

Insight Report

# Value in Healthcare

## Mobilizing cooperation for health system transformation

In collaboration with The Boston Consulting Group (BCG)

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# Foreword



Cheryl Martin,  
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The World Economic Forum is pleased to share details of the progress being made on how stakeholders in the healthcare industry are mobilizing to transform health systems so that they deliver better value to patients.

In the first year of the Value in Healthcare project, we presented an overarching framework comprising the key foundations and enablers vital to the recalibration of global healthcare systems towards value – that is, delivering outcomes that matter to patients at a sustainable cost.

Frameworks mean little, however, if they are not tested in the real world. That is why we have spent the past year working with stakeholders across the care chain to begin the translation of the theory into practice. For example, the World Economic Forum acted in leading the Atlanta Heart Failure Pilot in which more than 40 stakeholders in the Atlanta metropolitan area in the United States have come together to transform the way in which care for congestive heart failure is delivered to patients. This report highlights the initial results of this effort, shares learnings and methodology, and puts forward recommendations on how we can continue to mobilize and scale cooperation for health system transformation.



Vanessa  
Candeias, Head,  
System Initiative  
on Shaping the  
Future of Global  
Health and  
Healthcare

The work thus far is just the beginning of a journey towards building more sustainable health systems globally. The commitment of the project's executive board and steering committee, and our knowledge partner, The Boston Consulting Group, has been critical to the successful progress to date and to the work in the coming years. We are thankful to all of the healthcare stakeholders who have devoted their efforts and resources to this project. We cannot underestimate the depth of this task. Together, however, we can transform health systems globally. Join us and we can translate our ideas into action and improve outcomes that matter to patients.

# Preface

## by the Executive Board, Value in Healthcare project

We live in challenging times. Current political, economic and social narratives are divided. Communities are dismantling. The focus is on the self. And yet, if there is one topic that unifies populations around the world, it is the desire for better health and healthcare. Value-based healthcare puts the health outcomes of individuals at the very centre of care delivery. This people-centred approach emphasizes the delivery of health outcomes that matter to patients in a financially sustainable manner.

We have been delighted by the response of the global healthcare community to the challenge and opportunities of this paradigm shift. In the past year, our initial report, “Value in Healthcare: Laying the Foundation for Health System Transformation”, was released in English and Mandarin Chinese, and our framework for a value-based health system has re-focused the vision and the mission of many stakeholders, ranging from individual healthcare organizations to national ministries of health.

Ultimately, realizing the full potential of value-based healthcare requires moving from fragmented healthcare systems to unprecedented cooperation among all stakeholders. This has been our focus for the past year. We have identified three key elements of this transformation:

- **New models for multistakeholder cooperation.** The experience of the Atlanta Heart Failure Pilot, a comprehensive example of value-based healthcare at a municipal level, highlights what is possible. Approximately 40 healthcare stakeholders operating in the Atlanta metropolitan area – providers, payers, patient advocacy groups, public-sector organizations, academic institutions and pharmaceutical and medical-device companies – have united to focus on heart failure patients. The vision is bold: to make Atlanta a national leader in the heart failure survival rate by 2022 while significantly improving quality of life and reducing the average cost per capita. The Atlanta pilot offers a model for organizing similar initiatives in other parts of the world.
- **New standards for health informatics.** Transformation towards a value-based, people-centred health system similarly demands an integrated approach to the capture and use of health data – what we call *health informatics*. More precise and personalized healthcare requires more advanced informatics, with broad access to disparate data sources in order to generate statistically significant findings. Individuals also expect access to a holistic view of their own health data. Many recent technology developments are now making it possible to meet these informatics needs. However, global standards are a prerequisite to enable providers, payers, researchers and policy-makers to learn from each other about what works and what does not. In this report, we outline the minimum sufficient set of informatics standards required to deliver the value-based healthcare revolution.

- **New directions for leadership.** System transformation requires transformative leadership. Although healthcare leaders, of course, need to play an active role in transforming their own organizations to improve value, this is only the first step. Leaders also need to articulate a vision that looks beyond the interests of their individual organizations in order to transform the system as a whole. Government leadership creates the broader policy and the regulatory and legal framework necessary to make it easier for stakeholders to cooperate on delivering healthcare value. Leadership on a global scale will ultimately create a healthcare community in which best practices can be shared and innovation can drive improvement of patient outcomes across nations.

In 2018, the Value in Healthcare project will continue to apply these principles to additional system-level pilots around the world. We also plan to develop a common data model for the structured exchange of information on patient care pathways and outcomes, as well as a reference implementation for a global set of outcome measures.

In conclusion, we would like to acknowledge the dedication and contribution of the many healthcare leaders in our steering committee as well as the vision and ambition of the Value in Healthcare project team. This journey is just beginning, but the momentum continues to build, and we are excited to see the global community come together and cooperate for better health outcomes, putting people back at the centre of health systems.

# The imperative of cooperation

The \$8 trillion global healthcare sector is at a critical juncture. Costs are growing at roughly double the rate of GDP growth, putting severe pressure on healthcare budgets.<sup>1</sup> Reimbursement mechanisms based on volume rather than on value cause substantial waste in health systems and contribute to an underinvestment in prevention. Despite rapid advances in medical science and a revolution in health technology, a lack of global standards remains an obstacle to taking full advantage of the explosion in health-related information. And an exponential increase in system complexity has led to increasing fragmentation that makes it easy – too easy – for health systems to lose their focus on the patient.

In response to these challenges, more and more leaders in the industry are embracing an alternative strategy for the organization and delivery of care known as *value-based healthcare*. According to this strategy, the delivery of improved health outcomes for the same or lower cost is – or ought to be – the primary objective of global health systems. Value-based healthcare is founded on the systematic measurement of health outcomes and on the costs required to deliver these outcomes for clearly defined population segments. Interdisciplinary teams of clinical specialists use this data to develop customized interventions or treatment pathways to improve the value delivered to each patient group over time. (See the sidebar, “What value means in healthcare”.)



