How will you design information architecture to unlock the power of data?

Creating the right data environment for a connected health ecosystem

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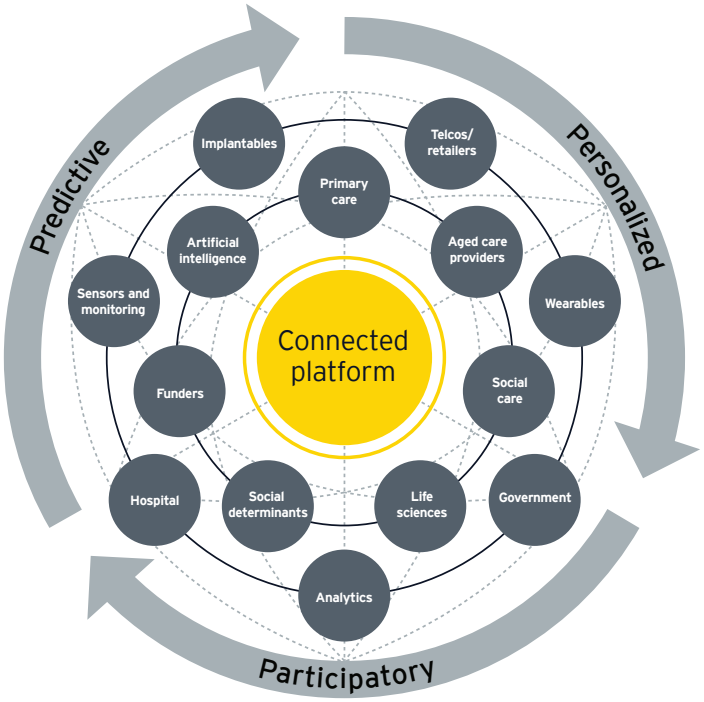
INTRODUCTION

The health industry after the COVID-19 pandemic won't be the same as before. In the long run, the upside of this disruption is a permanent change in the way health systems, organizations and consumers use digital health technologies. Widespread adoption of tech-enabled care and emerging technologies will transform the very foundations of health and care. In this paper, we explore our vision of an information architecture that will unlock the power of digital technologies to create the connected health ecosystem of tomorrow.

What it means to be healthy has become broader, moving beyond the traditional confines of the health industry to embody a more diverse, integrated and seamless system of care and well-being. Powered by digital health technologies, consumers are actively engaging with health systems in vastly different ways. Rather than being content with touch points only when ill or injured, health and care are transitioning to continuous engagement by individuals, with many different stakeholders, and across the lifespan. Accustomed to on-demand and self-directed experiences in other areas of their digital lives, consumers expect something more; within the next decade, they believe that health care will be anchored around digitally enabled care, including virtual delivery, remote monitoring and interactive person-centered tools.[1]

We live in a highly connected society, and advances in technologies and 5G connectivity are making possible a suite of new solutions around well-being, remote care, smart homes and communities. And while complex and high-risk cases and trauma care within a hospital will always play a vital role in health systems, care models across the board are migrating to lower-cost settings. Many of these lie beyond the four walls of the clinic or hospital and are happening closer to the consumer — at home or in the community. (Figure 1)

Figure 1



More data than ever before will be collected by, and on behalf of, individuals. Today, complete health records from birth (if not before) that record care received and other relevant data and that travel with the individual are still largely an ambition. But eventually, our data will be captured and used over a lifetime. Health and social care systems create data with ease, but the many technological, regulatory and cultural challenges associated with the ownership, sharing and usage of personal health data impede data integration. (See the inset, "Fair data – unlocking data in the public interest.")

However, sharing organized and complete data to generate insights for better health outcomes is the driving force behind improving health. Using better data in better ways will result in integrated and prevention-focused care rather than merely treating disease.

New care models and locations give rise to streams of data, including behavioral, environmental and social, that must be integrated with clinical data to provide holistic and personalized care. For consumers, this means tailored care and lifelong engagement. For providers and payors, it means a longitudinal view of the drivers of health and current and future demand. For entrepreneurs, it means opportunities to bring disruptive solutions to the market.

As this shift in the way health and care flows through the system, an infrastructure that can connect and share data, at scale, will be necessary.

To deliver what the health ecosystem needs next would require a new information architecture – one that not only spans the health and social dimensions of an individual's life journey but also realizes the immense value of health data in accelerating novel approaches for better and more efficient health and care.

In this paper, we describe a new approach to health information architecture that we believe will create the right data environment for a consumer-enabled care system and thus bridge the gap between the information systems of today and the connected health system of tomorrow.

