PUBLICATION 2

The Digital Health Landscape, What is Broken and Why

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DHCF
DIGITAL HEALTH
COMMONS FOUNDATION

Contents

1 Abstract and How to Use this Document

This is the second publication in the DHCF foundational suite. It provides a structural diagnosis of why digital health systems repeatedly fail to deliver coherent, sustainable outcomes.

Publication 1 introduced the concept of the Digital Health Commons and described the role of the Digital Health Commons Forum (DHCF) as a neutral enabler of alignment across standards, organisations, and initiatives.

This publication steps back to examine a more fundamental question: **What exactly is going wrong in digital health, and why?**

Across the world, digital health programmes continue to struggle with fragmentation, vendor dependency, and repeated reinvention. Significant innovation, funding, and goodwill exist. Yet outcomes rarely scale beyond individual programmes or organisations. Health systems remain fragmented, misaligned, and trapped in cycles of vendor lock-in, reinvention, and unsustainable delivery.

These are not isolated deployment problems. They are symptoms of deeper structural weaknesses in how digital health ecosystems are organised and governed, a lack of structural maturity across the ecosystem.

> Health systems do not fail for lack of vision. They fail for lack of systems thinking.

This publication examines those structural failures. It explores how governance, procurement, and standards efforts often operate in isolation from one another; how patients, professionals, and policymakers experience the consequences of fragmented systems; and why repeated investment cycles have struggled to produce durable, reusable infrastructure.

This paper is intended for national and regional planners, policymakers, funders, and technical advisors who want to:

- understand the structural causes of persistent digital health failure
- recognise recurring patterns of fragmentation across systems, roles, and incentives
- identify where existing approaches fall short and where coordination is missing
- build a clearer picture of the systemic conditions required for sustainable digital health infrastructure

You may find this publication useful if you are:

- reviewing a national or regional digital health investment strategy

- attempting to align health IT delivery with wider policy, data, or procurement reform
- seeking alternatives to fragmented platforms and vendor-led approaches

This publication prepares the ground for the remainder of the DHCF suite. It helps the reader understand why current approaches struggle to produce lasting outcomes and why new forms of coordination and stewardship are not just preferable, but essential.

For context and continuity, this publication should be read alongside:

- **Publication 1 – Defining the Digital Health Commons -** Introduces the Commons model and the role of DHCF in enabling alignment across the ecosystem.
- **Publication 3 – The Role of Custodians -** Explores the institutional structures required to sustain shared digital health infrastructure.

2 Context and Purpose

Digital health has never lacked ambition or investment. Across the world, governments and funders have committed billions to new platforms, pilots, and programmes. Each cycle of funding has promised transformation. Yet the results remain uneven. Systems are fragmented, data is restricted, and delivery models remain fragile.

Digital health has never lacked ambition or investment

These outcomes are not isolated shortcomings. They are structural. Fragmentation is not accidental; it is embedded in how health systems are governed, how technology is procured, and how standards are applied. Procurement deadlines, short funding cycles, and investment models that favour proprietary control create conditions in which lock-in and reinvention become the default.

This publication is not concerned with assigning blame. Policymakers, funders, professionals, and vendors often operate in good faith, under significant pressure. Digital health therefore has evolved across a spectrum of maturity, with genuine progress in some areas alongside persistent structural weaknesses in others.

The purpose of this publication is to examine those weaknesses clearly. It identifies recurring patterns that continue to undermine digital health efforts: vendor dependency, fragmented procurement, inconsistent standards adoption, and the absence of durable mechanisms for coordination across programmes and organisations.

Where Publication 1 introduced the concept of the Digital Health Commons, this publication provides the complementary diagnosis. It explains why current approaches struggle to produce reusable, scalable infrastructure and why fragmentation continues to dominate many digital health environments.

Digital health will always operate within complex political, financial, and organisational constraints. That reality makes structural clarity more important, not less. By understanding how fragmentation emerges and why reinvention persists, policymakers and system leaders can begin to recognise the conditions required for more mature and cooperative digital health ecosystems.

This publication therefore focuses on clarity rather than fault. It examines the systemic conditions that shape digital health outcomes and prepares the ground for exploring how greater coordination and stewardship may be achieved.

3 What Bad Looks Like: A System Design to Fragment

Digital health systems across the world share a common pattern: fragmentation. Hospitals, clinics, laboratories, and public health organisations frequently operate separate information systems that struggle to communicate effectively with one another. Data remains trapped within organisational and technical silos, limiting its reuse and reducing the overall value of digital investment.

This fragmentation is often described as a technical problem. In reality, it is structural. It emerges from how digital health ecosystems are organised, funded, and governed. Over time these structures have produced a system that tends to fragment rather than integrate.

> Fragmentation is not accidental. It is the natural outcome of the system we have built.

The result is a landscape in which integration becomes increasingly complex and expensive, where innovation is constrained, and the long-term sustainability of digital health infrastructure remains uncertain.

The following sections help explain why this occurs.

3.1 Lack of Architectural Coordination

One of the most significant weaknesses in many digital health environments is the absence of shared architectural coordination. There is a self-perpetuating cycle of fragmentation that must be broken in order to move towards a more open, commons-based digital health ecosystem.

In mature infrastructure sectors such as energy, transport, or telecommunications, large systems are built against clearly defined architectural principles, standards and long-term frameworks. Core infrastructure layers are designed deliberately and reused across organisations and programmes.

Digital health rarely operates in this way.