## What value means in healthcare

In the first year of the Value in Healthcare project, we developed a comprehensive framework for a value-based health system. (See Figure 1.)

**Figure 1:** A Comprehensive Framework for a Value-Based Health System



Value-based healthcare puts the individual patient at the centre of the health system through the systematic measurement of the health outcomes that matter to patients and the costs required to deliver those outcomes across the full cycle of care. The relevant outcomes tracked for any individual patient depend on their profile matching a specific population segment – for example, all patients suffering from a specific disease such as type 2 diabetes or groups that share a similar risk profile such as all newborn infants. Tracking outcomes and costs by population segment makes it possible to compare clinical units or locations and, thus, to identify clinical best practices, reduce outcome variation across providers, and develop increasingly customized interventions and ever more precise treatment pathways to improve value for each segment over time. This ongoing cycle of continuous improvement ultimately leads to what clinical experts term precision medicine.

Four enablers support this value-based delivery model:

- An integrated informatics infrastructure that permits the routine capture, sharing and analysis of health outcomes and other relevant data for each population segment
- New analytical tools for benchmarking and research, including sophisticated decision-support tools for clinicians and patients
- New forms of value-based payment that create incentives for continuous improvement in patient value
- New roles and organizational models that allow networks of providers and suppliers to deliver better access to appropriate care, engage clinicians in continuous improvement, and adapt to new opportunities and innovations.

Finally, the entire value-based system requires public policies and a legal and regulatory environment that support and accelerate the transition to a value-based health system.

(For a more detailed description, see “Value in Healthcare: Laying the Foundation for Health System Transformation”, World Economic Forum, April 2017; available at: [http://www3.weforum.org/docs/WEF\\_Insight\\_Report\\_Value\\_Healthcare\\_Laying\\_Foundation.pdf](http://www3.weforum.org/docs/WEF_Insight_Report_Value_Healthcare_Laying_Foundation.pdf).)

Although leading stakeholders around the world are embracing elements of this value-based model, the challenge, and the opportunity, lies in unlocking the potential of this approach at the level of entire health systems – regionally, nationally and internationally. Aligning all stakeholders in the health system around the shared objective of improving healthcare value brings important collaborations, with the potential to deliver substantially enhanced health outcomes at lower costs than are currently being achieved. The approach also improves access to appropriate care, creates an environment that encourages innovation in treatment and care delivery, and provides new opportunities for healthcare organizations in both the public and private sectors.

To make value-based healthcare a reality, however, will require significantly higher levels of cooperation and alignment among stakeholders than is the rule today.<sup>2</sup> For example, specialists in key disease areas need to agree on the most important outcomes to measure for each subpopulation. Then, they need to come together in interdisciplinary teams and work with patients and patient advocacy groups to create more integrated, customized care pathways to achieve the outcomes most important to patients. Payers also need to work closely with providers, pharmaceutical companies and medical-device manufacturers to create the right incentives for value and develop the most cost-effective modes of treatment. And governments need to create legal, regulatory and financial incentives to encourage greater cooperation.

In 2016, the World Economic Forum launched the Value in Healthcare project to help achieve these goals. In the first year of the project, we created a compelling vision for value-based health systems and brought together a breadth of case-examples to build the case for change and document the feasibility of the vision. In the second year, we have focused our efforts on three critical mechanisms for accelerating the cooperation and alignment necessary to make this vision a reality. These three mechanisms are the focus of this report.

– **New models for multistakeholder cooperation.** Improving healthcare value requires system-wide transformation. Every aspect of a local or national health system – how outcomes are tracked, how research and benchmarking are conducted, how clinicians are paid, how care is organized and delivered – needs to change, with value delivered to patients as the central focus. To begin this transformation, the Value in Healthcare project has initiated a series of pilots around the world, working with local stakeholders to transform their abilities to jointly deliver improved healthcare value. The following section of this report describes one such pilot in detail: the Atlanta Heart Failure Pilot. We draw lessons from the Atlanta pilot for organizing similar initiatives in other parts of the world.

– **New standards for health informatics.** The cornerstone of a value-based health system is the systematic measurement of health outcomes and costs by population segment. The routine collection of detailed information on health outcomes makes it possible to identify variations in outcomes across clinical sites, analyse the root causes of those variations and codify best practices. Therefore, just as value-based healthcare is a people-centred model for healthcare delivery, health informatics systems must be equally people-centred. Whereas efforts such as the Atlanta pilot focus on mobilizing local stakeholders, creating this informatics infrastructure depends upon defining global standards for data capture, mapping and access. Global standards will make it possible to gain access to disparate sources of health-related information from systems around the world so that providers, payers, researchers and policy-makers can learn from each other about what works and what does not. Why is this the right time for an informatics transformation? What standards are necessary? How can the global healthcare community get started in defining them? We address these and other key questions in the third section of this report.

– **New directions for leadership.** Whether launching local initiatives such as the Atlanta pilot or developing global informatics standards, creating the cooperation necessary to make value-based healthcare a reality will require strong and active leadership. Not only will industry leaders have to transform their own organizations, they will also need to think beyond their immediate institutional interests and take a system-wide perspective. Politicians and policy-makers need to bring stakeholders together and create legal, regulatory and financial incentives to encourage greater cooperation. Finally, leadership on a global scale can create dynamic public-private partnerships committed to continuous improvements in health outcomes. Without these multiple levels of leadership, the vision of precision medicine and a more productive and innovative value-based health system will be significantly delayed. In the fourth section, we discuss the key leadership challenges that industry stakeholders must address to accelerate progress towards the goal of health system transformation and provide examples of emerging system-wide leadership.

Finally, this report concludes with a discussion of the initiatives that the Value in Healthcare project plans to undertake in 2018 to support and accelerate multistakeholder cooperation in the service of value-based healthcare.