THE POWER OF DATA

Fair data – unlocking data in the public interest

The concept of a fair data economy is based on a broad sharing of data, not only among individuals but also among service providers. This empowers individuals with the knowledge and tools to access and use their personal data. But making data available to others facilitates medical research, innovation and further development of public goods. This reflects not only the rights of individuals to control their own data, but also recognizes the social and economic value of open data. Based on consent-based data portability, the concept is consistent with Article 20 of the European General Data Protection Regulation (GDPR). Data movability should be seamless, requiring no effort from the consumer, similar to telephone number portability. This not only puts people in charge of their own data (as a right of citizenship) but also seeks to maximize the use of, and value from, data.

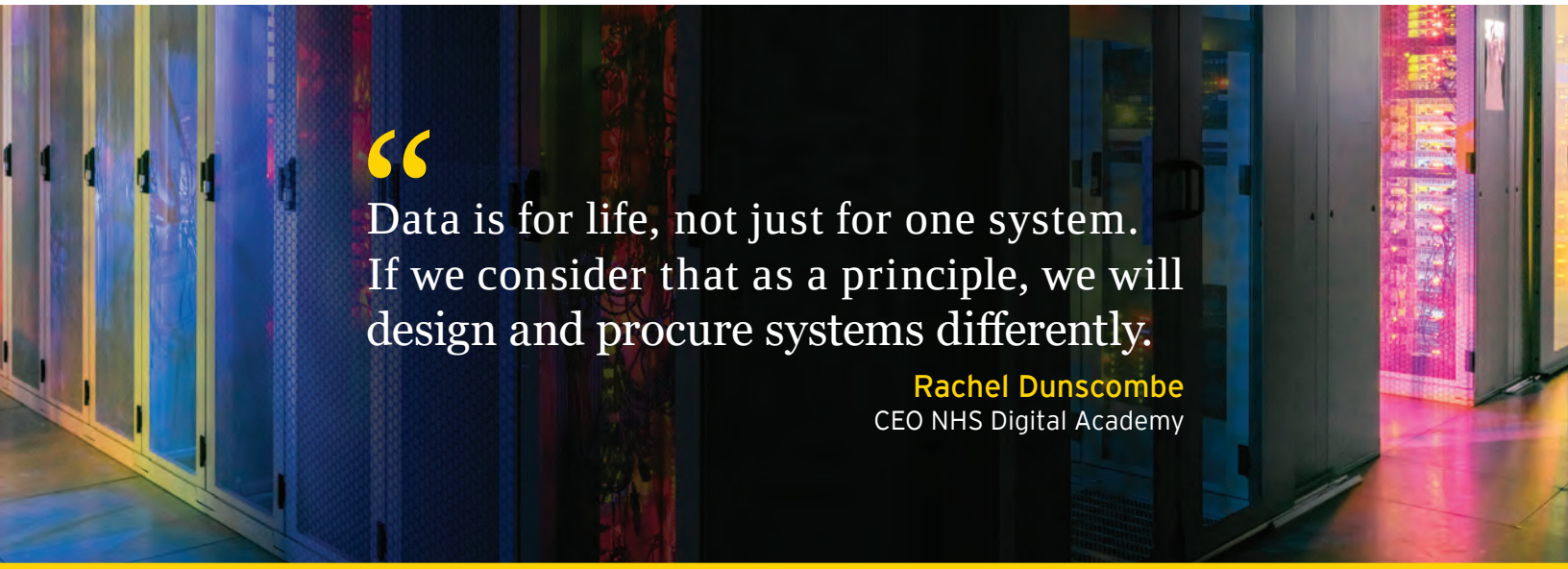
HEALTH SYSTEMS TODAY ARE NOT BUILT TO ENABLE DATA LIQUIDITY

Herein lies the problem — structural and technological issues, including access, (re)-usability and interoperability of data, are barriers to moving toward systems built on data liquidity. Current health information architectures have integration capabilities, but limitations around what can be integrated and the sheer quantity of solutions (and thus integration points) make sharing data within and across systems difficult.

Data is trapped in unconnected silos and incompatible through the use of different standards, interfaces and semantics. Data sharing can be limited by vendor restrictions and by information blocking by providers, payors and vendors for competitive advantage.[2,3] The logic layer that makes use of the systems' data is hardwired within proprietary systems, which means that customization is expensive and can't be done in a modular fashion. Consequently, major changes are out of scope for most health organizations.

At present, interoperability issues are resolved using intermediaries such as Fast Healthcare Interoperability Resources (FHIR) standards that allow different applications and different health systems to talk to one another. However, if health information systems shared a common language (standards, semantics and structure), there would be no translational interoperability friction, and bridging would not be required.

Even so, in a relatively short time, moving from paper-based to electronic health records (EHRs) has greatly advanced the collection, management and usability of health data. And while the current generation of EHR systems is built for a clinical care environment, layers of modifications over time mean that systems may be less agile in responding to changing models of care. True portability, persistence and completeness of data records are still a long way off, and clinicians' dissatisfaction with EHR systems is well-recognized.[4] The ability of consumers to access their own information and share it with others is, at best, an afterthought. Typically, upward of 400 systems[5,6] may exist within a complex health organization. Continued use of paper records and the existence of feral systems,[7] those that lie outside of authorized IT systems, further complicate data liquidity.



