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Capgemini

WORLD ECONOMIC FORUM

Better Together:
Building a Global Health Network Economy through Data Collaboration

WHITE PAPER

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Contents

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Foreword

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The convergence of digital technology and health presents an unprecedented opportunity to address the systemic challenges that have long plagued global healthcare systems. Despite advances in digital tools, artificial intelligence (AI) and other frontier technologies, the true potential of digital healthcare transformation remains unrealized. In large part this is due to an inability to make full use of health data, the fundamental enabler of all digital health technology. Systemic barriers have hindered progress, preventing healthcare systems from fully embracing the digital revolution.

Health data, for the purposes of this paper, broadly encompasses any information collected about the health and well-being drivers, status or outcomes of individuals or populations. This includes data from electronic health records (EHRs), genomic information, medical imaging, dental data, wearable devices and social determinants of health among other sources. These diverse datasets are critical for driving informed healthcare decisions, enabling better patient outcomes and supporting systemic innovation.

The World Economic Forum and Capgemini, through their partnership in the Forum's Digital Healthcare Transformation (DHT) initiative, recognize the pivotal role of health data collaboration in reshaping the future of healthcare. By fostering a global health data network economy, this initiative aims to help catalyse a new era of health data sharing and collaboration, unlocking far-ranging new possibilities.

With healthcare systems globally facing mounting pressures – from ageing populations and rising chronic disease rates to the impacts of climate change – maximizing the societal value of health data is not merely an opportunity but a necessity. By uniting stakeholders across the healthcare spectrum, we aim to build an ecosystem that thrives on trust, collaborative innovation and new value creation for patients, business and society.

This paper lays the groundwork for a data-driven healthcare future. It invites leaders to join us in shaping a world in which digital transformation is no longer an aspiration but a reality that saves lives and improves health worldwide.

Executive summary

Developing a global health data network will enable data to fulfil its potential to transform health systems and delivery.

In the evolving landscape of global healthcare, health data stands out as an immensely powerful yet largely untapped resource, poised to revolutionize patient outcomes, broaden healthcare access and enhance systemic efficiency. Despite the rapid growth in health data, much of it is not shared and remains underused – hindered by fragmented standards, uncoordinated practices and misaligned incentives – resulting in a lack of significant real-world clinical applications. This gap between data creation and practical use underscores the need for transformative health data collaboration to unlock its potential.

The need for a connected health data network extends beyond enhancing current health systems to reduce patient harm and resource waste; it is also essential for reimagining the future of health through AI-driven solutions and emerging technology. While sectors outside healthcare advance in artificial intelligence (AI) and data analytics, healthcare systems remain constrained, missing critical opportunities. Compounding these challenges are systemic pressures, including rising rates of chronic disease, ageing populations and insufficient resources. These issues highlight the urgent need for a coordinated global response to align health data practices with health system objectives.

This report envisions a global health data network economy – an interconnected system in which diverse stakeholders including healthcare providers, patients, pharmaceutical companies, tech innovators, governments, researchers and others collaborate to maximize the value of shared information. By enabling secure data exchange and broader access to rich datasets, this network economy can drive advances in diagnostics, accelerate research, support precision medicine and deliver highly personalized patient care. Integrating healthcare data nodes within this ecosystem would create a network worth far more than the sum of its parts.

Moving towards this powerful network will require significant, concerted and coordinated effort to overcome key barriers that have prevented its formation. This paper outlines the strategic steps needed to promote trust, standardization and interoperability in building a robust health data network economy. These steps must bridge existing divisions, ensure data quality and governance and better align health data policies, practices and standards with global health objectives. Collaborative action is necessary to create a clearer pathway towards a global healthcare transformation that takes a coordinated, data-driven approach – setting the stage for sustainable improvements in healthcare for years to come.

1 A global need for data-driven health

There is an urgent need to collaborate on collecting health data to transform the delivery of care.

1.1 The potential of health data

In the rapidly evolving landscape of global healthcare, health data presents a remarkable opportunity to enhance patient outcomes and systemic efficiency. Despite health data's exponential growth – fuelled by advances in big data, AI and generative AI and constituting about 30% of the world's data volume[1] – its practical use lags dramatically behind its accumulation.

The key opportunity lies in collaboration between the public and private sectors to combine multiple data sources to drive new value. While substantial amounts of health data originate from traditional sources such as hospitals and research institutions, these datasets are often not shared or are restricted and lack a common global standard. Although standards such as Fast Healthcare Interoperability Resources (FHIR) exist, offering a foundation for interoperability, they are not yet fully implemented or optimized across all regions and systems. Additionally, a significant volume of data not explicitly tagged as health-related (e.g. ranging from wearables data to weather data to automotive data) still holds immense potential for improving health outcomes; in the new paradigm of digital health, a broad spectrum of data can serve health purposes, provided it is appropriately integrated and analysed.

As the volume of health data continues to rise, the gap between data availability and its practical use in healthcare grows even wider, exacerbating these systemic challenges. This underscores the importance of establishing a robust framework for collaborative data integration and use. Numerous stakeholders have been advocating for this; for example, the National Academy of Medicine's report[2] highlights the steps needed to create a learning health system through effective health data sharing, offering a roadmap for overcoming barriers to integration. The Organisation for Economic Co-operation and Development (OECD)'s report *Health in the 21st Century*[3] emphasizes the critical role of digital health systems in improving care delivery, identifying integration and standardization as key enablers for transformative change.

1.2 Why health systems should act now

The urgency of the need for immediate action on health data collaboration cannot be overstated, and it is highlighted by the potential benefits for improved health outcomes and significant economic savings. By making use of this vast yet largely untapped resource, the healthcare sector could dramatically enhance care quality, reduce mortality rates and cut healthcare costs.

Reduction or elimination of patient harm presents an opportunity for systemic data improvements. More than 50% of the harm[4] that occurs in healthcare settings is preventable. Inaccurate diagnoses[5] frequently arise due to incomplete patient information, while delays in treatment occur when medical histories are not readily accessible between providers. Medication errors[6] stem from inconsistent patient data, and opportunities for preventative care are often missed because of fragmented patient records. Poor care coordination, exacerbated by a lack of data sharing, further compounds the complications and increases the risk of harm.

These preventable issues highlight the critical impact that better data management, sharing, analytics and insights can have in addressing the gaps in healthcare practices and improved patient outcomes – gaps that have a real impact on lives and costs. Better data collaboration could help lead the way to preventing approximately 3 million deaths[7] worldwide each year, which equates to more than five deaths per minute.

Stronger value models for data collaboration could significantly reduce the financial implications and costs, too, while also presenting significant opportunities for growth and investment. Currently, poor health data use costs more than $800 billion annually,[8] representing a chance for reinvestment in health improvement and economic development. Each day, this amounts to a loss of approximately $2.2 billion – funds that could otherwise be channelled into enhancing health outcomes, particularly in regions with stark health disparities.