Instead, organisations frequently procure and implement systems independently, each pursuing local priorities and short-term delivery targets. As a result, architectureal decisions are made repeatedly at programme or vendor level, rather than coordinated across the ecosystem.

This has been shown to impact every layer of the digital environment, from the data models used to the software tooling and infrastructure, including:

- the data models used to represent clinical information
- the standards and interfaces used for exchange
- the software tooling used to build systems
- the infrastructure on which services are deployed

> The lack of architectural coordination is the foundational problem

Without shared architectural direction, the ecosystem evolves as a collection of separate platforms rather than a coherent digital infrastructure. Each new programme, vendor solution, or implementation introduces additional variation.

Over time several recognisable patterns emerge:

- incompatible data models, requiring complex mappings between systems
- inconsistent use of standards
- duplication of infrastructure, where multiple systems replicate the same foundational capabilities
- integration architectures based on point-to-point connections, which become fragile and difficult to maintain

These patterns make digital environments increasingly difficult to evolve. Over time the system becomes harder to align and control, and integration becomes increasingly dependent on bespoke interfaces and fragile technical workarounds such as point-to-point integrations. Control over system architecture gradually shifts away from public health organisations and towards the vendors who supply the platforms.

In this environment, vendors often define the practical architecture of the ecosystem through the platforms they deliver. Public health organisations remain responsible for outcomes but have limited control over how the underlying digital infrastructure evolves.

This lack of architectural coordination is often reinforced by fragmented governance and procurement structures.

3.2 Fragmented Governance and Procurement

Digital health decision-making is frequently distributed across multiple organisations and administrative levels. Ministries, regional authorities, hospital groups, and specialised agencies may all procure and deploy digital systems independently.

While decentralised governance can support local innovation, it also introduces significant coordination challenges. Procurement decisions are often made within individual programmes or organisations without a clear mechanism for aligning those decisions with wider ecosystem needs.

As a result:

- systems are purchased independently
- interoperability requirements vary widely

- architectural consistency is rarely enforced across programmes

In many environments procurement is structured around the **purchase of software licences or complete systems**, rather than the development of shared digital infrastructure. Contracts are typically designed to acquire a defined product from a single supplier, often evaluated primarily on capital cost, functionality, and delivery timelines.

These models reflect long-standing public sector procurement practices and financial structures. Budgeting processes frequently favour discrete purchases over sustained infrastructure investment, and organisations may have limited mechanisms for jointly funding or governing shared platforms.

Risk management also plays a significant role in shaping procurement decisions. Purchasing a complete system from a single supplier can appear to reduce organisational risk by concentrating technical responsibility with the vendor. In practice, however, accountability for clinical, operational, and data outcomes ultimately remains with the deploying organisation.

This dynamic can create tension. Organisations seek to reduce perceived delivery risk by delegating architectural decisions to suppliers, yet doing so reduces their ability to shape the long-term evolution of their digital infrastructure.

Governance structures may further reinforce this pattern. Many healthcare organisations do not have established mechanisms for participating directly in the development or stewardship of digital platforms following an open approach. Procurement therefore becomes the primary mechanism for obtaining technology, even when the underlying problem is infrastructural rather than transactional.

This environment also affects how organisations perceive openness. Open-source software, collaborative development, and shared governance models can appear unfamiliar or difficult to manage within traditional procurement and regulatory frameworks. In the absence of clear governance structures that support these approaches, organisations may default to purchasing proprietary platforms that offer clearer contractual boundaries.

These patterns do not arise from poor intent. Policymakers, procurement teams, and healthcare organisations operate within regulatory, financial, and operational constraints that shape their decisions.

Earlier policy work has already recognised many of these challenges. For example, the OpenUK paper[1] outlines how procurement models, governance structures, and policy incentives can either enable or constrain openness. The persistence of fragmentation therefore reflects not a lack of awareness, but the difficulty of translating these principles into sustained system-wide practice.

However, the combined effect of fragmented governance and traditional procurement models is to reinforce a digital health landscape in which systems are repeatedly purchased as isolated solutions rather than developed as shared infrastructure.

3.3 Fragmented Standards and Implementation

Digital health does not lack standards. A wide range of mature technical standards already exist for representing and exchanging health information, including clinical data models, messaging formats, terminology systems, and interoperability frameworks.

These standards provide essential foundations for interoperability. However, the existence of standards alone does not guarantee consistent implementation across systems.

In practice, standards are frequently adopted in fragmented or incompatible ways. Organisations may interpret specifications differently, implement only partial elements of a standard, or introduce extensions that are not interoperable with other implementations.

Several patterns commonly emerge:

- different organisations create incompatible profiles of the same standard
- vendors introduce proprietary extensions to otherwise open specifications
- standards are used only at the integration layer rather than within core system architecture
- multiple standards are applied to solve the same problem without clear coordination

These variations accumulate over time. Instead of enabling interoperability, standards can become another source of fragmentation when they are implemented independently across programmes and suppliers.

> No standard solves system fragmentation by itself. Coordination does

This does not reflect a failure of the standards themselves. Rather, it reflects the absence of mechanisms for coordinating how standards are applied across the ecosystem.

Without shared governance or architectural direction, each programme or vendor interprets standards within its own context. The result is a landscape in which systems may technically support the same standards but remain difficult to integrate in practice.

In this environment, interoperability becomes dependent on bespoke mappings, interface engines, and integration projects rather than emerging naturally from shared architectural foundations.

3.4 Lock-in as a Structural Outcome

Fragmentation creates conditions in which lock-in becomes increasingly likely. When digital health systems are developed without shared architectural coordination and procured as isolated platforms, various forms of lock-in emerge as a structural outcome.