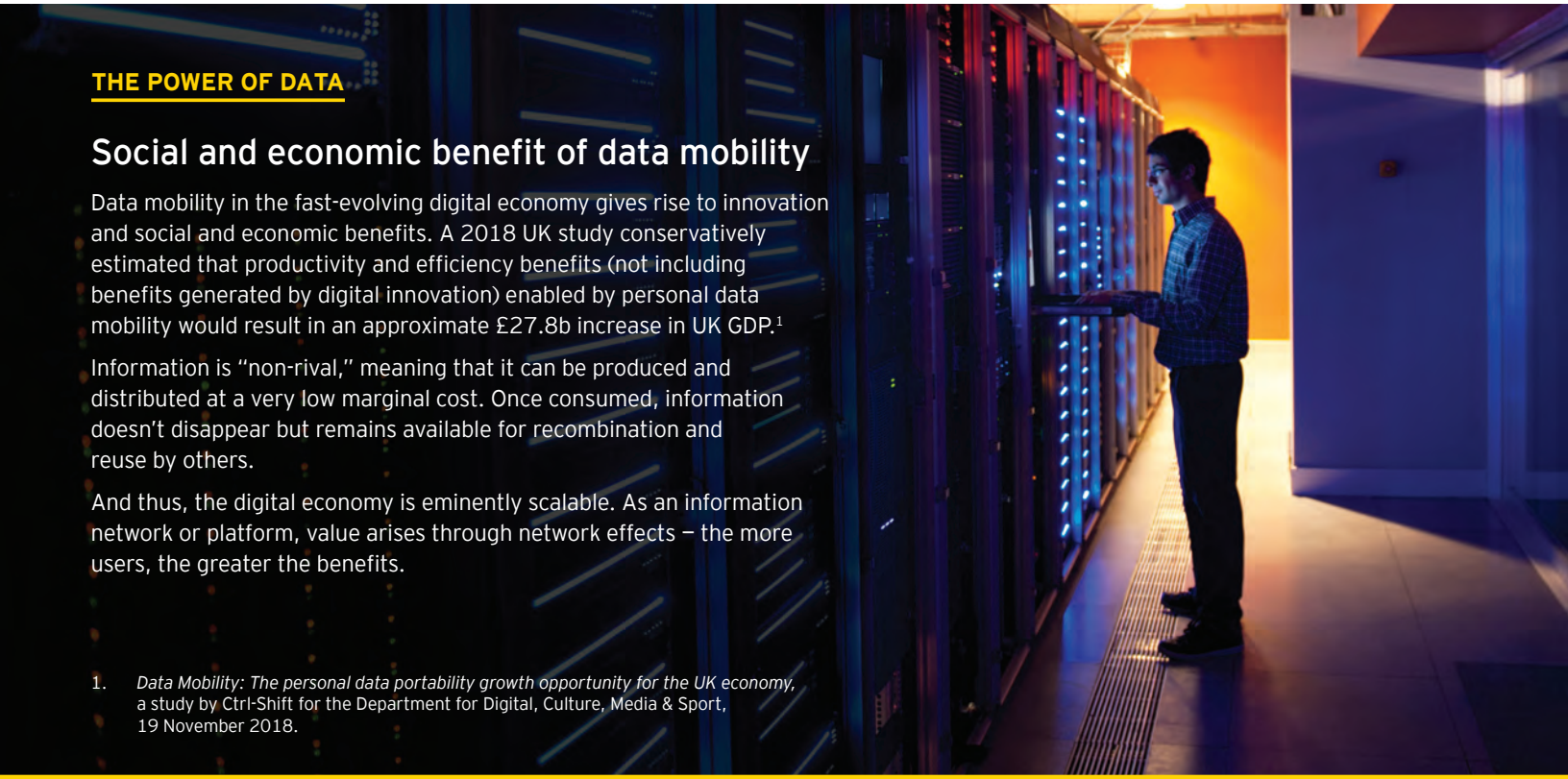
> "Data is for life, not just for one system. If we consider that as a principle, we will design and procure systems differently."
>
> **Rachel Dunscombe**
> CEO NHS Digital Academy

KEEPING UP WITH THE VELOCITY AND VARIETY OF HEALTH DATA

It's clear that we are reaching a pivotal point, where health and social data needs to be better connected, combined and shared. Lessons from other industries are insightful. Open banking, for example, caused a significant shift in the financial sector. It was built on strengthening consumers' control of their own data. Secure and permissioned sharing of financial data with accredited third parties through application programming interfaces (APIs) is opening the sector to new entrants, including non-bank FinTech companies, bringing new revenue streams and better customer experiences and mobility across the sector.[8]

In health care, we don't yet have the means to connect the volume and variety of data in a way that keeps pace with the velocity at which health and social data is generated. What data linkages there are, aren't comprehensive or seamless, nor are they accruing for optimal benefit. We must remedy this by designing for the future, with the entire system in mind. The potential for societal and economic dividends is a powerful incentive for scaling the exchange of data across health systems.