While inadequate use of available health data is not the root cause of these challenges, using data more effectively presents a significant opportunity to address them. Enhanced access to and use of health data can support safer, more informed care, ultimately reducing fatalities and improving patient outcomes.

1.3 How health data can transform the future of health

The current underuse of health data not only fails to prevent these harms but also hampers the transformative potential of new developments in healthcare. There are several major strategic rationales for investing in health data collaboration.

Fuelling AI transformation in healthcare. The healthcare sector risks falling further behind in technological advances without robust health data and a well-developed digital infrastructure. This foundation includes everything from secure platforms and cloud environments to manage data, to advanced medical devices and wearables capable of real-time, high-quality data gathering. Effective data foundations are crucial for enabling AI technologies[9] that can significantly enhance healthcare efficiency and outcomes.

Unlocking value-based care. Existing health systems struggle with transparency and measuring outcomes, which impedes the progress towards value-based care models. Strategic data use could drive substantial improvements in this area. Establishing a data-driven approach[10] lays the foundation for transformative shifts in health systems that prioritize measurable outcomes and patient-centred value.

Promoting international health cooperation. Global health challenges such as pandemics, the health impacts of climate change and chronic disease management necessitate unprecedented levels of simultaneous data sharing and global collaboration[11] to ensure swift and effective responses. International cooperation can also bridge resource gaps in low- and middle-income countries, enabling them to use shared data and lessons learned to improve healthcare systems.

Driving frontier innovation on complex health challenges. Advances in medical science allow for complex global healthcare issues – such as oncology, neurodegenerative diseases, chronic conditions and mental health – to be tackled more effectively. These challenges stem from intricate root causes requiring comprehensive data from diverse populations. Solutions include systems for longitudinal patient data, integrated data ecosystems and progress towards personalized medicine. These foundations support population health management, new treatments and targeted prevention. Collaboration via federated approaches, as outlined in the Forum's *Sharing Sensitive Health Data in a Federated Data Consortium Model*, ensures secure data sharing, revealing actionable health trends and driving breakthroughs.

The collection and sharing of health data alone cannot address all of the challenges outlined above. While data is a critical enabler, transforming healthcare requires a collaborative, multistakeholder approach that integrates diverse expertise, resources and perspectives – new data approaches must be combined with new approaches on other key aspects such as organizational and business models, incentives, policies and more.

2 Vision for a health data network economy

Collaboration on data can speed innovation, improve delivery, boost prevention and advance research in health systems.

2.1 The power of network effects in health

Health data collaboration has the potential to transform healthcare systems by promoting a network effect that amplifies the value of information shared between stakeholders. In this context, a network economy refers to an environment in which the value of data multiplies as more stakeholders contribute to and access it – an extension of Metcalfe's Law[12] into the healthcare sector. This creates an expansive web of insights that benefits both individual and collective healthcare outcomes: as participants engage with interconnected health data within networks, insights deepen, enhancing the accuracy of diagnoses, treatments and innovations.

By advancing health data collaboration, this network economy establishes a foundation where each participant's data contributions yield system-wide benefits, promoting forward-thinking healthcare solutions. The collective intelligence within this system supports continuous breakthroughs in healthcare delivery, policy and innovation, creating a cycle of improvement and impactful growth across the sector. The following sections explore the specific impacts of a well-functioning health data network economy.

Accelerated innovation in precision medicine

As health data collaboration increases, access to large-scale, diverse datasets becomes possible. This data variety accelerates the development of AI-powered diagnostics, precision medicine and personalized care pathways. The principle benefits of these advances include:

- **Earlier disease detection**. Preventative care and early diagnosis can be achieved through pattern recognition and trend analysis. Current models can predict the onset of chronic diseases such as diabetes and cardiovascular disease, which together account for around 20 million deaths annually worldwide.[13]
- **Personalized treatment plans.** Insights from patient health records, genomic data, connected sensor technologies, demographics and lifestyle factors enable the creation of tailored treatment plans for individual needs.
- **Population genomics.** Large-scale genomic projects, such as the Emirati Genome Programme[14] or the Genome of Europe,[15] use advanced DNA sequencing and AI technologies to generate comprehensive genomic data. This data helps in improving the understanding of genetic variations and developing targeted treatments for specific populations.

In a health data network economy, each participant contributes to and benefits from the growing pool of data, creating compounding value over time.

Improved healthcare delivery and operational efficiency

Collaborative data sharing among healthcare providers enhances care delivery by making it faster, more timely and better coordinated. With real-time access to patient records among and between institutions, clinicians can make better decisions, avoid redundant procedures and reduce costs. Not all healthcare data needs to be shared or used universally; a selective and strategic approach can optimize resource use and streamline processes.

The principle impacts include:

- **Care coordination.** Health data sharing ensures that care systems can adapt to each patient's journey, enabling personalized, data-driven decisions that enhance outcomes.
- **Real-time patient records.** More seamless sharing of patient records can significantly improve care coordination and decision-making across institutional and jurisdictional boundaries.

- **Financial optimization.** Streamlining processes and reducing inefficiencies can lower unnecessary medical procedures, improve diagnosis accuracy, decrease readmissions and cut overall costs.

- **Enhanced efficiency for healthcare providers.** Streamlined data access reduces administrative burdens, freeing up time for healthcare providers to focus on patient care.

- **Enhanced patient safety.** Access to comprehensive and up-to-date patient data reduces the risk of medical errors. Real-time health data allows for faster identification of adverse drug interactions, allergy alerts and potential complications, ensuring that healthcare providers can make safer decisions.

These efficiencies are amplified within a network economy, where the more stakeholders adopt data-sharing practices, the more streamlined healthcare delivery becomes across the system.

Enhanced public health monitoring and prevention

Increased collaboration enables real-time public health surveillance and more agile responses to health crises. With data-sharing networks, stakeholders can see benefits such as:

- **Real-time monitoring.** Timely access to data from health records, wearables and other digital sources provides current insights into disease outbreaks and health trends, facilitating rapid detection and response to emerging threats.

- **Predictive analytics.** By integrating clinical, laboratory and social data, a comprehensive view of population health emerges, allowing predictive models to identify potential disease hotspots and forecast health trends, improving preparedness.

- **Evidence-based health policies.** Comprehensive health data access informs policies tailored to specific regional and population needs, enabling more effective and locally relevant public health strategies.

- **Improved resource allocation.** Health data networks help prioritize resources in low-resource settings by directing essential supplies and personnel to areas of greatest need. Also, during health crises, real-time data enables the timely allocation of medical supplies and resources to hotspots.