The current market structure often incentivises vendor control rather than long-term interoperability or cooperation

Lock-in occurs when organisations become unable to change systems, adopt new capabilities, or introduce alternative suppliers without significant technical, financial, or operational disruption. While lock-in is often attributed to vendor behaviour alone, it is more accurately understood as the result of architectural and procurement choices made across the ecosystem. Once a healthcare organisation commits to a particular digital platform, switching becomes difficult. Migration costs can be high, integrations may need to be rebuilt, and operational risk increases. Over time this reduces competitive pressure and limits the ability of organisations to evolve their digital environments.

Several forms of lock-in commonly appear in digital health environments.

Vendor lock-in

Once a healthcare organisation commits to a particular platform, switching to an alternative supplier can become prohibitively complex and expensive. Systems may rely on proprietary interfaces, tightly coupled components, or vendor-controlled extensions that make substitution difficult.

Over time this can reduce competitive pressure and limit the ability of healthcare organisations to influence system evolution. New functionality, pricing models, and development priorities become largely determined by the supplier rather than by the organisations using the system.

Data lock-in

Data lock-in occurs when information stored within a system cannot be easily extracted or reused in a structured and interoperable way. This often results from proprietary data models, incomplete data export capabilities, or contractual and technical restrictions on data access; however the same can apply when open standards are used without correct governance, or not shared widely as intended.

When data cannot move freely between systems, organisations face significant risks when attempting migration, replacement, or integration. Historical clinical information may become difficult to reuse, reinterpret, or analyse outside the original platform.

Technology lock-in

Technology lock-in arises when systems depend on proprietary tooling, infrastructure, or development environments that cannot easily be replaced. This can restrict the ability of organisations to adopt new technologies, integrate innovative applications, or develop capabilities independently of the original supplier.

Over time this creates closed technical environments where innovation becomes dependent on the roadmap and priorities of the platform vendor.

These forms of lock-in reinforce each other. Vendor, data, and technology dependencies accumulate over years of operation, making change progressively more difficult. The longer a system remains in place, the more costly and risky replacement becomes.

In many digital health environments this dynamic leads to long-term reliance on a small number of large platforms. Integration and innovation occur around these systems rather than within a flexible shared infrastructure.

The result is an ecosystem where interoperability requires increasing technical effort while the ability of healthcare organisations to shape their own digital infrastructure steadily diminishes.

When systems rely on proprietary interfaces, tools, or infrastructure, the ability to introduce new applications or services becomes limited. Innovation must occur within the boundaries defined by the existing platform rather than across the broader ecosystem.

These forms of lock-in are not always intentional. However, once established they can significantly constrain the use of digital health systems. In this environment, claims of openness and interoperability often become difficult to evaluate. Systems may technically expose interfaces or standards while remaining structurally closed in practice.

3.5 Closed Ecosystems Marketed as Open

In environments where lock-in is structurally embedded, claims of openness and interoperability can become difficult to evaluate. Vendors frequently describe systems as "open" because they expose application programming interfaces (APIs), support selected standards, or allow limited third-party integration.

These features can provide genuine benefits. However, they do not necessarily indicate that a system operates as an open ecosystem.

In many cases, openness exists only at the boundaries of a platform while the underlying architecture, data models, and governance remain tightly controlled by a single supplier. This creates environments that appear interoperable while remaining dependent on the vendor's infrastructure and development roadmap.

Several patterns are common:

- APIs are available but provide access only to limited subsets of system data
- integration interfaces are technically open but require vendor-controlled certification or commercial agreements
- standards are supported but implemented with proprietary extensions
- third-party applications can participate only through vendor-operated marketplaces or approval processes

These approaches allow platforms to support some level of interoperability while maintaining strong control over the surrounding ecosystem.

This phenomenon is sometimes referred to as **"open washing"**, where systems adopt the language of openness without providing the structural characteristics required for genuine interoperability and reuse.

The challenge for healthcare organisations is that evaluating openness requires architectural and technical expertise that may not always be present within procurement or

governance processes. As a result, systems that appear open in procurement documentation may still create long-term dependency once implemented.

This does not imply malicious intent. Vendors operate within the incentives created by procurement models and market expectations. When ecosystems reward platform ownership and long-term customer dependence, suppliers naturally optimise for those conditions.

The consequence, however, is a digital health environment where openness is frequently defined by marketing language rather than by verifiable architectural properties.

In digital health, debates about openness often extend beyond marketing claims. Even software released under open-source licences may operate within tightly controlled development communities or governance structures. Some observers describe these environments as "open in licence but closed in practice," particularly when decision-making authority over architecture, roadmap, or contributions remains concentrated within a small group.

These discussions reflect an important reality. In safety-critical domains such as healthcare, software development cannot be entirely unstructured. Clinical systems require controlled contribution processes, formal review mechanisms, and clear accountability for safety and regulatory compliance. Openness therefore does not mean the absence of governance. Rather, it requires transparent and well-defined governance that allows collaboration while protecting safety and system integrity.

3.6 Security and Transparency Challenges

Digital health systems handle sensitive clinical information and support critical healthcare operations. Ensuring the security and reliability of these systems is therefore essential for patient safety, data protection, and public trust.

When digital platforms operate as opaque or tightly controlled environments, organisations may have limited visibility into how systems function internally. In these situations healthcare providers effectively rely on vendor assurances regarding security practices, system architecture, and vulnerability management.