# New models for multistakeholder cooperation



Value-based healthcare is a compelling element of the vision for sustainable global health systems. There are many examples of individual healthcare organizations or networks turning their focus to value. However, the immense potential of value-based healthcare will be realized in full only when this people-centred approach is implemented at a regional, national or even international scale.

Since February 2017, the Value in Healthcare project has been working with approximately 40 healthcare stakeholders in the Atlanta, Georgia, metropolitan area in a demonstration pilot. The first of a series of pilots that the World Economic Forum is initiating worldwide, the Atlanta pilot is pioneering a systemic approach to value-based healthcare, with all stakeholders working together to transform the local health system. As such, it represents a model for multistakeholder cooperation and alignment based on the shared goal of improving value delivered to patients.

## The Atlanta Heart Failure Pilot

The Atlanta Heart Failure Pilot has an ambitious goal: in the words of the project's vision statement, it aims "to create a continuously improving value-based healthcare system that positions Atlanta as a national leader in heart failure patient survival rate by 2022 while significantly improving quality of life and reducing the average cost per patient". Initiated by the World Economic Forum and launched under the leadership of former Atlanta Mayor Kasim Reed, the pilot brings together a broad cross-section of local

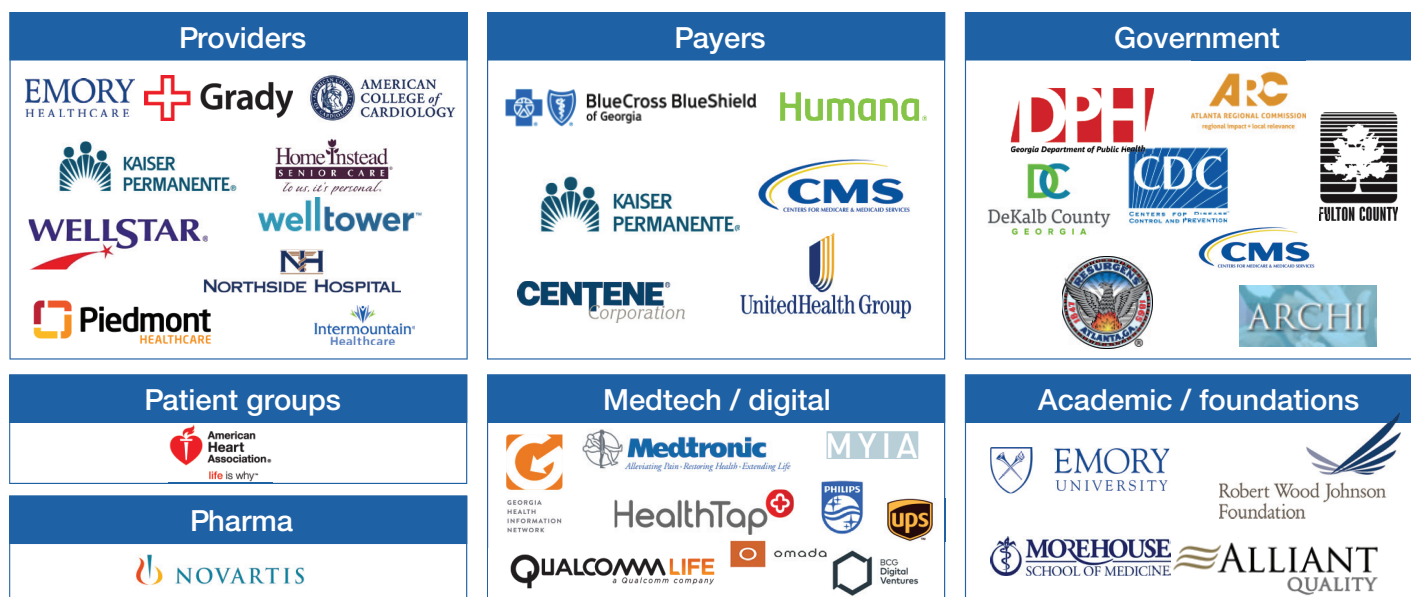
and national healthcare organizations, including Grady Health System, WellStar Health System, Emory Healthcare, Kaiser Permanente, Morehouse Healthcare, Humana, Centene Corporation, UnitedHealthcare, the Georgia Health Information Network (GaHIN), the Georgia Department of Public Health and the DeKalb County Board of Health. (For a complete list of participating institutions, see Figure 2.)

The pilot focuses on congestive heart failure (CHF) because it is one of the most serious medical conditions in the world. Nearly 6 million people in the US suffer from CHF – about half of whom die within five years of the initial diagnosis.<sup>3</sup> CHF prevalence is projected to increase by nearly 50% between 2012 and 2030, resulting in more than 8 million adults suffering from the disease.<sup>4</sup> One out of every nine deaths in the US lists CHF as a contributing cause.

CHF is not only deadly, it is also extremely costly. In 2012, the total costs associated with the disease were roughly \$30.7 billion – with about 70% attributable to direct medical costs. By 2030, the total cost of CHF is projected to more than double to \$69.7 billion.<sup>5</sup> There are also wide variations in health outcomes and costs for CHF patients across US hospitals. A recent study found a 2.7-fold difference between the top- and bottom-decile hospitals for risk-adjusted mortality from CHF<sup>6</sup> (the highest variation among the six causes of acute mortality analysed in the study) and a 2.2-fold difference for risk-adjusted admission rates of patients suffering from CHF. Only about 25% of the observed variation in outcomes for CHF mortality could

**Figure 2: The Atlanta Heart Failure Pilot Includes Stakeholders from Across the Local Healthcare Ecosystem**

Source: BCG analysis



be attributed to factors such as regional differences in population make-up or the prevalence of patients with comorbidities (which increases the risk of death). A full 75% of the variation was unexplained. It is likely that at least part of this variation is due to specific approaches to care delivery and the internal functioning of providers in a given region.