The technologies that will connect us to a wellness-oriented, anytime, anywhere health ecosystem are available today. But the challenge we face is creating something that doesn't yet exist in health — a ubiquitous information technology infrastructure that is built around data persistence (where an output lasts longer than the system that generated it), extensibility (additional elements or features can be added to an existing structure) and true interoperability[9] (the coordinated access,



THE POWER OF DATA

Social and economic benefit of data mobility

Data mobility in the fast-evolving digital economy gives rise to innovation and social and economic benefits. A 2018 UK study conservatively estimated that productivity and efficiency benefits (not including benefits generated by digital innovation) enabled by personal data mobility would result in an approximate £27.8b increase in UK GDP.[1]

Information is "non-rival," meaning that it can be produced and distributed at a very low marginal cost. Once consumed, information doesn't disappear but remains available for recombination and reuse by others.

And thus, the digital economy is eminently scalable. As an information network or platform, value arises through network effects — the more users, the greater the benefits.

1. *Data Mobility: The personal data portability growth opportunity for the UK economy*, a study by Ctrl-Shift for the Department for Digital, Culture, Media & Sport, 19 November 2018.

exchange and collaborative use of information within and across organizational boundaries).

Improving patient outcomes and system performance by integrating care among the patchwork of health and social care agencies requires a networked and modular information framework. Widespread deployment of artificial intelligence (AI) and natural language processing (NLP) that support the management and usability of the sheer volume and complexity of heterogeneous health data is central to the new integrated data environment.

This requires a system-level infrastructure to serve a three-part purpose: safe clinical care, appropriate automation of clinical and back-office operations, and the delivery of personalized care and prevention. This will not lead to abandoning existing core services, such as EHRs, imaging and laboratory systems; rather, these will become part of the broader data ecosystem. (Figure 2)

Although the overall goal is ecosystem-wide interoperability, health organizations wanting to unlock interaction data and to modernize their consumer and staff experience face hard decisions around what to pursue, what to repurpose or divest, and where to invest. This means weighing the current state, including existing deployments and contractual obligations, the life cycle stage of legacy systems, and the regulatory and reporting environment. Strategy decisions will hinge on whether to optimize existing assets (by modification or extension), introduce new modular resources that complement the existing core or invest in creating a new ecosystem from the ground up.