- **Improved communication and public awareness.** Health data networks can enhance communication between public health officials and the public. Through data-driven alerts and information dissemination, citizens can be better informed about emerging health risks, increasing public engagement and making it possible for people to take proactive health measures.

A well-developed health data network empowers public health systems to better anticipate, prevent and manage crises, delivering widespread benefits to society. However, achieving equity within these networks requires prioritizing data collection in underserved areas to ensure they are not left behind. While data-rich regions can already make use of extensive datasets to advance healthcare innovation, underserved regions must first focus on establishing foundational systems. This dual approach ensures that health data networks are inclusive, enabling impactful outcomes for all populations and promoting global health equity.

Advanced medical research and innovation

A collaborative network economy creates incentives for the development of innovative business models that thrive on data exchange and analytics. This system benefits not only health technology start-ups but also pharmaceutical companies, healthcare providers, insurers and other stakeholders struggling with limited data access. The evolving data economy offers transformative opportunities across the healthcare landscape, enabling automated advances in AI and algorithmic-led care delivery, research and operational efficiency. Examples include the following:

- **Streamlined new drug development.** Longitudinal real-world data collected via remote monitoring enhances safety, validates efficacy and shortens drug development timelines, significantly reducing costs that currently range from $300 million to $3 billion.[16]
- **Enhanced medical research.** Aggregated patient data enables researchers to identify correlations in ongoing and failed research, improving disease understanding and drug development and refining treatments. With more data, these insights can accelerate breakthroughs beyond current capabilities.
- **Collaborative clinical innovation.** The fragmented drug discovery process often leads to duplicated efforts and inefficiencies across various fields. Establishing a central, open-source database for clinical research accessible to all stakeholders could significantly improve success rates, reduce costs and encourage broad collaboration in many therapeutic areas.
- **Data-driven wellness.** Since the early 2010s, innovative business models have emerged that employ health data for predictive analytics, diagnosis and preventative care. Notable examples include the "artificial pancreas"[17] and the Apple Watch, which uses algorithmic care to detect issues such as atrial fibrillation (AFib) and alert users to patterns indicative of potential obstructive sleep apnoea (OSA). Moreover, longevity indicators are using health data to forecast outcomes and suggest lifestyle modifications to prevent chronic diseases.[18]

These four approaches amplify network effects in healthcare, driving scalable growth while ensuring the responsible development and validation of tools to maximize healthcare benefits. They offer a dynamic model for collaborative innovation,[19] enabling diverse forms of data sharing, including open interfaces, trusted intermediaries, pooled datasets, research partnerships and open challenges.[20] The network increases with participation, leading to scalable and sustainable growth throughout the healthcare system. However, as the availability of health data grows, it must be accompanied by the responsible development, testing and validation of AI algorithms to prevent potential harm and ensure meaningful benefits.

Success depends on assembling the right ingredients: robust data infrastructure, regulatory alignment, ethical frameworks, innovative technologies, skilled professionals and active engagement from the public and private sectors. Only by promoting collaboration and aligning goals can we create sustainable, trustworthy and impactful healthcare transformation.

BOX 1 **Collaboration between stakeholders: Case studies**

Several case studies exemplify the significant benefits of collaboration between stakeholders (for full case studies, please see the Appendix):

- **C4IR Telangana:** Digital health profiling in Telangana: A pathway to streamlining healthcare delivery
- **Novartis Foundation:** CARDIO4Cities, a strategy for reducing overall cardiovascular risk in urban populations
- **Takeda:** Health Outcomes Observatory (H2O)
- **European Health Data Space**
- **Henry Schein:** Enhancing global health through multistakeholder collaboration on health data integration
- **Mayo Clinic Platform and Google Cloud:** Redefining healthcare collaboration and business models
- **World Health Organization Health Data Collaborative**

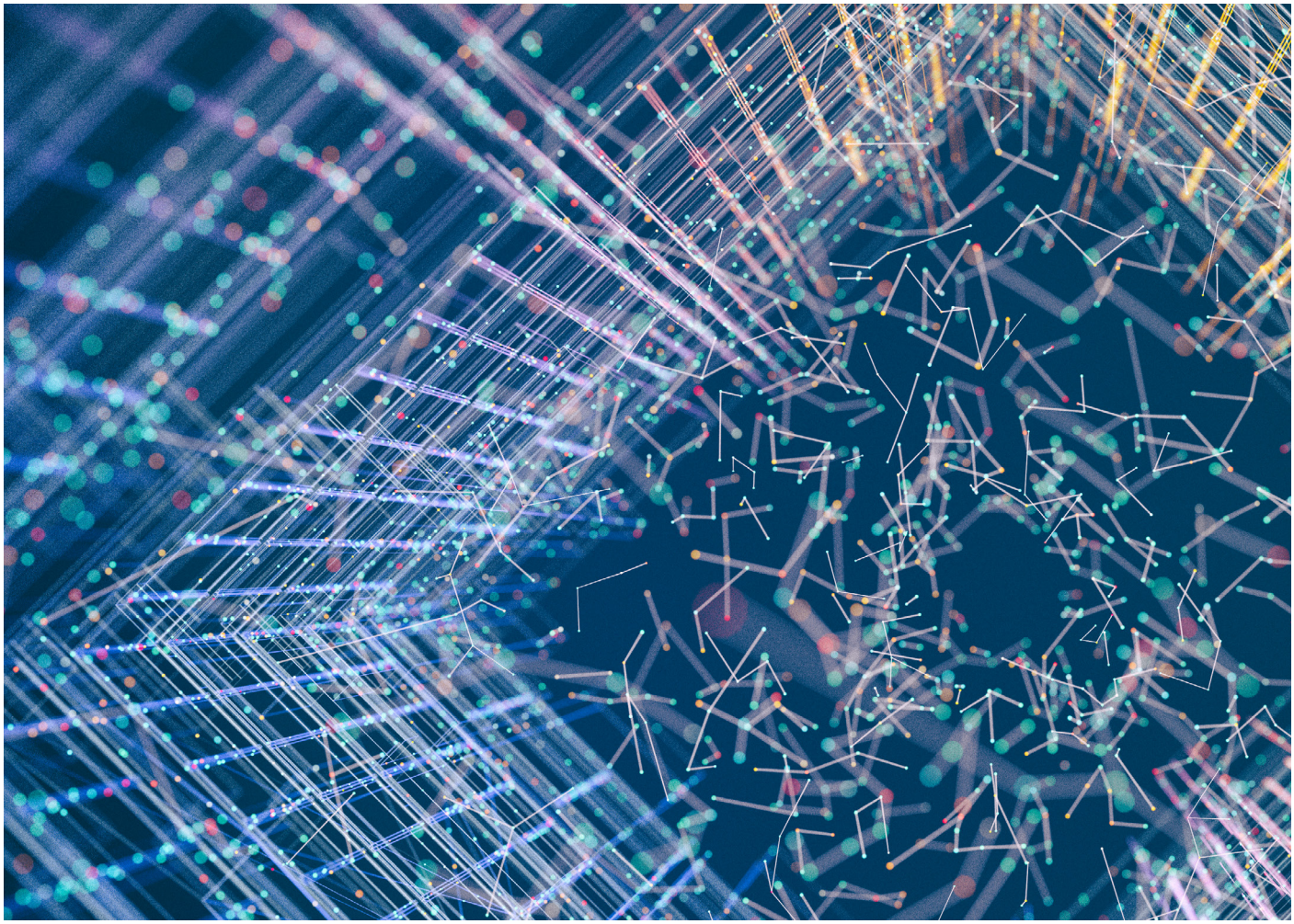
3 Framework for health data collaboration

Establishing trust and regional collaboration are important elements for building a robust framework for sharing health data.