CHF is also highly prevalent in the south-eastern US, and it is a significant health burden for patients in metropolitan Atlanta. Nearly a third of the 100,000 people estimated to suffer from CHF in the region die within a year of initial diagnosis.<sup>7</sup>

During the first six months of the Atlanta pilot, participants conducted an exhaustive design and road-mapping exercise. Focusing squarely on health outcomes and the patient experience, stakeholders performed a comprehensive self-assessment of the strengths and weaknesses of CHF care delivery in the Atlanta region, using the criteria defined in the Enabler Transformation Roadmap for value-based healthcare introduced in last year's Value in Healthcare report. (See Figure 3.) This assessment then informed a broad collaborative effort to define the solutions, activities and milestones necessary to achieve a step-function improvement in health outcomes and cost of care for CHF patients in the Atlanta metropolitan area.

This initial phase of work led to the creation of four implementation teams with ambitious goals to start building the necessary local capabilities in each of the four enablers of value-based healthcare:

- **Informatics.** The informatics team is establishing a set of standard metrics for tracking CHF health outcomes. By the end of 2018, providers in the Atlanta metropolitan area will collect the full set of outcomes measures, including selected patient-reported outcome measures (PROMs), and share their data with the Georgia Health Information Network (GaHIN), a non-profit organization that manages the use and exchange of electronic health information for Georgia health providers.
- **Benchmarking, research and tools.** The benchmarking team is working with GaHIN to create an outcomes baseline by the end of 2018, to begin anonymized benchmarking of participating providers by 2019, and to start reporting best-in-class performance to providers by 2020. The identification and spreading of best practices will ultimately lead to better patient outcomes.
- **Payments.** In parallel, a payments implementation team is exploring mechanisms for shifting reimbursement towards value-based mechanisms such as bundled payments or outcome-based capitation. The goal is to introduce and test between three and five value-based payment models by 2020.

### Figure 3: The Enabler Transformation Roadmap

Source: BCG analysis

Note: "VBHC" stands for "Value-Based Healthcare"

	Phase 1 Internal performance improvement	Phase 2 System learning and performance improvement	Phase 3 Transparency and value competition	Phase 4 A continuously improving VBHC system
Informatics	Data collection by individual stakeholders	Standardized measurement of value	Interoperable IT systems with risk adjustments	Increased patient data collection and ownership
Benchmarking, research & tools	Comparisons within organizations only	Anonymized benchmarking among organizations	Competition based on public reporting; data available for research	Decision support tools and new clinical guidelines
Payments	Experimentation with new models	Shift away from fee-for-service	Quality improvement efforts with bundled payments & capitation	Value-based payments, optimized by patient group
Delivery organization	Increasing clinician engagement and ownership of value	Coordinated care across care chain	Quality improvement programs	Reorganization around population segments

- **Delivery organization.** Finally, the delivery organization team is working with the Atlanta Regional Commission, a regional planning and intergovernmental coordination agency, to compile a catalogue of clinical and non-clinical interventions that have been demonstrated to improve health outcomes for CHF. Over the course of the project, the team will also work with local providers to implement the most effective interventions, starting in the area of care transition, to ensure quality in-home care after a CHF patient is discharged from hospital.<sup>8</sup>

On 5 October 2017, the participating institutions in the Atlanta Heart Failure Pilot signed a formal Letter of Intent to continue working together to jointly implement these goals. The implementation effort is being led by the community-based non-profit Atlanta Regional Collaborative for Health Improvement (ARCHI), in collaboration with the American Heart Association.



On 5 October 2017, representatives of the participating institutions in the Atlanta Heart Failure Pilot signed a formal Letter of Intent to jointly implement the goals of the pilot. Centre: then-Mayor of Atlanta, Kasim Reed.

## Lessons from the Atlanta pilot

In the first six months of the Atlanta pilot, we have identified eight key factors for success that can be applied to any similar effort:

- 1. Build a clear case for change and an ambitious vision statement.** In order to engage a broad cross-section of participants, it's critical for the stakes to be clear and the potential payoff high. The Atlanta pilot chose to focus on CHF because it was a widely recognized "pain point" in the local health system. The pilot also set a highly ambitious goal, one that spoke to the professional pride of local providers and national health experts and which served to mobilize the local health community to engage with the project.
- 2. Enlist strong and visible public-sector leadership.** Given the many different stakeholders in healthcare (exacerbated in the Atlanta case by the especially fragmented nature of the US health system), it is critical for value-based initiatives to have a strong and visible leader with the power to convene the key institutional players and get them to think beyond their immediate self-interest. The Atlanta pilot has been extremely fortunate to have the active support and leadership of Atlanta Mayor Kasim Reed. Although Mayor Reed has recently left office, his work during the past year has laid the foundation for the long-term success of the Atlanta pilot.
- 3. Focus on system-wide transformation – beyond individual initiatives.** When many different institutions rally around an ambitious goal, there is a natural desire to "do something" – to jump right to the solution. Although this is understandable, it is also a mistake. The goal is not to implement any one initiative or set of initiatives; the goal is system-wide transformation. In Atlanta, participants were careful to keep their focus on creating the necessary conditions (shared outcome metrics, an informatics infrastructure, new value-based payment mechanisms and the like) that would enable the ongoing improvement of health outcomes for CHF. Although specific short-term initiatives – for example, implementing the care transition intervention – are part of the pilot, the ultimate goal is to lay the foundation for continuous innovation in care delivery and outcome improvements over the long term.
- 4. Take the time to design a detailed roadmap.** Similarly, an important factor in the Atlanta pilot was investing considerable time – the first six months of the project – to design what implementation would look like and develop detailed roadmaps for each of the working groups of the project. We believe that the time and effort invested in preparing these roadmaps has already paid off in terms of the strong alignment among stakeholders over what needs to be done and their shared commitment to the project's goals. That alignment and commitment represent the all-important foundation on which the implementation of the project's work plan will rest.
- 5. Aim for broad multistakeholder representation, with senior decision-makers represented on the steering committee.** Given the complexity of the healthcare environment, no one institution or sector can drive the necessary change. It is therefore critical that efforts have broad stakeholder representation and, in particular, that senior decision-makers are represented on the steering committee. In Atlanta, for example, we deliberately chose to have a large steering committee, consisting of some 25 senior executives from the leading providers, payers, pharmaceutical and medical technology (medtech) companies, and governmental agencies in the region. Since the goal of the pilot was system-wide transformation, it was essential that all of the leading players in the local health system were represented on this decision-making body.
- 6. Create an active working group with extensive (weekly) engagement.** In addition to a broadly representative steering committee, it is also important to set up an active working group that regularly dedicates significant time to the project. An engaged and active working group creates the momentum required for successful change management. In Atlanta, we held weekly meetings in which one or two experts from the participating organizations all took part. This group included doctors and nurses from local hospitals and provider networks, policy experts from local government, payment specialists from insurance companies and other professionals. Using the roadmaps developed during the first year of the Value in Healthcare project, they assessed their institutions and the local health system and identified the current starting point, the barriers standing in the way of progress, and the initiatives necessary to move the entire system forward. They also did the hard work of defining the key activities in the pilot and the roadmaps that participants are currently implementing.
- 7. Dedicate onsite resources to project management.** In addition to the steering committee and the working group, another key success factor was having a small team dedicated to ongoing project management. It is this team's responsibility to set the pace of project meetings, develop the content for those meetings with the working group, synthesize the views of the participants and build shared understanding and alignment around project goals over time. One important responsibility of the project-management team is to make sure participants stay true to the ambitious vision of the pilot. In any project involving a complex array of multiple stakeholders, there is always a tension between ambition and consensus, a tendency of participants to agree on the most modest or least aggressive version of a particular goal. It's the job of the project-management team to nurture and sustain the project's initial vision and participants' commitment to it.
- 8. Build strategic commitment to implementation.** Designing the detailed roadmaps for implementation is critical. It is equally important to build the strategic commitment of institutional participants to the implementation phase. In Atlanta, the mechanism for building and acknowledging this commitment was the Letter of Intent signed by representatives from participating institutions in which they publically agreed to work together to fulfil the goals of the pilot's five-year plan.

The Value in Healthcare project will be applying these lessons to additional pilots around the world in the years to come. (For more detail, see the appendix, "Next Steps for the Value in Healthcare project".)

# New standards for health informatics



Value-based healthcare is an evidence-based approach to health maintenance and improvement. One of its most critical elements, therefore, is the development of an integrated informatics infrastructure that allows for the easy capture, sharing and analysis of health information. By *infrastructure*, we mean not only the hardware and software of health informatics systems, but also the standards governing such systems and the organizational capabilities necessary to use them effectively. If society is to realize the promise of predicting disease risk, delivering appropriate prevention and precisely targeting treatment pathways to meet the specific needs of subpopulations, then access to comprehensive data from large numbers of patients is a prerequisite.

The key to creating a genuinely people-centred health informatics system is to define broadly shared global informatics standards. Standard-setting may sound like a technical topic, but it is another critical mechanism for encouraging cooperation across healthcare. What's more, for reasons tied to the rapid development of health technologies, establishing such standards has become increasingly urgent. The time to act is now.

## Healthcare's information revolution

Like many industries, healthcare is in the midst of a digital transformation. An explosion in medical knowledge is making the practice of medicine an increasingly data-intensive enterprise. For example, as our knowledge of

human genetics grows, it is becoming possible to fashion highly targeted therapies for individuals with specific genetic profiles. But translating genetic information into clinical treatments requires access to vast bodies of data from disparate sources in order to generate statistically valid recommendations. According to one recent study, in order to discover the so-called cancer "drivers" (genetic alterations that promote malignant phenotypes) in 2% or more of patients with cancer, researchers would need to analyse more than 100,000 cancers.<sup>9</sup> And genomics represents only one category of relevant health information. Healthcare is fast becoming a highly complex information business.

Healthcare's digital transformation is exacerbated by the growing demand among consumers for a more holistic view of their own health and by their increasing willingness to track their own vital health statistics. Take the example of the rapidly expanding market for health-related wearable technologies. Between 2016 and 2022, revenues in the healthcare wearables market are expected to grow by about 40%, from \$7 billion to \$10 billion.<sup>10</sup> Such patient-derived data can help drive value. One study, for example, used wearable-device data to identify five key patient segments for chronic obstructive pulmonary disease, based on different patterns of physical activity.<sup>11</sup> This suggests one way in which the growing body of personalized health data can be used to inform the segment-specific treatment interventions that are at the core of value-based healthcare.

Wearables are just the tip of the health-technology iceberg. Healthcare’s information revolution is also being driven by rapid advances in health informatics. Between 2014 and 2019, the global revenues of health-informatics companies should grow by 8% per year to \$37 billion.<sup>12</sup> Electronic data capture is expanding. New approaches to assembling and sharing information such as blockchain have the potential to ensure privacy and security by providing transparency about the provenance of information and the automatic auditing of data use.<sup>13</sup> Developments in data-processing and data-connectivity speeds enable the acquisition and processing of real-world data. Finally, advances in artificial intelligence and machine learning make it possible to create continuously learning information systems and develop automated decision-support tools that are sufficiently advanced to support real-time clinical decision-making.