This situation is sometimes described as purchasing a "black box." The internal design of the system, the software components it depends on, and the processes used to manage security vulnerabilities may not be fully visible to those operating the system.

Limited transparency can create several challenges:

- organisations may struggle to independently assess security risks
- vulnerabilities may be difficult to detect without vendor disclosure
- long-term software dependencies may be unclear
- incident investigation and remediation can become more complex

These risks are not unique to proprietary software. Any system that lacks transparency in its architecture, development practices, or governance can present similar challenges.

However, when transparency is limited, healthcare organisations must rely heavily on contractual assurances and vendor processes rather than being able to verify system behaviour directly.

Modern cybersecurity practice increasingly recognises the importance of transparency in software supply chains. Approaches such as Open Chain, software bills of materials, independent security auditing, and open security review processes are designed to improve visibility into how software systems are constructed and maintained.

For digital health systems, transparency is particularly important because software failures can have direct clinical consequences. Healthcare organisations must therefore balance the need for robust vendor partnerships with the need for sufficient visibility into the systems that support clinical care.

Where transparency is absent, both security oversight and long-term system governance become significantly more difficult.

3.7 Why Organisations may Remain in the Existing Model

Despite these challenges, the existing model persists.

For many healthcare organisations, the traditional approach of procuring comprehensive systems from established vendors appears to offer the lowest immediate risk. A single supplier may promise integrated functionality, clear contractual accountability, and a predictable procurement process.

> "Organisations believe they can transfer "risk" to vendors, in reality they are transferring control"

At the same time, introducing more open or modular approaches can appear complex. Organisations may face concerns about regulatory responsibilities, cybersecurity obligations, procurement rules, or internal technical or specialist expertise.

These pressures create a powerful cycle:

- organisations purchase integrated platforms to reduce perceived delivery risk
- those platforms reinforce lock-in and fragmentation
- fragmentation makes future change progressively more difficult
- the next procurement cycle repeats the pattern

Over time, this cycle produces a digital health landscape characterised by disconnected systems, limited interoperability, and repeated reinvention of similar capabilities across organisations.

These patterns persist not because they are poorly understood, but because existing financial, regulatory, and organisational incentives reinforce them.

Understanding these structural patterns is essential before meaningful change can occur. Recognising these patterns allows policymakers and system leaders to move beyond treating fragmentation as an operational inconvenience and instead address it as a structural challenge.

4 The Impact of Fragmented Digital Health Systems

The structural fragmentation described in Section 2 is not simply a technical inconvenience. It has significant consequences for patients, healthcare professionals, policymakers, and innovators across the healthcare ecosystem.

When health information systems cannot operate effectively, clinical data becomes trapped in organisational and technical silos. This limits the ability of healthcare providers to deliver coordinated care, increases operational inefficiencies, and restricts the ability of health systems to learn from their own data.

The effects of fragmentation cascade through the entire healthcare system, influencing patient outcomes, professional working conditions, innovation capacity, and the sustainability of digital health investment.

4.1 Impact on Patients and Healthcare Professionals

For patients, fragmented digital health systems often translate into disjointed care experiences. Medical information may be distributed across multiple organisations and systems, preventing clinicians from accessing a complete view of a patient's health history.

For individuals living with complex or chronic conditions, this can create particular difficulties. Clinical decisions may be made with incomplete information, increasing the risk of delayed diagnoses, inappropriate treatments, or medication errors. It can also lead to repeated tests and procedures when previous results are not easily accessible.

Fragmentation also limits the ability of patients to access and manage their own health information. Data portability, which allows individuals to access and share their records easily across providers or with family members, remains restricted in many health systems. This lack of continuity can undermine patient confidence and trust in digital health services.

Healthcare professionals experience the consequences of fragmentation in their daily workflows. Clinicians and care teams often need to navigate multiple disconnected systems in order to access patient information or complete administrative tasks. Time that could be spent on patient care may instead be spent searching for records, manually re-entering information, or reconciling inconsistent data.

These inefficiencies contribute to professional frustration and administrative burden. Fragmented systems can disrupt clinical workflows, increase cognitive load, and make it more difficult to coordinate care across organisations. Over time this can contribute to stress, burnout, and reduced job satisfaction among healthcare professionals.

4.2 Impact on Innovation and System Sustainability

Fragmented digital environments also create barriers to innovation and technological progress.

When health data is locked within separate and incompatible systems, it becomes difficult to introduce new digital services or applications. Integrating innovative technologies often requires complex technical work to access and standardise data that should already be interoperable.

This limits the ability of health systems to adopt emerging capabilities such as advanced analytics, predictive modelling, or artificial intelligence tools that rely on large, well-structured datasets. Even when promising technologies exist, fragmented infrastructure can prevent them from being deployed effectively.

Fragmentation can also trap organisations within outdated technology environments. Legacy systems that are difficult to integrate or modify may remain in place for long periods, not because they are optimal, but because replacing or extending them carries significant operational and financial risk.

These conditions can slow the overall pace of digital health improvement. Instead of building on shared digital foundations, organisations often invest in duplicating similar capabilities across multiple systems.

The cumulative result is reduced efficiency in digital investment and a slower path toward more advanced and data-driven models of healthcare delivery.

4.3 Impact on Policy, Research, and Market Innovation

Fragmented digital health systems also affect the ability of health systems to govern, evaluate, and improve care at a population level.

Policymakers depend on reliable health data to understand population health trends, evaluate policy interventions, and allocate resources effectively. When data is distributed across disconnected systems, assembling a coherent view of health outcomes becomes difficult.