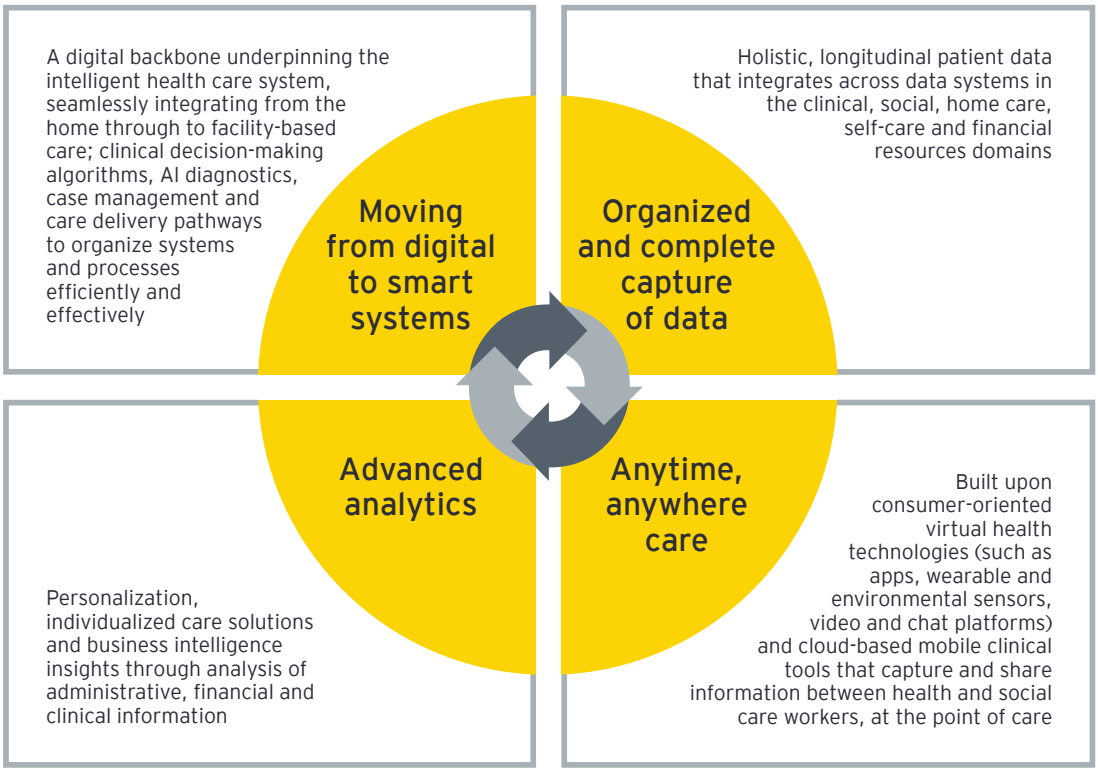


Figure 2

CREATING THE RIGHT DATA ENVIRONMENT FOR TOMORROW

Over a decade ago, eight global health agencies called for a common data architecture for the efficient generation and use of health information.[10] And although progress has been slow, consumer demand and supportive legislation will likely lead to greater health data exchange and interoperability within the next five years.

Recent trends suggest that in some quarters, significant change is underway with reports of modern interoperability platforms. For example, large-scale open platform implementations have been introduced in 16 countries, covering over 22 million patients.[11] The European Commission has set standards for the exchange of patient health information across borders, and regulators are taking an interest in data portability and interoperability in the European General Data Protection Regulation. In the US, the Office of the National Coordinator (ONC) for Health Information Technology in March 2020 made an important final ruling. The ONC rule gives patients secure access to their data and implements interoperability requirements through open data sharing via standardized APIs, and it sets out provisions against information-blocking.[12]

As the focus of health systems moves toward supporting wellness — anytime, anywhere — an open platform environment is required to connect and share data, at scale, within and among enterprises and systems. The optimal platform will separate content and technology and will be vendor neutral, distributed and modular — incorporating third party as well as legacy systems.

This demands a new way of thinking about data. Rather than keeping it locked away in siloed systems, a decentralized and networked infrastructure could unify disparate information from multiple sources and make sense of it. This means capturing and linking all relevant data regardless of where it is stored.

To progress toward a truly connected health system, a data environment with no connection restrictions other than permissions and security is foundational. This, in turn, necessitates an open platform architecture that allows for the storage and linking of structured and unstructured data and that determines how data flows. Design considerations should provide clear data provenance to deliver trusted algorithms. Built on common standards, this platform forms the base for third-party applications, ensuring safe and interoperable systems.

A gradual process of change

Adoption and scaling of such an architecture will be a gradual process of localized activity and interest. Enterprises will build micro-ecosystems based on the current state of their technology journey — these may be internal to an enterprise or coupled as networks between different enterprises. But over time, and when all enterprise and local area activities are added together, the overall ecosystem coalesces and a connected health ecosystem emerges. This is perhaps more easily visualized with an analogy. Think of a cell with a permeable membrane that allows for an orchestrated but free-exchange of material. The cell, along with many others, ultimately forms part of a larger, interconnected entity.

SECTION 1

A FRAME OF REFERENCE

To architect for the future requires a reference framework around technology, data and end-user primacy

	What this means	What this delivers
User-centric	▸ For consumers, permissioned free-flow exchange of data built around a unique individual identifier with a full audit trail. ▸ For businesses, clinical and operational data relevance.	Consumer control of their own health data for engagement and better health outcomes. Customizable and adaptable operational systems that meet business needs.
Interoperable	▸ Built upon common rules that govern access, content management, with semantic and technical interoperability referenced to internationally accepted standards.	Vendor- and technology-neutral infrastructure that works seamlessly to allow frictionless permission-based electronic sharing of usable health information among patients, clinicians, researchers and others.
Decentralized	▸ Information and metadata reside at the point of creation while connecting with, and contributing to, local and national area health information systems.	Underlying data structure remains unchanged at the site of collection and is fully provenanced to guarantee future insights, research, and third-party innovations and apps.
Agile	▸ An architecture that is modular, built on micro-services with no need for reconfiguration. Plug-and-play integration of devices and equipment, and extensible. Separation of data and application layers.	Allows for rapid changes as they occur, incorporating new data elements as they arise and scalability. Supports portability and safe and secure development and integration of third-party innovations.
Heterogeneous	▸ APIs integrate data within an enterprise and across enterprises. Integration with open platforms.	Accommodates heterogeneity in legacy systems, including EHR design, implementation and use across the ecosystem; applications seamlessly access information from multiple sources.
Secure	▸ Based on accepted data security frameworks, assurance schemes and standards for handling personal health and social care information.	Governance and cybersecurity in a trusted system that is secure, safe, reliable and performs as expected.