This section serves as a blueprint for collaborative efforts, stressing the need for a robust system to enable health data collaboration and sharing. In achieving a network economy for health data, certain foundational elements ensure efficacy. Central to this process is the establishment of a clear framework to assess data quality, which includes standardizing data management, ensuring reliability and embedding ethical governance practices to build trust and accountability.

Transforming health data systems into a cohesive network economy demands a well-defined theory of change. By identifying and implementing practical steps to enhance collaboration, an interconnected health data environment can be established to accelerate the sharing and effective use of health data.

The Digital Healthcare Transformation (DHT) Initiative, launched in January 2024, exemplifies the commitment of the World Economic Forum and its partners to this vision. Acting as a global platform, the DHT Initiative has convened more than 150 organizations from sectors including medtech, pharmaceuticals, academia, government, multilateral organizations, healthcare providers and payers. This diverse community is united by the shared goal of improving health outcomes, accessibility and efficiency through transformative data usage. Insights from various meetings over the past year have provided an initial blueprint for advancing global health data collaboration.



3.1 Comprehensive health data environment

To realize this vision, several critical enablers must be addressed, as gaps in these areas could impede progress.

FIGURE 1 **Eight enablers for digital healthcare transformation**

Source: DHT Initiative dialogues, Capgemini and World Economic Forum analysis

To enact market transformation and propel this system forward, collaborating with regional governments and key stakeholders is essential. This involves creating coalitions that promote faster adoption and integration of these principles in various regions and healthcare systems. By working together, these coalitions can create a movement that uses the network economy for health data to bring diverse data to the forefront and make significant progress in global healthcare.

3.2 Priority enablers for health data collaboration

Understanding the critical factors for successful health data use, the DHT Community conducted a comprehensive analysis of the eight enablers illustrated in Figure 1. While all enablers were recognized as pivotal, the community prioritized four that it is essential to mobilize first to promote a successful network economy.

- **Cultural mindset change:** Beyond technical and governance enablers, shifting attitudes to data sharing is crucial. Many healthcare systems and organizations are traditionally cautious about sharing data due to concerns over competition, privacy or reputational risk. Bold leadership is needed within the healthcare sector to champion and implement actions that drive collective benefits through health data sharing, embedding a culture of openness within organizations and across the industry. Achieving this requires well-designed change-management programmes that integrate education, effective communication and active leadership engagement. These efforts should be tailored to address the specific cultural and geographical contexts of each region, ensuring a comprehensive approach that promotes openness and collaboration throughout the healthcare sector.

- **Value in data sharing:** Creating tangible incentives for stakeholders to share health data is vital for achieving meaningful collaboration. Without clear value propositions, organizations may view data sharing as a burden rather than an opportunity. Identifying specific use cases and effectively validating and communicating the benefits – from individual projects to the broader ecosystem – can help drive the shift towards a more collaborative approach.

- **Data rights and governance:** Establishing a transparent and secure governance framework is fundamental to managing the complexities of health data sharing. Without clear rules and enforcement, trust among stakeholders and patients can erode, limiting collaboration. Public-sector organizations should focus on setting standards that create equal playing fields for all organizations, ensuring appropriate levels of sharing and consuming.

- **Standardization and interoperability:** Health data exists across multiple systems, applications and formats, leading to fragmentation. Without standardization and interoperability,[21] it becomes challenging for stakeholders to seamlessly exchange and use data across regions, organizations and platforms. Public-sector organizations should focus on reinforcing and aligning existing standards to create a level playing field for all participants, enabling appropriate levels of data sharing and access throughout the system. An example of successful implementation is Estonia's X-Road,[22] an advanced interoperability platform that enables secure and seamless data exchange between diverse systems, demonstrating how effective standardization can drive a connected health ecosystem.

BOX 2 The importance of trust for the health data network economy

Trust is the cornerstone of a successful health data network economy, enabling sustainable growth and meaningful collaboration among stakeholders.

Foundation for effective collaboration
Trust-based frameworks – including structured policies and standards for data privacy, governance and security – are essential for promoting collaboration. They help regions and organizations position themselves as global leaders in health data by ensuring transparency and ethical data sharing.

Driving innovation
Trust accelerates innovation by encouraging the creation of environments in which stakeholders cooperate more effectively. It enables comprehensive patient records that improve diagnosis, enhance personalized care and fuel advances in AI-driven healthcare solutions.

Enhanced data sharing and patient participation
Strong trust frameworks encourage patients to share complete and accurate health data, improving treatment outcomes and enabling better AI-powered predictions. When privacy and security are prioritized, data sharing increases, leading to more robust healthcare insights.

Improved crisis management
In health crises such as pandemics, trusted data-sharing systems enable quick response times and effective resource allocation, improving resilience and adaptability. Trust also ensures that critical health data is exchanged securely across institutions, boosting public health efforts.

Sustained growth of health data networks
As trust strengthens within the system, more participants join, leading to scalable growth. Increased participation enhances the collective value of the health data network, driving long-term impact and creating new opportunities for global health collaboration.

3.3 Components for implementation

Regional collaborative initiatives are designed to accelerate digital health adoption, aligning public and private efforts to address critical gaps and scale impactful solutions in a particular region.

With input from the community, the Forum identified key components essential for building effective collaborative initiatives:

Regional maturity awareness

Recognizing and addressing differences in regional maturity is crucial for driving impactful outcomes. Markets can be categorized into three stages – emerging, standardizing and innovating, each reflecting distinct levels of awareness, mobilization and trust in health data. This categorization helps tailor strategies to regional needs, ensuring progress at every stage of development.