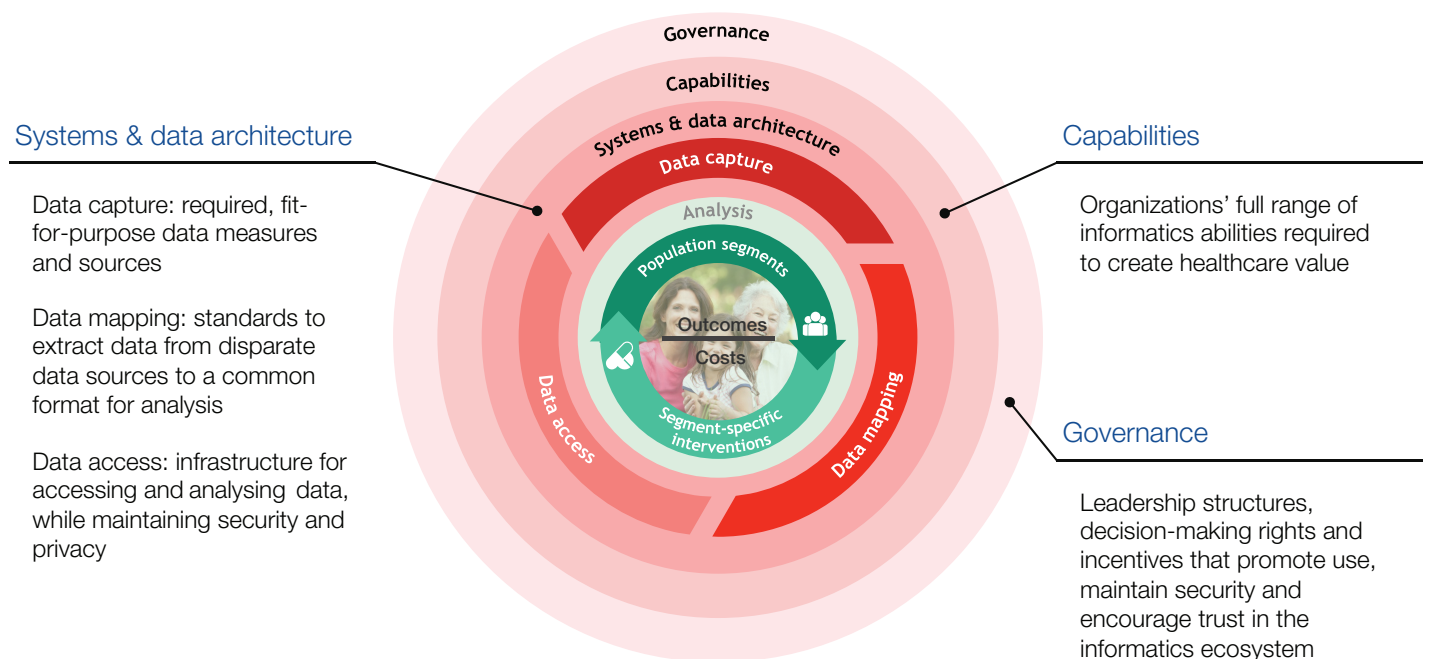
All of these innovations are rapidly expanding the “art of the possible” when it comes to integrating health data around the patient. But harnessing their potential to the goal of improving healthcare value will require overcoming a series of obstacles that currently stand in the way of developing a genuinely people-centred health-informatics infrastructure. For instance:

- **No consensus on data measures and formats.** Rather than simply collecting more and more data, there has to be agreement on what needs to be measured and what form the measurements should take. Without such clear priorities, important data measures may go uncollected and resources may be wasted collecting data that does not affect outcomes.

- **Inability to connect disparate data sources.** Despite the billions invested in electronic health records (EHR) and other health information systems, it remains extremely challenging to link all the data associated with an individual patient. Data is collected by different institutions for different ends and stored in different databases.
- **Inadequate informatics capabilities in healthcare organizations.** Many healthcare institutions lack the data science capabilities and skills needed to perform advanced analytics and integrate the insights that arise into clinical practice.
- **Limited transparency and trust between stakeholders.** There is a general lack of transparency about where data comes from, how it is collected and for what purposes (known as *data provenance*). Lack of transparency makes it difficult for clinicians and researchers to know with confidence whether data is fit for its intended uses and, as a consequence, a lot of duplicate analysis takes place. Poor transparency also hinders the development of trust. Such trust is necessary if clinicians are to put their faith in the algorithms underlying new analytical decision-support tools. Finally, lack of trust reinforces the natural inclination of individual stakeholders to “hoard” data.
- **Insufficient incentives to change the status quo.** The industry as a whole lacks effective governance mechanisms and incentives to encourage stakeholders to collaborate on informatics.

**Figure 4: A Framework for a People-Centred Approach to Health Informatics**

Source: BCG analysis



Until these obstacles are addressed, it will be impossible to realize the full potential of precision medicine in clinical practice or to translate healthcare’s digital revolution into systematic improvements in healthcare value.

The Value in Healthcare project has developed a framework for describing an integrated informatics infrastructure that puts precision medicine and the value delivered to patients at the very centre of the industry’s information system. (See Figure 4.)

The purpose of a people-centred health informatics infrastructure is to support the fundamental care-delivery and innovation model of value-based healthcare. This model defines the continuous-improvement loop of the value-based health system in which the ongoing analysis of data on outcomes and costs leads to ever-more precise definitions of the key population segments and customized interventions for optimal treatment of those segments.

The informatics infrastructure to support this continuous improvement cycle requires the development of a systems and data architecture with comprehensive standards for what data to collect (data capture), how to combine data from diverse sources so that it is comparable (data mapping), and how to access data for the purposes of benchmarking and analysis (data access). Ideally, these standards should be *universal* and *global* to encourage data sharing across health systems and multiple industry stakeholders to accelerate learning and innovation.

Once in place, these standards will greatly accelerate the ability of clinicians and researchers at hospitals, academic institutions and insurance, pharmaceutical, medtech and

analytics companies to analyse ever-larger sets of structured and compatible data. Informatics standards will also accelerate the development of sophisticated analytical tools (for instance, automated decision-support tools) that extract insights from the data to inform clinical methodology and life-sciences research and development. Done right, defining the minimally sufficient standards will encourage maximum innovation on the basis of standardized data.