This limits the ability of governments and health authorities to measure the impact of healthcare policies, identify emerging risks, or evaluate the effectiveness of new programmes. Without consistent and accessible data, decision-making becomes slower and less evidence driven.

Fragmentation also affects the broader innovation ecosystem. Smaller technology companies and specialised solution providers often struggle to enter digital health markets dominated by large, monolithic platforms. Integration barriers, proprietary interfaces, and restricted access to data can make it difficult for new entrants to introduce innovative services.

Small and medium-sized enterprises frequently play a critical role in driving innovation across digital industries. When market structures prevent these organisations from participating effectively, the diversity and pace of technological innovation may be reduced.

The result is an ecosystem where digital health progress becomes constrained not by a lack of ideas or technology, but by the structural limitations of the underlying digital infrastructure.

The consequences described in this section, illustrate that fragmentation is not simply an operational inconvenience. It affects clinical care, professional working conditions, health system governance, and the ability of digital health ecosystems to innovate.

Addressing these challenges therefore requires more than improved technology procurement or collaborative interoperability initiatives. It requires reconsidering how digital health systems are organised, coordinated, and governed at a structural level.

5 What the Middle Ground Looks Like: Good, but Not Enough

In response to the limitations of traditional monolithic systems, many healthcare organisations have begun moving towards more open digital architectures. These approaches typically separate data from applications and make use of open standards such as openEHR, HL7 FHIR, and OMOP.

Each of these standards plays an important role in addressing different aspects of digital health interoperability. openEHR focuses on structured clinical data persistence, HL7 FHIR supports data exchange between systems, and OMOP CDM enables harmonised datasets for research and analytics. Initiatives such as the European Health Data Space (EHDS) reflect growing recognition that coordinated data infrastructure and governance are required at a system level, rather than isolated implementations.

The adoption of open standards represents a significant step forward. By providing shared technical languages for representing and exchanging health information, open standards enable systems developed by different vendors or organisations to communicate more effectively.

However, while this transition represents real progress, it often leads to a middle ground where fragmentation continues to exist.

In many environments, openness is introduced at a technical level but not supported by the governance, coordination, or ecosystem structures required to sustain it. As a result, systems may appear open while still producing new forms of fragmentation.

This reveals a critical limitation of current approaches; openness at the technical level does not prevent fragmentation if governance remains fragmented. Without coordinated stewardship, open standards can reproduce the same patterns of divergence and lock-in they were intended to resolve.

5.1 Incomplete Implementation of Open Standards

Open standards are a major step forward. Standards such as openEHR, HL7 FHIR, and OMOP help create shared technical foundations for structured data, exchange, and research. They are essential components of a more open digital health ecosystem.

HL7 FHIR profiling provides a useful example. Profiles allow the base standard to be adapted to specific clinical contexts, which is necessary for practical implementation. However, if profiles are developed independently without coordination, the result can be a proliferation of incompatible variants.

Open standards alone do not guarantee interoperability. In practice, standards are frequently implemented in inconsistent or partial ways. Organisations and vendors may

adopt only selected parts of a standard, interpret specifications differently, or introduce local profiles and extensions that reduce compatibility with other implementations.

This creates a middle-ground problem. Systems may appear open because they use recognised standards, yet still fail to interoperate in practice.

> The issue is not only technical. It is also one of governance. Lock-in can shift from software to semantics."

Open standards define how data can be structured or exchanged, but they do not by themselves determine who creates models, who validates them, how they are shared, or how competing implementations are aligned over time. Without independent governance, modelling and implementation decisions can become localised, vendor-controlled, or programme-specific.

This creates a new risk: dependency may shift from the software layer to the semantic layer. Even where data is stored or exchanged using open standards, organisations may remain dependent on particular vendors or local teams to interpret, evolve, and safely maintain the models that give that data meaning.

In this way, poor governance can undermine the benefits of open standards. The ecosystem becomes more open in form, but not yet open enough in practice to deliver durable interoperability, portability, or reuse.

5.2 Vendor and Customer-Specific Extensions

Most open standards are intentionally designed to be flexible. Healthcare systems operate in diverse environments, and standards must allow implementers to represent local requirements, regulatory constraints, and specialised clinical information.

This flexibility is necessary for practical implementation. However, without coordination it can also introduce new forms of fragmentation.

A common example is the use of extensions and profiles in HL7 FHIR. Profiles allow the base standard to be adapted for specific use cases, while extensions allow additional data elements to be included when the base specification does not cover a particular requirement.

When these adaptations are developed within coordinated governance frameworks, they can improve interoperability. However, when they are created independently by vendors, regions, or individual programmes, they can produce a proliferation of incompatible variants.

In such cases, systems may technically use the same standard while still being unable to fully understand each other's data.

Vendor-specific extensions can introduce an additional challenge. A system may store data using an open format while embedding critical functionality in proprietary exten-

sions that other systems cannot interpret without vendor-specific knowledge. In these situations the data structure may appear open, but practical interoperability remains limited.

These extensions are often introduced in response to legitimate customer requirements. However, when they accumulate without architectural oversight, they gradually erode the interoperability that open standards are intended to provide.

The result is a familiar pattern across digital health environments: systems built on the same standard that still require significant custom integration to communicate effectively.

5.2.1 Tools Built on Open Standards Can Still Create Silos

A growing ecosystem of tools now exists that supports the development of applications based on open standards.

These tools are often designed to accelerate development and enable domain experts to participate in modelling or configuration activities. While this can increase productivity and flexibility, it can also introduce new challenges.

