" of data fields for sharing across the country. The problem with this work, he stated, is that there is often a lack of funding and incentives to do it.

When asked about a minimum dataset, McNicoll pointed out that this helps to "not try to boil the ocean," but it jeopardizes the progress of standardizing when there are groups that fall outside of that minimum. "The trouble is, if you do that, because the data is so complex, you keep just having minimal datasets all over the place. So, you don't pick up the edge cases for that one project," he explained. His work mapping data with the NHS Christie cancer hospital instead tries to capture as many edge cases as possible.

As discussed above, standards need to address semantic interoperability. An architect at a U.S. health department spoke to the work being done by the World Wide Web Committee and the Solid Foundation to develop semantically interoperable technology in order to link data. He stated, "where we need to go is to adopt the World Wide Web standard for linked data as the data model for healthcare, which is a form of JSON-LD." Open source is key to semantic data standards, according to McNicoll. "The sweet spot for the open bits is around the data and the data definitions." OpenEHR's approach is to "separate the apps from the data, store the data in common ports using the OpenEHR standards … and ask the applications to work directly on that common data. So, the standard is inside the data store rather than outside."

To build sustainable and lifelong records, standardization should be reconceptualized to consider health data as patient-centric as opposed to organization-centric. McNicoll explained this difference by arguing that data should be "in a patient-centric data store, and everybody reads and writes to that as they go along … We shouldn't have multiple copies of a patient's problem list. We shouldn't have multiple copies of their allergies list; there should be one for the patient. And we all read and write to that." He elaborated that there is an important distinction between patient-held and patient-centric, where he has seen confusion in the past: "They're two separate things. Patient-centric is about the way you organize the information. And actually, there's no necessity for the patient to be able to see or interact with that at all … Patient-held records, or patient access to records, is a separate thing. Patients can still have access to organization-centric records."

Patient-centric records mean more effective data capture, where integrated data reduces duplication of efforts—which can have impacts ranging from freeing up resources all the way to saving lives. As an architect at a U.S. health department explained, "the only way to run a cost-effective, seamless healthcare system is to have integrated data. Otherwise, you'll have duplicated tests, duplicative reports. And if you don't have a coherent, complete picture of a patient's data, you cannot make good decisions." Shannon also explained how standardizing data at the patient level is the lowest level, meaning you can go on to "feed other levels, you can then support the cohort management, and you can support the enterprise of the population."

From conversations with our interviewees, the key to moving to a more interoperable health data environment is in the standardization of data within an open architecture. As Harlan argued, "if we can standardize and create open source protocols around how we are moving data around … then we essentially are creating something that doesn't get owned by any single entity as the warehouser. And, instead, all the participants in the ecosystem just simply stand up their kind of node, and they can begin interoperating according to whatever rules are written into the network." This architecture means built-in interoperability on which innovators can build and, ultimately, from which healthcare stakeholders can benefit.

"As applications are modernized, there needs to be some good policy … that there's some data standards to adhere to that will allow us to share data."

Niraj Dalmia
Partner in Omnia AI at Deloitte Canada

Trying new business models: Innovation around incumbents

As seen throughout this study, incumbent players hold a tight grip over data sharing. Instead of trying to reduce the market power of these organizations directly, some interviewees suggested working around them. Shannon gave the example of a "dual track approach," where more innovative and agile solutions are built up in areas such as community care or where work is happening across borders, while the more monolithic structures remain in the hospitals. "You accept that you're going to have some monoliths for some time to come, but you don't just leave those as they are," he explained. "You also seed some parallel innovation, which can then grow from the bottom up."

Harlan also discussed how non-incumbent players are gaining wider and wider traction in this space. He gave the example of Amazon buying One Medical, where "now you have Amazon running a pharmacy, running a national healthcare network of primary care." He posited, "the world today is filled with non-incumbent players who are gaining increasing amounts of resources to fight against incumbents," who might be more interested in using products and services from innovative healthcare startups where there are options that allow them to use more open source software on which to run their applications. He argued, "I can pretty much guarantee you that Amazon is not beholden to the wishes of [an incumbent EHR]." This shift in ownership of health providers, at least in the U.S., may open up the market away from the larger incumbents.

Next steps: The role of the foundation

How can we get to a point where we have a standardized architecture? As a professor at a European university of technology explained, this is not a job for one digital health company, whose incentives are to drive profit, not standardization and integration—this requires a platform to govern relationships and standards. She suggested that, instead, "open source should take this role of providing a general platform with governance rules with standards, you know, and really developing a medium for all the players to safely exchange data and services."