- **Emerging.** Characterized by promising but still-developing initiatives in areas with limited digital public infrastructure (DPI), these demonstrate a need for enhanced engagement and a coherent strategy. The focus is on developing awareness and encouraging leadership commitment to integrate health data more effectively into public and private healthcare frameworks while also strengthening infrastructural foundations.
- **Standardizing.** There is already a defined vision for health data transformation supported by consolidated initiatives and substantial leadership engagement. Efforts are aimed at scaling these initiatives and enhancing interoperability between systems to streamline health data usage as a core component of healthcare innovation.
- **Innovating.** Health data is treated as a strategic asset, fully integrated into healthcare systems with robust data governance structures. The focus in these markets is on expanding the reach and depth of data-driven innovations and promoting a secure environment for data sharing across borders.

Stakeholder selection and engagement

To build a health data collaboration network, it is vital to involve stakeholders from both the public and private sectors who bring complementary expertise, infrastructure and incentives. The types of organization listed in Table 1 should be included in the initial cohort.

TABLE 1 **Stakeholders to be involved in a health data collaboration network**

Public-sector participants	Private-sector involvement
– Health ministries, government departments and regulators overseeing data infrastructure and governance	– Healthcare providers and private hospitals sharing clinical data to improve care and efficiency
– National and global health agencies (e.g. the Centers for Disease Control and Prevention, the World Health Organization, EU health authorities)	– Pharmaceutical companies contributing real-world data for drug development
– Public hospitals and research institutions	– Health insurers providing actuarial data to promote preventive care models
– Other stakeholders providing policy guidance and funding and ensuring compliance with privacy laws such as the General Data Protection Regulation (GDPR) and the Health Insurance Portability and Accountability Act (HIPAA)	– Technology companies offering infrastructure for data exchange – Healthtech start-ups and digital health companies driving innovation through new data-powered applications and services

Value model considerations

A sustainable health data network requires innovative collaboration models that align incentives and share value across the public and private sectors. These include:

- **Mutual value creation.** The framework should outline how each partner benefits from the collaboration, whether it is financial gain, positive health impact and/or improved value generation from data. This helps maintain a balanced partnership in which all parties feel invested.
- **Clear and shared objectives.** All parties should have a shared vision of the partnership's purpose and goals. Objectives should align with each partner's mission and core values to ensure buy-in from all stakeholders.
- **Performance metrics and accountability.** Success metrics, agreed from the outset, enable partners to track progress and adjust strategies as needed. Metrics should focus on outcomes, process improvements and financial impacts.

Definition of data types

The network effect emerges as stakeholders share interoperable and accessible data between organizations, increasing the collective dataset's value and unlocking new insights and capabilities.

As more data is shared, the collective dataset becomes more valuable, unlocking new insights and capabilities for all participants. The network will prioritize certain high-value data types including:

- **Electronic health records (EHRs):** Offer detailed insights into patient histories and health trends
- **Behavioural and social determinants of health (SDOH):** Critical for addressing broader health inequities and enhancing community health outcomes
- **Claims data:** Reveals patterns in healthcare use and associated costs
- **Genomic data:** Supports personalized medicine and early disease detection initiatives
- **Remote monitoring data:** Extends care and access to treatment and enhances chronic disease management and preventive care efforts
- **Patient-generated data:** Active and passive data generated from patients' use of health or wellness-related products and services or direct inputs; importantly, this can include patient-reported outcomes measures (PROMs) and patient-reported experience measures (PREMs)
- **Dental data:** Indicators can drive more holistic care decisions, given the many direct links between oral health and overall health and well-being[23]

4 Activator Network: An approach for systems change

The Activator model foregrounds collaboration to unleash the potential of health data.

Broader health data collaboration begins with strategic activation. By integrating the components outlined in Section 3, a solid foundation can be established to initiate and amplify the network effect across diverse regions. To this end, the Forum is developing an "Activator Network", designed to demonstrate how these building blocks can be combined to accelerate the growth and adoption of health data collaboration initiatives.

4.1 The DHT Initiative's approach and role in health data

While there are many initiatives aiming to enhance health data collaboration, substantial challenges remain, largely due to misaligned incentives, protective business models and the perceived risks of data sharing. Via the DHT Initiative, the World Economic Forum and its partners are engaging the Forum's broad and influential network of global leaders in the public and private sectors, international organizations and academia around a shared vision for a health data network economy, bridging gaps while working constructively with existing initiatives. As a global coordinator, the Forum is working to promote a shift in mindset to recognize health data as a strategic asset, encourage the adoption of best practices and raise the visibility of critical health data issues.

The Forum supports several critical actions:

- **Putting health data collaboration on the global agenda:** Elevating health data sharing in international forums encourages a shift from siloed models to open data-driven frameworks. Promoting derisking strategies also helps underfunded or cautious health systems embrace data sharing responsibly.
- **Aligning incentives and championing collaborative models:** By gathering insights from public and private stakeholders, business models can be established that align financial gain with patient benefits, creating incentives that foster a collaborative approach to health data sharing.
- **Inspiring responsible leadership of network models:** Emphasizing the strategic benefits of a network economy encourages leaders to adopt a mindset focused on balancing innovation with patient care, sustainability and equitable value distribution.
- **Facilitating cross-sector perspectives to inform policy:** Acting as a neutral facilitator, private-sector insights are brought to policy-makers to guide policy development that balance data protection with responsible public health use.
- **Outlining a long-term strategic vision:** Laying out a strategic roadmap will support nations and organizations in evolving their health data systems over the coming years.

4.2 Using the Activator model to create proof points

The future of digital healthcare hinges on the ability to create a network economy driven by collaborative efforts across regions and sectors. This process starts by aligning and amplifying the effects of strategic efforts in the markets where they can have the most impact. Building or highlighting programmes that integrate key components – data, technology and stakeholder engagement – into a cohesive model delivers tangible improvements.

To drive this change, the DHT Initiative is launching an "Activator Network", originally conceptualized in the World Economic Forum report *Transforming Healthcare: Navigating Digital Health with a Value-Driven Approach*. Activators are multisectoral coalitions being established at the regional, national or subnational level to catalyse meaningful systemic change in health systems around the world in coordination with local health transformation strategies.

- Activators will focus on specific priority healthcare challenges and digital transformation opportunities unique to the geography and population.
- Activators will benefit from the broader network and expertise of the DHT Initiative and the World Economic Forum, including knowledge, best practices and recommendations.
- In addition, as multiple Activators are established globally, the initiative aims to interconnect them into a mutually supporting network that can amplify impacts of each Activator.

While the Network will work broadly across digital health topics, select Activators will be fully dedicated to driving health data collaboration. The focus will be on identifying promising opportunities, enhancing their impact and accelerating progress in health data systems. In areas where unmet needs are identified, Activators will work to address these gaps. The approach prioritizes the use of existing tools such as interoperability standards rather than the development of new ones, so it makes the most of resources and strengthens existing frameworks.