Of course, making full use of these tools will also require healthcare organizations to develop new analytical and data science capabilities, as well as effective governance mechanisms (both within individual institutions and across multiple stakeholders) for the development and maintenance of the informatics infrastructure over time. However, since the development of global standards is the critical linchpin, it is the main focus of this section.

### Standards for data capture: The measures library

Health systems around the world are routinely collecting more and more data. But not all such data is necessarily relevant to the goal of improving patient value. What’s more, many types of data that *are* relevant are currently not being recorded on a systematic basis. Therefore, the first step in setting global informatics standards concerns data capture – defining which data is relevant. It’s useful to think of the standards for data capture as a kind of library in which the “books” are all of the standard measures that could possibly be collected for each patient category or population group. (See the sidebar, “What data do we need to capture?”.)



## What data do we need to capture?

There are three categories of standard measures that a comprehensive value-based measures library needs to include: measures for health outcomes, for health-related population segments and for segment-specific clinical and non-clinical interventions.

**Health outcomes measures.** Since value-based healthcare is founded on the systematic tracking of health outcomes, the measures library needs to include both clinical outcomes (for example, basic mortality, post-surgical infections or patient mobility) and patient-reported outcomes measures or PROMs (for example, patient-reported quality of life). The measures library needs to define the relevant measures for all diseases or conditions.

**Population-segment measures.** In value-based healthcare, the key unit of analysis is the population of patients suffering from a specific condition or all individuals sharing the same risk profile. Therefore, another important set of measures is made up of those that serve to classify individuals so that they can be mapped to the population segments or risk groups most relevant to their health condition. Examples include a patient’s genetic and medical history, diagnoses and physical diagnostics (for instance, patient test results), but also demographic and socioeconomic information and even a behavioural profile that tracks health-related behavioural information (for example, whether an individual is a heavy smoker or regularly engages in exercise).

**Segment-specific intervention measures.** In value-based healthcare, interdisciplinary teams of clinicians use data on health outcomes to develop segment-specific interventions for each population segment across the full cycle of care. A third and final category of measures, therefore, covers the range of clinical (drugs, surgeries, physiotherapy, counselling, etc.) and non-clinical interventions (for example, access to healthy food) designed to meet the needs of each segment.

Meaningful standards are necessary, however, not only for these specific data categories but also for the metadata associated with them. Metadata is “data about data”, or contextual information that travels with a given piece of data and provides important information about it. Some metadata categories are necessary to link data from different data sources – for example, a standardized time concept, a patient identifier or a licence governing consent and access. Other metadata categories provide information about the data’s provenance – for example, the data source, the original purpose of its collection and who recorded the data. Capturing metadata is critical because it provides information about whether the data in question is “fit for purpose” for the clinician or researcher who wants to use it. (See Figure 5.)

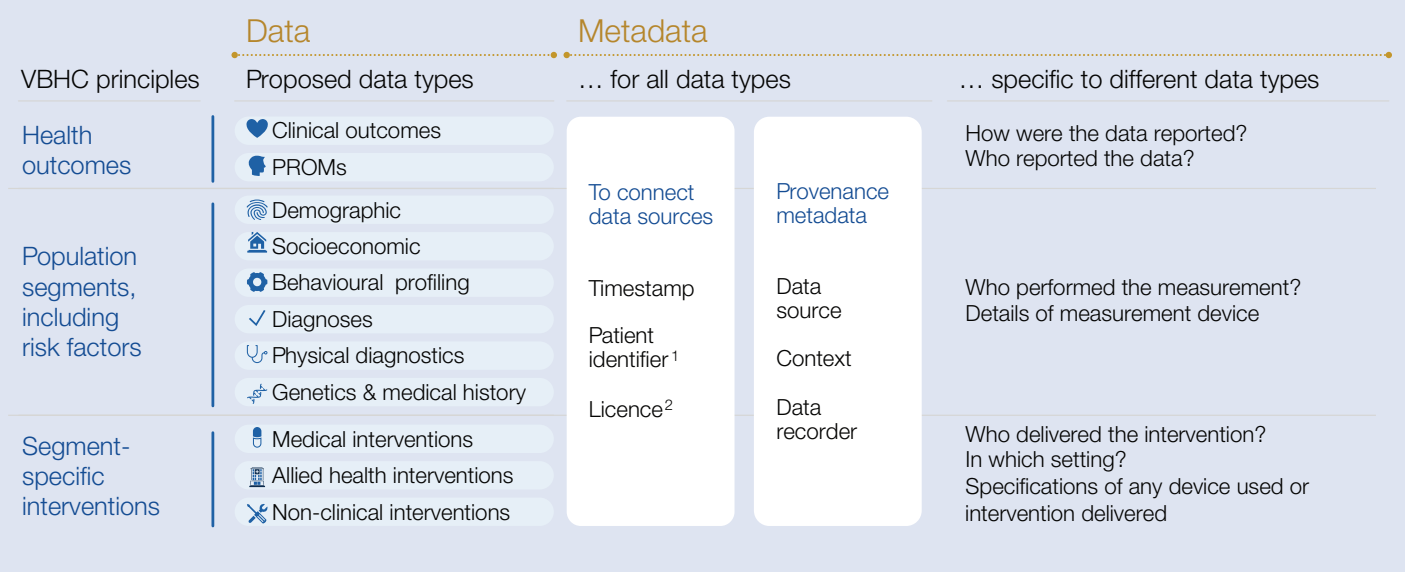
**Figure 5: The Measures Library Must Include Standards for Both Data and Metadata**

Sources: “Value in Healthcare: Laying the Foundation for Health System Transformation”. World Economic Forum, 2017; BCG analysis.

Note: “PROMs” stands for “Patient Reported Outcome Measures.”