Harlan listed the stakeholders needed to collaborate on this kind of effort. "You need a not-very-large but strong set of foundational companies to stand it up. And you're going to need probably at least one of the major health platforms, you know, preferably a couple of them, because if you can show that the two of them can participate, then that leads the way. I think you need some of the social care platforms." Practically, he argued that the Linux Foundation (LF) may be the right group to bring these stakeholders together. "I think that the LF stands in a unique position—and I mean unique—to bring together the only companies in the world, probably, that have this scale," Harlan posited. Shannon described the LF's role in this collaboration from more of a philosophical perspective, following a conversation on healthcare as a public good. He said, "I think the LF has done a really good job of tackling some of the big societal issues that are out there with open source," and healthcare is the next one.

The role of the foundation is not just to build the architecture but to create a meeting point for all the different open source work taking place in the healthcare sector. Scammon argued that there currently lacks an umbrella organization bringing together these various projects in healthcare. As he said, what the LF does best is that it "plants the flag, invites people into the tent, and then tries to create the community and the hype in the best possible way so that there's momentum and a center of gravity around this. And what will come out of it is a place where a whole bunch of these different disparate groups can come and share notes, gain visibility, and make their voices heard as a whole on a political and regulatory level." Once these projects come together, activities naturally fall out of that collaboration, where people working across the sector—including people who don't

traditionally work together, and even beyond healthcare—can address common questions such as "How can we share data in a safe way?" "If you can bring all of them together, all of a sudden, you have a lot of voices who can contribute to a bunch of those conversations," said Scammon.

Leadership of this collaboration is crucial. "What's required from a foundation is leadership in a complex environment," Shannon explained. Leadership to align different groups around similar patterns and solutions, and leadership to also educate about what is taking place in this sector to solve these intractable issues. Before actually building the architecture, stakeholders require education on the value of this architecture: "The common ground all [jurisdictions] share is a need for clinical and management and technical people to come together to support the care process with an architecture," said Shannon, and leadership must demonstrate how everyone all fits together and benefits from this kind of collaboration.

Scammon also discussed the value of education. He pointed out the misconception that open sourcing software will restrict an organization's ability to make a profit. He gave the example of a medical company he was working with that "was under the mistaken belief that if [it] open sourced its work, that it wasn't going to be allowed to use it to make money. We had to sit down and repeat over and over, 'No, this is an Apache license, you can do whatever you want with it, including building a platform and using it to make money. Go for it.' But it was because they weren't educated on all of the different licenses and whether the one that we were using allowed them to do what they wanted. It takes a bunch of education—that's one of the ways that we can defang [open source]."

As seen in other industries undergoing technological transformations, the foundation plays an important role in a context where multiple stakeholders with competing priorities and expectations must come together to build a precompetitive layer that all parties use and trust.

"The common ground all [jurisdictions] share is a need for clinical and management and technical people to come together to support the care process with an architecture."

Dr. Tony Shannon
Head of Digital Services, Government Chief Information Officer, Government of Ireland

Conclusion

Current health data management systems around the world lack the sustainability to meet healthcare demands and technological advances such as AI. The complexity of health systems, the market dynamics, and the unique characteristics of the sector all lead to poor interoperability and innovation. There are strong philosophical, economic, and technological reasons why open source should be considered when looking for solutions, but many challenges and perceptions of open source hinder its adoption. This study calls for the adoption of an open architecture to build interoperability into the foundations of health systems, which will improve innovation, standardize efforts, and, ultimately, improve health outcomes. A foundation would play an important role in the adoption, development, and maintenance of this architecture, bringing collaborators together to solve shared problems and benefit from a standard protocol on which they can build their own applications. The LF invites stakeholders across the sector to consider these recommendations and the role they can play in their adoption.

Methodology

The researcher interviewed 20 health technologists working across three different geographic regions in various health specializations. Members of the project's working group developed and reviewed a question guide. The interviews were recorded, transcribed, and then coded following a thematic analysis approach. Codes were grouped according to their thematic overlap with each other, which developed into emergent topic areas on the uniqueness of the healthcare market; interoperability and data sharing issues; the perceptions, benefits, and adoption of open source in this sector; and actionable next steps. Findings were written up and peer-reviewed before publication.