The strategy proposed in this paper is to launch one or more Activators focused on promoting health data collaboration through public–private partnerships. Activators aim to bring together a diverse set of stakeholders, establish sustainable collaborative business models, define high-impact data spaces and create measurable success metrics to ensure scalability and effectiveness. The compounding effects of data collaboration will drive better patient outcomes, accelerated research, cost savings and public health improvements, establishing a foundation for long-term, scalable transformation in global healthcare systems.

4.3 Path forward: Markets and roadmap

Market considerations and potential focus areas

Four markets within the "standardizing" and "innovating" stages of the maturity model are under initial consideration as possible focus areas, customizing interventions for addressing local needs while supporting broad-scale advances in health data practices:

- **European Union:** The European Union (EU) is advancing data-driven health innovations within a robust trust framework, facilitating safe and productive data exchanges across borders. The EU's regulatory structure, with key frameworks such as the European Health Data Space (EHDS), GDPR and the EU Artificial Intelligence Act, serves as a foundation for data security, privacy and interoperability. This landscape, while sometimes complex for stakeholders to navigate, reinforces the EU's vision of health data as a strategic asset integrated within healthcare systems. Notable leaders such as Estonia and Denmark illustrate the EU's commitment to innovation through digital health initiatives and cross-border data sharing. Despite regulatory hurdles, the EU remains focused on building a trusted and interoperable health data environment, setting high standards for collaboration and data-driven healthcare transformation across member states.
- **India:** India illustrates the vast potential for health data innovation, bolstered by the government-led Ayushman Bharat Digital Mission (ABDM), which focuses on establishing unified health data and digital infrastructure. This initiative exemplifies India's strong commitment to a comprehensive digital health environment, aiming to create catalysts for transformative change. India's focus is on building foundational momentum through awareness campaigns and pilot programmes, showcasing the benefits of integrated health data systems as essential components for future healthcare innovation.
- **United States:** The United States is advancing health data interoperability and patient access through a mix of regulatory

efforts and technological initiatives. The Office of the National Coordinator for Health Information Technology (ONC) plays a central role in developing interoperability frameworks, notably encouraging the adoption of standards such as Fast Healthcare Interoperability Resources (FHIR). Initiatives such as the Trusted Exchange Framework and Common Agreement (TEFCA) aim to establish a unified nationwide infrastructure for secure health data exchange between diverse systems. Despite these efforts, the US healthcare landscape remains fragmented, presenting challenges in achieving cohesive data integration due to the multitude of stakeholders and varying technological capabilities. Privacy regulations such as the HIPAA continue to safeguard patient information, while ongoing endeavours focus on balancing innovation with stringent privacy and security requirements to enhance the overall digital health environment.

– **Latin America:** Latin America emphasizes policy alignment and scalable health data initiatives. This region demonstrates a growing commitment to cohesive, system-wide improvements, driven by collaborations among governments, private stakeholders and regional organizations such as the Pan American Health Organization (PAHO). Efforts such as the Pan American Highway for Digital Health underscore this commitment.[24] Key countries are actively driving this transformation; for instance, Brazil, through its 2024 G20 presidency, is emphasizing digital health access and interoperability as a strategic priority and using its national health system, Sistema Único de Saúde (SUS), to enhance pandemic preparedness and health access.[25] Latin America's complex healthcare landscape presents unique challenges; however, significant mobilization and leadership engagement across countries are setting the groundwork for a unified approach to health data transformation, with a focus on shared regional goals and enhanced interoperability frameworks.

This multi-tiered approach enables localized solutions, encouraging regions to learn from each other's successes while adopting strategies that reflect their specific needs.

Roadmap: Key phases

Success metrics will be established to ensure the Activator achieves its objectives effectively through its different phases:

– **Phase 1. Design and initial partnerships:** Challenges are selected and the approach to be taken in addressing them is designed, including target stakeholders.

– **Phase 2. Defining collaborative business models and prioritized data types:** Innovative business models are developed to create incentives for stakeholders, developing a framework for effective collaboration. High-value data types such as EHRs and SDOHs are defined and prioritized to maximize health impact.

– **Phase 3. Data infrastructure and ecosystem building:** The digital and technical infrastructure necessary for effective health data collaboration among partners is put together. Beyond standards, success necessitates addressing broader infrastructure needs to ensure inclusivity and seamless data integration.

– **Phase 4. Growth and network effects:** As collaboration deepens, this phase focuses on operationalizing new business models, such as value-based care and data marketplaces.

– **Phase 5. Long-term impact and scaling:** The final phase focuses on measurable improvements in patient outcomes, such as reduced readmissions and better management of chronic diseases.

4 Conclusion

Collaborative systems to share data are urgently needed to transform global health.

Now is the time for all stakeholders – governments, healthcare providers, private-sector innovators, patients and international organizations – to unite and seize this unprecedented opportunity to revolutionize global healthcare by establishing a collaborative health data network economy. By joining this transformative effort, leaders can play a pivotal role in breaking down data siloes, fostering interoperability and unleashing the full potential of health data to save lives, reduce costs and drive innovation. Together, it is possible to create a sustainable, efficient and equitable healthcare system that benefits everyone. The time to act is now. Get involved in shaping the future of health.

Appendix: Case studies

CASE STUDY 1

C4IR Telangana

C4IR Telangana: A pathway to streamlining healthcare delivery

Challenge

The current system for accessing government services in Telangana is fragmented and cumbersome, requiring citizens to use multiple cards to access essential services such as healthcare, distribution of rations and welfare programmes. This complexity leads to inefficiencies, difficulties in managing comprehensive health records and frequent repetition of primary tests due to the lack of a unified health history. As a result, impoverished people struggle to navigate these systems and access the necessary medical services, which can negatively affect their health outcomes.

Solution

The Telangana Family Digital Health Card initiative addresses these difficulties by issuing a single digital card that consolidates access to various government services and welfare schemes. This "One State, One Card" initiative aims to streamline service delivery and enhance efficiency. Key features of the card include:

1. Single access point: Citizens use one card to access multiple services
2. Portability: The card is portable, allowing users to access services from any location in Telangana
3. Comprehensive health records: The card carries the health profiles of each family member, including past treatment details, which reduces the need for redundant diagnostic tests; this system helps streamline consultations by allowing doctors to make informed decisions quickly

Approach

The pilot project for Telangana's "One State, One Card" policy was launched by Revanth Reddy, the chief minister of Telangana. Families permanently resident in the state will be identified. The exercise, carried out in all 190 constituencies (one village and one municipality ward) will later be implemented across the state. The family digital card will have a woman as the head of the family (or the most senior man if there is no woman).

All families will be provided with family IDs irrespective of their economic status. Each person in the family will be provided with a unique personal ID. The family digital cards will help people access welfare schemes. Furthermore, a special monitoring mechanism will be established at the district level to oversee the family digital card initiative, ensuring its successful implementation and sustainability.