> Data may be technically portable, but the operational environment may not be."

Different tools may implement standards differently, introduce their own configuration models, or bind application logic tightly to a specific platform. In these cases, data may remain technically portable while the surrounding application environment becomes difficult to migrate.

This creates a new form of lock-in where the data format is open but the operational ecosystem remains dependent on specific tools or platforms.

5.2.2 Lack of Open Governance

> Technical openness alone does not guarantee a sustainable ecosystem."

Without open governance structures, even open standards and open-source software can lead to fragmentation. Governance determines how standards evolve, how implementations are validated, and how shared assets are maintained over time.

When governance is absent or controlled by a small number of actors, multiple incompatible interpretations of a standard may emerge. Systems may claim compliance while implementing only partial or vendor-specific versions of the specification.

Independent conformance processes, transparent governance, and community participation are therefore essential for maintaining trust in open ecosystems.

Without these mechanisms, systems can present themselves as open while remaining effectively closed.

5.2.3 Reinventing Instead of Extending

Another consequence of weak ecosystem coordination is the repeated reinvention of similar solutions across organisations.

Healthcare organisations frequently develop or procure systems that replicate capabilities already implemented elsewhere. This occurs even when open standards or open-source components are available.

Across digital health environments, organisations frequently invest in building capabilities that already exist elsewhere. Patient portals, appointment booking systems, referral platforms, and clinical messaging tools are often developed independently by different vendors and programmes.

Over time this duplication becomes visible at a system level. For example, in England many healthcare providers historically deployed their own patient portals and appointment systems. The NHS App was later introduced as a national access point that brings together services such as appointment booking, prescriptions, and messaging. While this represents an important step toward coordination, it also illustrates how similar capabilities had already been developed multiple times across the ecosystem before a shared approach emerged.

This pattern is not unique to the NHS. Similar duplication of digital capabilities can be observed internationally, including across European health systems, where regional and national programmes have independently developed patient portals, referral platforms, and data exchange services with limited reuse across implementations. At a European level, initiatives such as the European Health Data Space (EHDS) reflect growing recognition that these challenges require coordinated infrastructure and governance rather than repeated local implementations.

The result is a duplication of effort across the ecosystem, where multiple organisations invest resources in solving the same problems independently.

A more sustainable approach would allow organisations to extend and improve shared solutions rather than repeatedly rebuilding them. Collaborative development models can allow improvements made by one organisation to benefit the wider community.

When digital health ecosystems lack mechanisms for coordinated reuse, investment tends to produce repeated implementations rather than shared infrastructure.

5.2.4 Funding Models That Reinforce Fragmentation

Digital health funding models often reinforce the cycle of fragmentation.

Many digital programmes are funded as time-limited projects focused on delivering specific implementations. Once a project concludes, long-term stewardship of the resulting digital assets may be unclear or underfunded.

This approach prioritises the delivery of new systems rather than the sustained maintenance and evolution of shared systems with shared responsibility.

When funding cycles emphasise short-term delivery over long-term sustainability, organisations may repeatedly invest in new solutions rather than extending existing ones. Over time this reinforces fragmentation across the digital health ecosystem.

When funding, governance, and procurement structures all prioritise local delivery over shared stewardship, digital health investment repeatedly produces isolated solutions rather than sustainable ecosystem infrastructure.

6 What Good Looks Like: The Digital Health Commons

The Digital Health Commons builds on principles of commons-based peer production, where shared resources are collaboratively created, governed, and maintained by the communities that depend on them (Benkler & Nissenbaum, 2006). The model responds directly to the structural failures described in earlier sections. By introducing shared stewardship, coordinated governance, and reusable infrastructure, it addresses the fragmentation created by disconnected procurement, inconsistent standards implementation, and the absence of ecosystem-level coordination.

The transition towards a Digital Health Commons requires deliberate changes in governance, procurement, and stewardship. These are explored in more detail across the DHCF publication library, with *Publication 3 – The Role of the Custodians* focusing specifically on the institutional models required to sustain shared digital assets.

The challenges described in the previous sections do not arise from a lack of technology or standards. They arise from the absence of ecosystem structures capable of coordinating how digital health infrastructure is created, governed, and sustained.

> Fragmentation persists not because organisations are unwilling to collaborate, but because the ecosystem lacks structures that make collaboration sustainable."

A Digital Health Commons offers one possible response to this challenge.

In a commons-based model, key digital health assets such as data models, software components, integration specifications, and implementation knowledge are treated as shared infrastructure rather than isolated proprietary assets. These resources are stewarded collectively for the benefit of the healthcare ecosystem while remaining accessible to multiple vendors, organisations, and innovators.

The concept draws on the theory of commons-based peer production described by Yochai Benkler (2006), where distributed communities collaborate to develop and maintain shared resources. This approach has already demonstrated success in other domains such as open-source software, internet infrastructure, and scientific research.

In the context of healthcare, a Digital Health Commons enables multiple organisations to contribute to and benefit from shared digital capabilities while maintaining the ability to build differentiated services and applications. Vendors play a critical role in this ecosystem, but their focus shifts from controlling infrastructure to delivering value on top of shared foundations.

Vendors play a critical role in this ecosystem, but their focus shifts from controlling infrastructure to delivering value on top of shared foundations.

The goal is not to eliminate competition, or innovation or to centralise control. Instead, the Digital Health Commons provides a stable foundation on which diverse ecosystem of organisations can build interoperable, sustainable digital health systems.