SECTION 2

AN ARCHITECTURE BUILT IN LAYERS

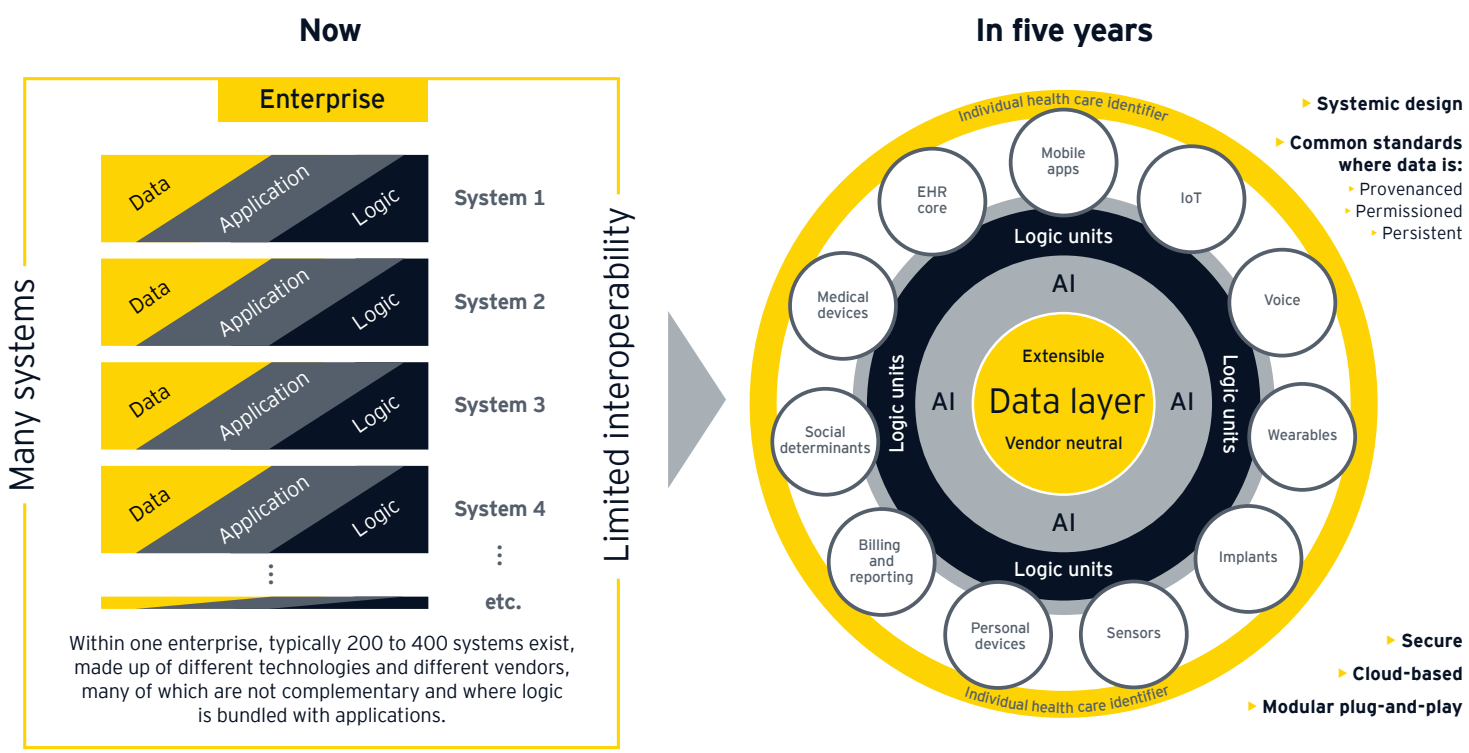
The future health and care information platform we describe separates the architecture into different layers that organize transactions and interactions: the data layer, the application layer and the logic layer: (Figure 3)

- The **data layer** helps deliver data that is up to the task. It is standardized in terms of format, nomenclature, terminologies and definitions, which allows it to flow into other systems, as specified by the data owner. Good rules for data storage will not change much, if at all, allowing for persistence and, ultimately, interoperability over time.
- The **application layer** requires a fully systemic design of workflow. This means knowing context, or what comes before and after, in the care journey. It is based on triggered events of care or intervention (e.g., clinical workflows or health consumer alerts) rather than constant human monitoring.
- The **logic layer** incorporates AI that is governed by a set of rules that define boundaries and exceptions and can form workflows. AI and intelligence are monitored and managed by humans and are subject to regular monitoring for audit and clinical safety.

Data is stored separately from the applications that collect, edit and display it. Greater flexibility allows for multiple use cases, multiple vendors and future growth. Such flexibility enables data to flow for better care models and data extensibility (e.g., across a patient's lifetime). Clean, standardized, shared data will enable both AI and predictive analytics to come out of the data stream. Also necessary is a rules base that governs access and content management. It's also essential to incorporate internationally recognized standards for terminology, interfaces, storage and coding of records, documents and images. For example, SNOMED CT and LOINC and other standards developed and adopted over time.