Outcome

The pilot project conducted in Mulugu and Rajanna Sircilla revealed higher prevalence rates of cardiovascular diseases and cervical cancer, respectively. As part of the pilot, 30 different tests were conducted and insights gathered through door-to-door data collection, facilitated by 30 teams in 15 primary health centres (PHCs), enabling comprehensive health profiling. This led to improved health outcomes and better resource allocation.

CASE STUDY 2

CARDIO4Cities – Novartis Foundation

CARDIO4Cities: An effective strategy for reducing overall cardiovascular risk in urban populations

Challenge

Cardiovascular (CV) risk factors (hypertension, high cholesterol and diabetes) are highly prevalent in the world's populations and cause millions of heart attacks and strokes every year, resulting in CV disease remaining the largest burden of disease globally.[26] Acute CV events are largely preventable through early detection and prompt and adequate management of CV risks. Ample evidence exists as to what needs to be done, but effective strategies to safeguard heart health are not implemented as they should be. That leads to extensive suffering and death, which is largely preventable.

Solution

The Novartis Foundation developed the CARDIO4Cities initiative to improve overall CV risk in urban populations, leveraging intersectoral collaboration, digital innovation and data-driven decision-making. It rests on three pillars:

- Set targets for screening, diagnosing and treating people with CV risk factors
- Co-design roadmaps with concrete action plans to achieve these targets
- Use data, technology and intersectoral partnerships to implement these population health roadmaps

The programme worked with city authorities and stakeholders in São Paulo (Brazil), Dakar (Senegal) and Ulaanbaatar (Mongolia) to pioneer and validate the approach in different geographical contexts in three continents.

In São Paulo, the Novartis Foundation collaborated closely with the health authorities, health system managers, patients, the education authorities, sport and workplace sectors and other stakeholders. Design thinking was used to co-create a CV population health roadmap, with innovative interventions targeted at the gaps in this roadmap. These innovations included digitalized CV risk-screening corners for all visitors in health facilities and optimized early detection in non-traditional venues – such as sports and dance clubs or metro stations – around the city, simplified CV risk management protocols translated into digital decision support tools, as well as a local digital CV risk assessment, self-care plans for patients and school programmes to improve physical activity and nutrition. While the CARDIO4Cities approach implements existing evidence and global best practices (such as the World Health Organization Hearts package), its success was mainly driven by the use of real-time data for decision-making. Local health authorities decided with the CARDIO4Cities partners on a shared measurement system and the monthly or quarterly results coming out of that data system were reviewed in a simple dashboard, allowing decision-makers to adapt interventions accordingly.

Outcome

Within one to two years of implementation, control rates for hypertension, the prime risk factor for CV disease, increased threefold or more across the three cities. This translated into an estimated reduction of 13% for strokes and 12% for heart attacks. The approach proved highly cost-efficient, e.g. a cost of $784 per quality-adjusted life year (QALY) was achieved in São Paulo. Across the pioneering sites, CARDIO4Cities is now being continued by local governments, while the World Heart Federation and the Novartis Foundation are expanding the approach to 30 megacities globally over the next three years to improve the heart health of 150 million people.

CASE STUDY 3

H20 – Takeda

Health Outcomes Observatory (H2O)

Challenge

Patient perspectives in healthcare are not listened to in a meaningful way. When healthcare professionals try to capture patient-reported outcomes, this process is fragmented and inconsistent. Lack of trust and incentives in sharing health data limit the ability to use digital technologies in healthcare and prevent the potential of AI in health being realized.

Solution

The Health Outcomes Observatory (H2O) initiative was created by a multistakeholder public–private consortium that includes patients, healthcare providers, researchers, regulators and industry representatives. The initiative has two pillars. First, it focuses on deploying digital tools to capture patient-reported outcomes incorporating a common language to enhance health professional–patient communication that allows for shared decision-making and remote monitoring. This common language is being created through a multistakeholder consensus process and relies on adapting patient-reported outcomes to the digital world. Second, H2O focuses on creating a data governance model that ensures patients remain in control of their data while health data can be analysed and researched when appropriate. This is being implemented through the creation of health data trusts known as "H2O observatories", independent legal entities with multistakeholder boards that serve as guardians of patients' health data and operate a secure data infrastructure. Hospitals that partner with the H2O observatories can participate in a healthcare learning ecosystem and benefit from access to digital tools to facilitate communication with patients. Independent technology partners deploying technologies to facilitate health professional–patient communication can join this ecosystem when they meet a set of criteria and offer their services to hospitals and patients.

Outcome

There are now four national H2O observatories operating as health data trusts in Austria, Germany, the Netherlands and Spain and an umbrella organization, the Pan-European H2O Observatory, in Denmark. These are being set up in partnership with patient organizations and public-sector entities. There are currently five technology partners that have joined the ecosystem and more than 1,000 patients who use the digital tools. The current emphasis is on diabetes, inflammatory bowel disease and cancer, and there are plans to expand to other countries and more diseases. The model has received innovation awards from the European Commission and can be seen as catalyst for the digital transformation of healthcare.[27]

CASE STUDY 4

European Health Data Space (EHDS)

European Health Data Space (EHDS)

Challenge

Health data in the European Union is fragmented, limiting patient control and research. Inefficiencies and privacy concerns persist due to poor data use. The EHDS[28] aims to create a secure and standardized data exchange framework, improving patient care, empowering individuals and driving healthcare innovation for 450 million Europeans.

Solution

The development of the EHDS requires a collaborative effort among various stakeholders, a strategic approach and technical implementations.

Stakeholders involved:

- European Commission: Led the EHDS initiative
- Member states: Shaped the EHDS through consultations and pilots
- Healthcare providers: Offered practical insights
- Researchers and innovators: Provided input for secondary data use
- Patients and citizens: Engaged via public consultations
- Technology providers: Developed infrastructure, services and tools

Strategic approach:

- Regulatory framework: Built on GDPR and the Data Governance Act
- Public consultations: Involved nearly 140 stakeholders
- Pilot projects: Tested technical and operational aspects

Technical and operational aspects:

- Interoperability standards: Developed for seamless EHR data exchange
- Data security and privacy: Implemented advanced measures
- Infrastructure development: Enhanced digital infrastructure

The EHDS will improve the use and sharing of health data by empowering individuals with data access and control (primary use) and enabling data reuse for research, innovation, policy-making and regulatory activities (secondary use).

These efforts aim to create a unified, secure and efficient health data environment in Europe, improving healthcare outcomes and driving innovation.

Outcome

The EHDS aims to yield significant outcomes for society, economy, innovation, well-being and healthcare in the European Union.