The Commons model directly addresses the structural issues described earlier. Shared governance reduces fragmentation in standards implementation, coordinated stewardship enables reuse across organisations, and transparent infrastructure reduces dependency on individual vendors. By shifting from isolated system ownership to shared responsibility, it provides a pathway to more sustainable and interoperable digital health ecosystems.

6.1 Shared Stewardship of Digital Health Assets

A Digital Health Commons changes how foundational digital assets are created and maintained.

Instead of each organisation independently developing similar capabilities, certain assets are stewarded collectively for the benefit of the ecosystem. These assets form the shared foundations upon which multiple systems, vendors, and healthcare organisations can build.

Examples include:

- clinical data models and information structures
- interoperability specifications and implementation guidance
- reusable software components
- testing and conformance tooling
- shared architectural patterns

By coordinating stewardship of these assets, healthcare organisations can reduce duplication of effort and focus investment on improving care rather than repeatedly rebuilding common technical capabilities.

This shift reflects a broader change in responsibility. Digital health infrastructure is no longer treated as a collection of isolated systems but as a shared ecosystem that requires ongoing collective stewardship.

6.2 Custodian-Based Governance

Shared infrastructure requires governance.

In a Digital Health Commons, stewardship is typically provided by independent custodian organisations responsible for maintaining the integrity, sustainability, and openness of shared digital assets.

Custodian organisations provide the governance structures that are often missing in fragmented digital health ecosystems, including stewardship of shared assets, coordination of contributions, and assurance that implementations remain interoperable and sustainable over time.

A custodian does not own the commons. Instead, it governs the shared resources on behalf of the community that creates and uses them.

Custodian responsibilities may include:

- managing intellectual property and licensing
- overseeing conformance and certification processes
- maintaining shared repositories and documentation
- coordinating contributions from multiple participants
- ensuring compliance with regulatory and safety requirements

This governance structure provides the stability and accountability required for healthcare organisations to participate in open ecosystems while maintaining appropriate levels of assurance and risk management.

Custodian models are discussed in more detail in **Publication 3: The Role of the Custodians**.

6.3 A More Sustainable Innovation Ecosystem

A commons-based approach enables a more sustainable digital health innovation environment.

When foundational infrastructure is shared, vendors and innovators can focus their efforts on developing applications, analytics, and services that build on that foundation rather than repeatedly implementing the same basic capabilities.

This reduces barriers to entry for smaller companies and research groups while allowing healthcare organisations to adopt new technologies more easily.

Instead of competing through control of infrastructure, organisations compete through the quality of services built on top of shared foundations.

This model supports a more diverse and competitive ecosystem while improving interoperability and long-term sustainability.

6.4 Enabling User and Patient Participation

A Digital Health Commons enables a deeper form of participation than traditional digital health systems.

In many existing systems, patients are primarily positioned as consumers of digital services. They may be able to view parts of their medical record, submit patient-reported

information, or connect data from personal devices. While these capabilities are valuable, they do not fundamentally change the relationship between individuals and the digital infrastructure that stores and governs their health information.

> A more interoperable digital health ecosystem also enables stronger patient participation in healthcare.

In a commons-based ecosystem, participation extends beyond access to include co-production, coordination, and governance.

Patients and clinicians can contribute data to shared health records through mechanisms such as patient-reported outcomes, home monitoring devices, and digital health applications. Because data is persisted within open and interoperable information structures, this information can be integrated across organisational boundaries and reused safely for care, research, and public health purposes.

More importantly, individuals can participate in **how their data is shared and coordinated**. Open interfaces and interoperable architectures allow patients to control consent, determine which organisations can access their information, and understand how their data is being used.

Transparency mechanisms such as access logs and consent management services provide visibility into data usage, enabling individuals to see who has accessed their information and for what purpose.

The commons model also allows patients, clinicians, and other users to participate in the evolution of digital health systems themselves. When digital health infrastructure is governed through open communities and custodian stewardship, users can influence priorities, features, and improvements to shared digital assets.

This shifts digital health systems from vendor-defined platforms toward **community-governed infrastructure**, where those who generate and use health information can participate in shaping how it evolves.

Approaches such as the **co-produced personal health record (Co-PHR)** model illustrate how patients and clinicians can jointly contribute to and benefit from shared health information environments within a governed ecosystem.

In this sense, the Digital Health Commons does not simply enable interoperability between systems. It enables meaningful participation by the people whose data and work sustain the healthcare system.

Approaches such as co-produced personal health record ecosystems demonstrate how patients and clinicians can jointly contribute to and benefit from shared digital health environments within a governed ecosystem[2].

7 Hidden Layers of Lock-in

Even where digital health systems adopt open standards or open technologies, dependency and fragmentation can still emerge through less visible mechanisms.

In digital health discussions, openness is often judged by visible technical indicators. A system may be described as open because it exposes an API, supports a recognised standard such as openEHR or HL7 FHIR, or incorporates open-source components. While these characteristics are valuable, they do not by themselves guarantee that a system is truly open or that it can participate effectively in a shared ecosystem.

In practice, openness must be examined more deeply. Systems that appear open at a technical level can still introduce dependency through governance, implementation choices, or operational constraints. For example, a system may store data using open standards but restrict access through proprietary interfaces, maintain control of the underlying data models, or prevent reuse by third parties. In these cases the technology may appear open, while the surrounding ecosystem remains effectively closed.