Rapid innovation will take place in the application and logic layers, all without altering the underlying data structure. As Figure 3 shows, in the next five years, the information architecture will shift from siloed vaults of data that don't talk to each other to a more harmonized arrangement.

Figure 3



Present: Many systems all with intimately bound data logic and applications

Future: A cohesive technology stack, giving a unified experience for clinicians, professionals and patients; unique data at the center accessed by applications in real time through micro-services

SECTION 3

MIX AND MATCH WITH EXISTING CORE SYSTEMS

As described, this will not require abandoning currently used core systems such as EHRs, laboratory and radiological information systems. Rather, these will be a component of the broader data ecosystem. Existing systems will still collect and reflect essential clinical and operational data. Policy levers and market-driven purchasing preferences will likely shape future commercial product development toward greater data standardization. Newer AI-driven solutions offer the opportunity to quickly and inexpensively deal with high-volume data and to take on data discovery and replications.

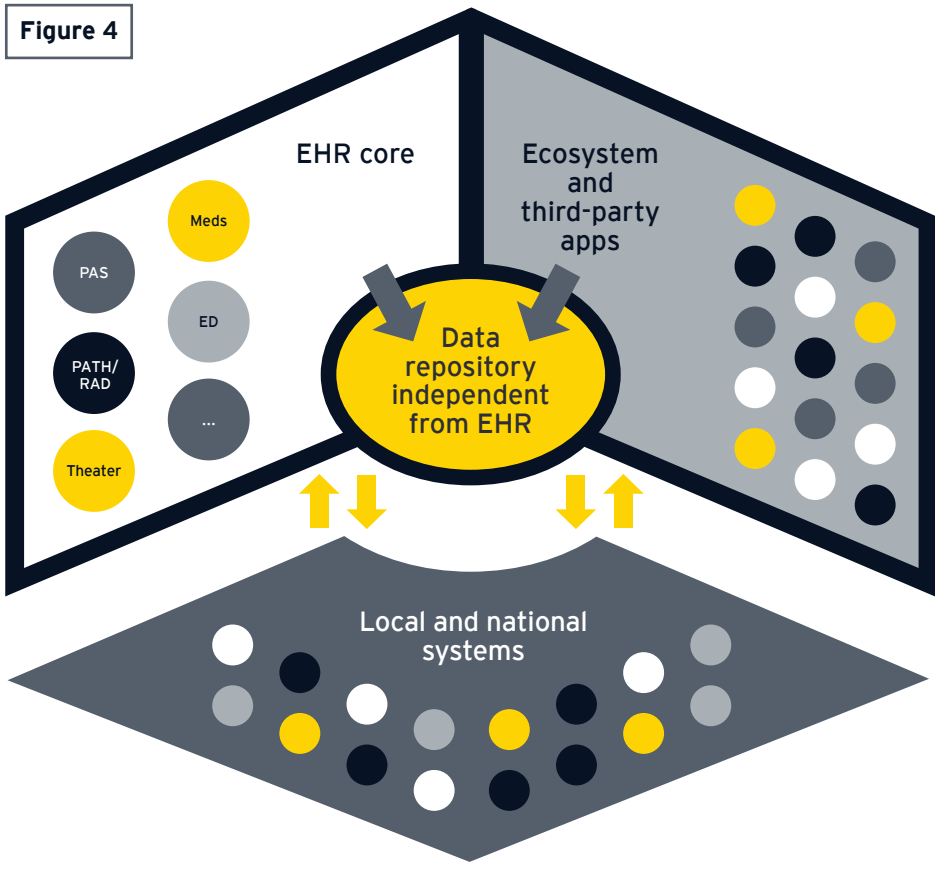
A more flexible, dynamic infrastructure will be built around existing systems, communicating through standard interfaces like FHIR and web APIs. The APIs of today will inform the technical design of tomorrow but will also bridge the gap in data models and current absence of system-level design. In the future, systemically architected systems will mean that this bridging function will not be needed. Web APIs will persist into the future as ways of creating the frictionless data layer, but they won't be necessary for creating terminology or future data standards. In the near term, platform-based systems and legacy EHRs will coexist by maintaining basic functionality in legacy systems while building and innovating in a platform-based environment.

Internationally, there are numerous examples of steps being taken toward more open and interoperable systems. Estonia, for example, has almost fully digitalized its health system and is currently integrating health and social data for clinical practice support and research. And several of the Nordic countries, including Norway and Sweden, are establishing permission-driven consumer and clinician accessible health records that follow the patient, irrespective of care location. In the UK, the Salford Royal NHS Foundation Trust has deployed an open EHR clinical data repository alongside a core patient record system to meet changing clinical requirements and to incorporate patient-recorded outcome measures. And in Germany, the AOK, a major health insurance provider, is developing a digital health network built around data interoperability to make health information available nationwide for its 25 million members.