Qualitative:

- Patient empowerment: Better access to and control over health data
- Healthcare delivery: Access to comprehensive patient histories leads to better diagnosis and treatment
- Research and innovation: Streamlined access to high-quality data

Quantitative:

- Economic savings: Projected €5.5 billion savings over 10 years
- Data use: Increased reuse for research and policy-making to improve public health interventions
- Healthcare costs: Reduced redundancies and improved efficiency in healthcare delivery

These outcomes highlight the EHDS's potential to transform healthcare in the EU by enhancing patient care, promoting innovation and reducing economic burdens.

CASE STUDY 5

Henry Schein

Henry Schein: Enhancing global health through multistakeholder collaboration on health data integration

Challenge

In partnership with the FDI (Fédération Dentale Internationale) World Dental Federation, Henry Schein initiated a multistakeholder project aimed at addressing the integration of oral health data within EHRs. Henry Schein is the world's largest provider of healthcare solutions to office-based dental and medical practitioners, and its software subsidiary, Henry Schein One, is a leading provider globally of dental practice management software, which generates a wealth of anonymized data that is central to the integration effort. Recognizing the global gaps in health data sharing, the FDI–Henry Schein collaboration sought to bridge the divide between oral and general health records, thus promoting a more holistic, person-centred approach to patient care.

Solution

A critical component of this initiative was the creation of a consensus statement, developed with international experts, encouraging a standardized core set of health indicators to be shared between medical and dental EHR platforms. This approach would capture data on conditions known to have strong medical and dental correlation, such as periodontal disease, caries and oral cancer – metrics with implications for systemic health, including heart disease and diabetes.

Outcome

The project's findings emphasize the potential of integrated health data for enhancing health outcomes by supporting more informed, coordinated care. By including dental data in medical EHRs and vice versa, healthcare providers gain a fuller view of patient health, which improves diagnostic accuracy and aids in disease prevention. Henry Schein's collaboration with FDI highlights the need for global policies that reinforce health data interoperability and advocates for inclusive engagement across all healthcare domains. The resulting framework not only aims to support improved patient outcomes but also sets a precedent for future multidisciplinary collaborations, underscoring the vital role of health data integration in achieving universal health coverage.

CASE STUDY 6

Mayo Clinic Platform and Google Cloud

Mayo Clinic Platform and Google Cloud: Redefining healthcare collaboration and business models

Mayo Clinic Platform demonstrates how secure, anonymized data can drive healthcare innovation. Through a federated data network, researchers, clinicians and partners can expedite medical breakthroughs while safeguarding patient privacy.

Tackling health data-sharing challenges

Mayo Clinic recognized the need for a new approach to sharing anonymized clinical data to address key challenges:

- **Protecting patient privacy:** Maintaining patient trust requires rigorous data protection, particularly for sensitive health information.
- **Eliminating data siloes:** Fragmented data across institutions limits comprehensive analysis and AI innovation.
- **Achieving scalable, cost-effective solutions:** Infrastructure for large-scale data analysis demands significant investment and resources.

A federated model for secure collaboration

Mayo Clinic Platform uses Google Cloud technology to create a federated data-sharing model that prioritizes privacy, security and seamless collaboration.

- **Privacy compliance:** Google Cloud's robust security framework and compliance certifications support Mayo Clinic's ability to meet stringent healthcare privacy standards.
- **FHIR and cloud healthcare application programming interfaces (APIs):** Google Cloud's healthcare API, based on FHIR standards, enables seamless data exchange and interoperability, powering advanced analytics and machine learning.
- **Federated learning:** With Google Cloud's federated learning capabilities, AI models are trained on decentralized datasets without moving data, and preserving privacy while enabling collaborative model development.

Mayo Clinic Platform: A reinvented business model for streamlined data exchange

Mayo Clinic Platform is designed to promote value exchange throughout the healthcare ecosystem and represents a new business model. This model allows external network and data nodes – such as research institutions, health systems and start-ups – to connect seamlessly to the platform. Through streamlined integration, these partners can securely share data and insights, benefitting from Mayo Clinic's advanced tools and resources while contributing to a larger pool of diverse health data. This approach enhances both Mayo Clinic's network value and the value created for each participant, facilitating a dynamic, mutually beneficial data-sharing ecosystem.

Driving innovation through a global network

By promoting a global innovation ecosystem, Mayo Clinic Platform enables a growing network of collaborators worldwide. Through this network, diverse data sources fuel the development of advanced AI models that drive progress in disease prediction, diagnosis and treatment.

Accelerating medical discovery and enhancing patient care

This collaboration between Google Cloud and Mayo Clinic unlocks the potential of health data while protecting patient privacy and security. By creating a collaborative environment for secure data sharing and insights, the platform accelerates medical discovery, facilitating the development of new treatments, diagnostics and preventative strategies. Ultimately, this leads to enhanced patient care and improved health outcomes.

CASE STUDY 7

World Health Organization Health Data Collaborative

The Health Data Collaborative (HDC) is an informal network of more than 1,100 people and 400 agencies from the private sector, governments, civil society, donors, academia and multilaterals. The HDC strengthens LMIC health information systems (HIS) by collaborating and aligning resources with government-identified data and digital priorities. The HDC uses global advocacy and works through communities of practice in technical working groups to ensure resources and good practices are shared to support country-identified data priorities.

Working group	Action	Countries engaged
Routine Health Information Systems (RHIS)	Share good practices and build country capacities to enhance data management and use	Rwanda and Uganda
Civil Registration and Vital Statistics (CRVS)	Strengthen the registration of vital events, contributing to better health data governance	Nepal and Togo
Community Data	Integrate community-level health data into national systems	Zambia
Digital Health and Interoperability	Create a platform for technical support for countries to implement national digital health strategies	Sri Lanka and Maldives
Data and Digital Governance	Develop health data governance framework to guide countries	Multiple
Geographic Information Systems (GIS)	Facilitate use of spatial data for health planning in countries	Cameroon

Other examples of HDC country impact include:

Nepal: HDC facilitated the prioritization of CRVS and GIS. A joint partner mission led to a government-led plan of action and investment.

Sri Lanka: A partner coordination mechanism (led by the Ministry of Health) was set up, resulting in more effective and efficient partner collaboration.

Malawi: The HDC approach has mapped and supported partner coordination, led by the Ministry of Health consistently convening the monitoring and evaluation technical working group. This has helped implement data HIS priorities together.

Uganda: HDC convened a meeting in February 2024 that resulted in the planning and partner commitment to implement the Health Information and Digital Health Strategic Plan together.

Francophone countries (Burkina Faso, Burundi, Cameroon, Madagascar, Mali, Senegal and Togo) are focusing on improving CRVS systems and broader HIS governance needs. These countries have mapped their HIS status informed by SCORE (survey, count, optimize, review, enable), planning cycles, resources and identified HIS needs.

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