A useful distinction can therefore be made between product openness and organisational openness. A product may implement open standards and provide interoperability capabilities, but if the organisation that governs the system restricts participation, withholds key artefacts, or controls decision-making internally, the practical benefits of openness may remain limited. Conversely, organisations may adopt collaborative governance practices even while parts of their technical stack remain proprietary during earlier stages of maturity.

Proprietary characteristics can therefore appear in several forms within digital health systems. These may include closed analytical tools applied to open data, proprietary extensions to open standards, restricted access to clinical models or APIs, or limitations on the reuse and redeployment of systems by other organisations. Each of these mechanisms can introduce forms of dependency even when the underlying technologies appear open.

The reality in most healthcare ecosystems today is therefore a **hybrid landscape**. Open standards, open-source technologies, and shared digital assets coexist alongside proprietary tools, platforms, and governance models. Moving toward a more open ecosystem is not a binary transition but a gradual process in which organisations increase the transparency, portability, and shared governance of the digital assets they depend upon.

Understanding these hidden layers of lock-in is an important first step toward recognising where openness genuinely exists and where structural barriers to interoperability and collaboration remain.

8 Evaluating Openness in Digital Health Systems

Assessing whether a digital health system is genuinely open is not straightforward. As described in earlier sections, systems may appear open through the use of standards, APIs, or open-source components while still introducing forms of dependency through governance, architecture, or operational control.

For policymakers, procurement teams, and system leaders, this creates a practical challenge. Decisions are often made based on visible signals of openness that do not reflect how a system will behave over time.

For this reason, openness cannot be assessed using a single indicator. Instead, it must be examined across multiple dimensions that reflect both the technical characteristics of the product and the behaviour of the organisation that governs it.

Superficial signals such as claims of standards compliance or the presence of APIs provide only a partial picture. A system may technically support interoperability while still restricting reuse, limiting portability, or preventing meaningful participation in its evolution. Similarly, organisations may promote openness in principle while maintaining governance structures that limit transparency or collaboration.

A more reliable assessment therefore requires examining the underlying capabilities that enable openness to function in practice. These capabilities reflect the maturity of both the system and the organisation responsible for stewarding it.

At the product level, openness is influenced by characteristics such as the portability of data, transparency of system behaviour, modularity of architecture, and the ability for other systems or developers to safely reuse and extend the platform.

At the organisational level, openness is shaped by governance practices, contribution models, and the degree to which participation in the ecosystem is genuinely enabled.

Taken together, these characteristics can be used to evaluate the maturity of openness across a digital health ecosystem.

The following characteristics are not a checklist to be applied mechanically. They are indicators of maturity that can be used during procurement, system evaluation, and governance review to distinguish between systems that are open in appearance and those that are open in practice.

8.1 Product characteristics that support openness

The following capabilities can indicate whether a digital health product can realistically participate in an open ecosystem:

- Commitment to open standards without proprietary extensions
- Capability for seamless data exchange with other products
- Ability for users and organisations to export data completely, including its structure and relationships, in reusable standard formats
- Software and service portability across environments
- Transparency in logic, algorithms, and methodologies used
- A modular architecture that allows components to be reused and extended
- Clearly defined interfaces and rules between system components
- Transparent clinical design assurance and risk management processes
- Comprehensive technical and operational documentation

8.2 Organisational characteristics that support openness

Equally important are the governance behaviours of the organisation responsible for stewarding the system:

- A clear, public, and binding governance model
- Documented processes for consensus and dispute resolution
- Collective decision-making mechanisms involving stakeholders
- Clear rules for contributors and reuse of shared artefacts
- Transparent software supply chains
- Documented processes for reviewing and integrating contributions
- Testing and conformance mechanisms that ensure interoperability
- A long-term strategy for maintaining openness and preventing lock-in
- Governance of shared artefacts and trademarks that protects community use

Together, these characteristics illustrate that openness is not a binary property but a spectrum of maturity. Systems and organisations may demonstrate different levels of openness depending on their architecture, governance structures, and ecosystem practices.

Recognising these dimensions allows policymakers, healthcare organisations, and technology providers to move beyond superficial indicators and better understand how digital health systems contribute to, or restrict, a sustainable and interoperable ecosystem.

9 The Missing Piece: stewardship of shared assets

> The technology exists. The missing piece is governance of the commons.

The digital health ecosystem does not lack technology. Open standards exist. Open-source platforms exist. Interoperability frameworks exist. Yet fragmentation persists because the structures required to govern shared digital assets are often absent. When no organisation is responsible for stewarding common infrastructure, coordinating contributions, and maintaining interoperability over time, even well-intentioned open initiatives can gradually fragment.

Shared digital assets require stewardship. Data models, interoperability specifications, reference implementations, and other foundational components of digital health infrastructure must be maintained, governed, and protected over time. Without organisations responsible for performing these functions on behalf of the wider community, openness alone cannot prevent fragmentation from re-emerging.

The absence of stewardship also contributes to the **perceived risk of open approaches**. Healthcare organisations often hesitate to adopt open ecosystems because responsibilities for governance, assurance, and long-term sustainability appear unclear. When stewardship is undefined, openness can be mistaken for a lack of accountability.

A Digital Health Commons therefore depends not only on open technologies but also on institutions that act as stewards of shared assets. These organisations protect openness, coordinate collaboration across vendors and healthcare providers, provide mechanisms for conformance and assurance, and ensure that shared artefacts remain interoperable, sustainable, and safe over time.

These stewardship roles are performed by custodian organisations, whose structure, responsibilities, and governance models are explored in the next publication in this series: *Publication 3 – The Role of the Custodians.*

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