What these examples have in common is a steady progress toward system change built around meeting end-user needs, vendor neutrality, data persistence, and demand for flexibility and data fluidity. None of these examples are big-bang changes; rather, they're staged building blocks for the future.

And so, to recap, for health care organizations, the shift in the ecosystem will likely look something like this: an open platform and a clinical data repository, with integration of legacy and third-party elements, that support easy data migration and are transparent to all applications connected to the platform. (Figure 4)

Figure 4



WHAT LIES AHEAD?

While the overall goal is ecosystem-wide interoperability, there are several steps that health care organizations and policymakers can take today to meet the demands of tomorrow. Even though industry stakeholders may be totally invested, positioning for the next wave of data-driven change is paramount.

Where we see success in the marketplace is when organizations understand that the way forward is built around data and technologies that grow the business of tomorrow, rather than just a repeat of today's procurement cycle. These organizations build from an ecosystem mindset identifying what data are critical, and the right strategy to access them. They follow a transformation agenda to create new business models as data becomes the central asset in the organization.

To shift with confidence toward an interoperable environment means making decisions around what to grow or transform in the existing business, scaling actions and investments at the right pace, and driving cultural change across the organization. Also key is fostering innovation to create and test effective blueprints for doing things differently by using technology. Organizations must adapt business models and partnering strategies to the realities of the emerging ecosystem, augmenting their skills mix and capabilities by working with other organizations.

Adaptive technologies will be best supported by agile operational processes and governance models and implemented by individuals with data expertise.

Introducing a new health information architecture, either at an enterprise or national level, requires alignment of facilitatory policies, determined leadership and clarity of governance. Good governance around data, for example, is necessary to establish user trust (both consumer and clinician) and that privacy and security are maintained. Yet the right environment for innovation must be fostered. As the care model shifts toward incorporating community and social care, policy attention will be necessary to align the governance and institutional factors around how health and social care organizations effectively work together.

Digital technologies form a data-driven foundation for the future health industry, and conversations about how we can use technology to make a real difference are long overdue. A systemically architected approach for the management of health data is an important step toward a connected health ecosystem, and the technical elements for such a system already exist. But to move forward, we will need to reconfigure the information backbone of health care as a new, frictionless information architecture, strategically and thoughtfully.

To lay the groundwork for the coming years, here are three things to consider:

1 Framing up the future

Perspective shapes the narrative in an organization — the future that stakeholders want to own and how they will create value in the emerging wellness ecosystem. The speed of technological change and complexity in the health market require reflecting on purpose, capabilities and priorities. One must also consider future market conditions and the services sought by the consumers of tomorrow.

To find out what creates value and how to get there, ask:

- What lens is your organization looking through? How is purpose defined, and where do value streams lie: with the consumer, the organization or both?
- How will data shape future business models and reimbursement, and what infrastructure must be in place to unlock interaction data and to modernize the employee and consumer experience?
- What risk is involved, and how deep is the appetite for change — incremental steps or redesign from the ground up?

2 How ready is the organization to change?

Future relevance requires both agility and confidence to shift, and to do so at scale. But where best to begin? Clarity around where the greatest challenges and opportunities lie can be elusive. The speed of change is often slow, hampered by contractual obligations, capital intensive infrastructures and legacy technologies.

To identify the problem, ask:

- What are the pain points to be resolved?
  - For example, wanting to:
    - Drive better clinical outcomes
    - Respond to growing demand
    - Migrate to new care models and teaming
    - Reverse clinician burnout
    - Secure revenue streams
    - Free investment resources through back-office automation
    - Step away from lock-in with long-standing entangled systems
- To what extent does the current tech environment cause or exacerbate the pain points, and how would changing the technology environment resolve the problems?
- What are the opportunities to personalize, simplify and streamline?

3 What is the road map, given the current stage along the technology journey?

Transformation must occur at the right pace for the organization and deliver the right combination of elements that are wanted and needed. Where legacy IT infrastructure already exists, the way forward may lie with maintaining core functionality while investing in adaptable infrastructure such as open architecture and blockchain-enabled solutions that support a connected ecosystem.

To develop the road map, ask:

- What is the plan?
  - To optimize existing assets (either by modification or extension), to introduce resources that complement the existing core, or to create a new ecosystem from the ground up
- What is the process?
  - A phased transition to new solutions, a greenfield approach of creating new capabilities on a new platform, or a big bang approach that converts all capabilities to a modernized solution in single or multiple events?
- What else must be done?
  - Design for trust, governance and align organizational culture — where boards and clinical and organizational leadership are comfortable with creating friction and deviating from the status quo, and have the skills to do so
  - Bring other stakeholders, including the board and policymakers, along on the journey
  - Build the right in-house team with the right capabilities to execute

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EYG no. 002544-20Gbl
CSG no. 2003-3446456

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