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Acknowledgments

The author would like to express her gratitude to the significant network of people who supported this research and gave their time to this project. Thanks to the 21 interviewees for sharing their time and insights and making up the foundation of this work; thanks to Cassie Jiun Seo at the World Health Organization for her contributions to the report; thanks to Michael Dolan, John Halamka, Hilary Carter, and the members of the LF Research Advisory Board for their guidance and enthusiasm; thanks to LF Creative and Christina Oliviero for their creative and operational roles; and, finally, a very large thank you to Irving Wladawsky-Berger for his support, encouragement, and engagement in this work—you were critical to its success.

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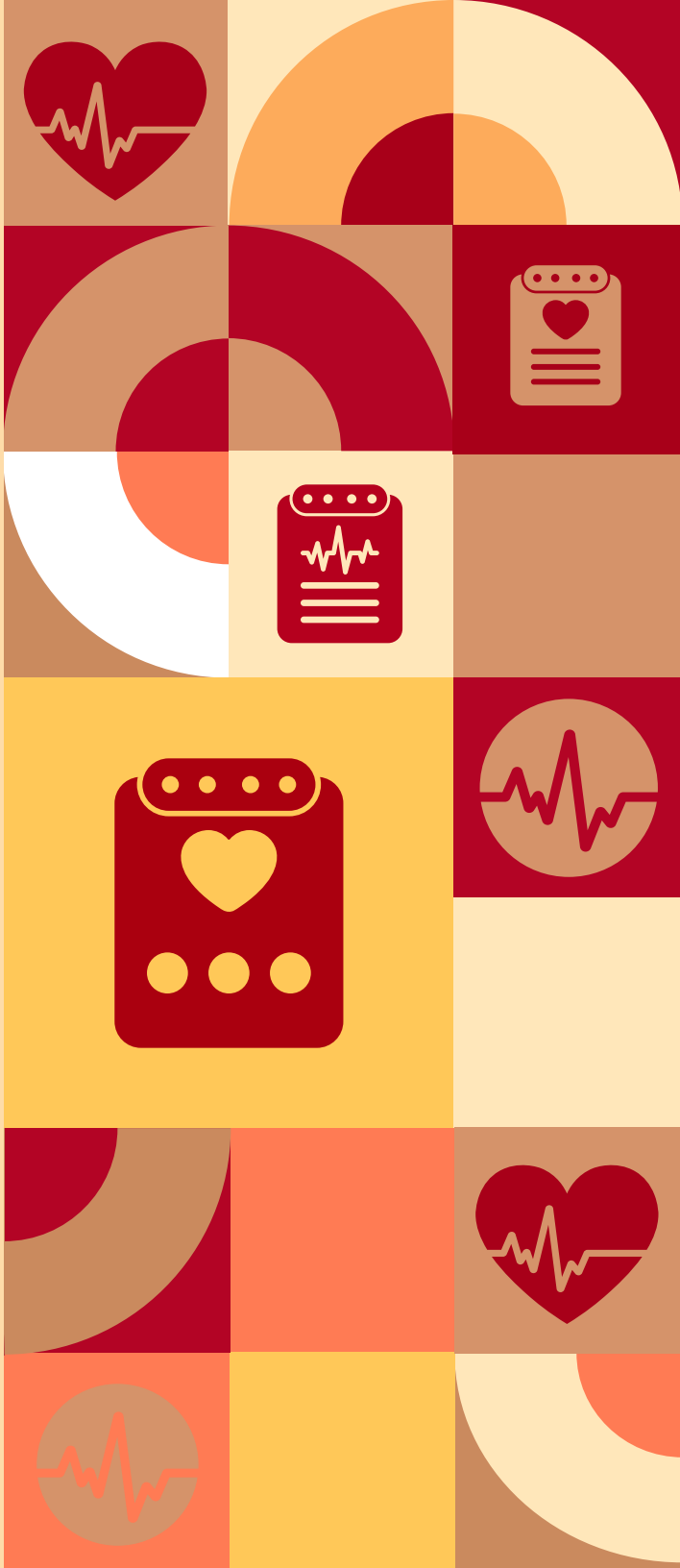

To reference this work, please cite as follows: Anna Hermansen, "An Open Architecture for Health Data Interoperability: How Open Source Can Help the Healthcare Sector Overcome The "Information Dark Ages"," foreword by Leo Anthony Celi, The Linux Foundation, October 2024.