1 Depending on local privacy legislation.

2 Governing consent and access.





Where does the industry stand in developing a standardized measures library? In recent years, there has been considerable progress in defining standard health outcomes measures for specific diseases and conditions. For example, the International Consortium of Health Outcomes Measurement (ICHOM) has published standardized metrics and risk-adjustment variables for 23 major conditions, with an additional 9 sets under active development, covering more than 50% of the global disease burden in developed countries.<sup>14</sup> ICHOM standard sets are being implemented by more than 650 hospitals and provider organizations around the world.

There have also been initiatives to develop detailed data standards in focused areas of clinical practice. For example, the International Consortium of Orthopaedic Registries (ICOR), sponsored by the US Food and Drug Administration (FDA), has created a global implant library to harmonize the nomenclature (naming system) used to characterize the attributes of implant devices and to standardize implant data. Finally, some companies such as the US health informatics company Aetion are developing measures libraries that compile real-world data from multiple sources – for example, claims data, electronic health records (EHRs), quality registries and clinical trials – so that the data is comparable, allowing users (for example, pharmaceutical companies) to benchmark the effectiveness of their treatments.

Aetion's measures libraries are, however, proprietary. And even public standards such as ICHOM's are still far from being universally implemented. What's more, major data gaps exist – for example, in identifying the critical health outcomes for mental health, in defining PROMs for key diseases and in defining the population segments that will be the basis of segment-specific interventions.

## Standards for data mapping: Semantic and data models

The relevant data defined by the categories within the measures library will come from a wide variety of sources: hospital information systems such as EHRs or laboratory databases, personal devices such as wearables or home-monitoring devices and patient surveys, to name just a few. Therefore, in addition to standards on what data to collect, technical protocols must also be developed for linking disparate sources of data in order to allow communication and sharing among multiple databases. Specifically, the informatics infrastructure will require:

- A semantic model that allows data collected using a variety of terminologies and coding systems (known as *ontologies*) to be mapped to a single, common language
- A data model that allows data to be extracted from disparate vendor systems and enables them to be mapped to a common template.

Think of the semantic model as a universal mapping of the data standards in the measures library to different ontologies. Since that data comes from a wide variety of

sources, it will have been collected and organized according to different categorization systems. The situation is akin to communication among a group of people who all speak different languages. Before they can understand each other, they need to translate what they have to say into a common shared language. The semantic model provides the rules for translating data from different data sets and different ontologies into a common language for analysis. The challenge, of course, in creating such a common language, is to find the right level of granularity, so that important information is not “lost in translation”.

In addition to a semantic model, standards will also need to be developed for a common data model. The data model is a template that makes it possible to capture and combine data from different sources in a consistent, logical manner. It organizes and defines the properties of individual data and metadata and sets standards for how they relate to one another. For example, a mortality outcome needs to be linked to a time stamp for when the event occurred, as well as to contextual information, such as who reported the information.

There is a great deal of current activity in the healthcare sector around building semantic and data models. One commonly used semantic ontology, for example, is SNOMED CT (an acronym for “Systematized Nomenclature of Medicine – Clinical Terms”).<sup>15</sup> SNOMED defines a standardized vocabulary of clinical terminology that is used by doctors and other healthcare providers for the electronic exchange of clinical health information and is widely considered to be the most comprehensive, multilingual clinical healthcare terminology in the world. However, SNOMED is a proprietary system requiring a licensing fee. The SNOMED taxonomy also focuses mainly on clinical terms and does not include several of the categories of information that a value-based health system would need to track (for example, a patient behavioural profile). At the moment, there are very few semantic standards for aggregating data about health outcomes. Any health informatics infrastructure for value-based healthcare should support different but linked semantic standards for each of the three measures categories of the measures library. This is currently not the case.

When it comes to data model standards, the non-profit Health Level Seven International, commonly known as HL7, has been developing a comprehensive framework for standards for the exchange, integration, sharing and retrieval of electronic health information. Its efforts are supported by more than 1,600 participating organizations in over 50 countries. A more recent open-source standard known as FHIR has been developed on top of the existing HL7 platform. FHIR (which stands for “Fast Healthcare Interoperability Resources” and is pronounced “fire”) defines the first truly open-source standards for electronic information sharing in healthcare and is designed to be easier to implement, more open and more extensible than HL7. Meanwhile, still other initiatives are building on the FHIR standard – for example, the Argonaut Project, a private-sector initiative in the US to advance industry adoption of modern, open interoperability standards, and SMART on FHIR, a set of open specifications to

integrate health-related apps built on the SMART Health IT technology platform with EHRs and other health IT systems.

These efforts are important, but a number of challenges remain. First, existing standard-setting efforts need to be aligned to the goal of improving healthcare value. For example, the FHIR standard does not currently include a comprehensive, structured representation of a care plan – that is, categories for tracking health outcomes in relation to clinical and non-clinical interventions along the patient treatment pathway. Second, the standard-setting process needs to be accelerated through consistent funding and effective governance.

## Standards for data access: Data security, privacy and transparency

As the healthcare industry makes progress in developing standards for a shared semantic model and data model for the data categories defined by the measures library, clinicians, researchers, statisticians and data scientists and health software developers will be in a position to analyse increasingly larger data sets and develop algorithms that help clinicians choose the most appropriate clinical interventions for a given patient.

Additional standards will be necessary, however, to address three critical data-access challenges. The first is encouraging data sharing while also protecting data security and patient privacy. The second is promoting the appropriate level of transparency so that the algorithms which extract insights from the data are intelligible to the researchers and clinicians who are relying on them. The third is creating the technical requirements for easy data access.

**Data security and patient privacy.** Here lies an unavoidable tension of value-based healthcare: on the one hand, patients and clinicians need to be encouraged to share their data for the purposes of benchmarking and analysis; on the other, health-related data is some of the most personal and private information about individuals that it is possible to collect. It is essential for any health-informatics systems to have stringent data security and patient privacy protections.

Managing this inevitable tension is partly a technical issue. It will be important to develop technical standards for privacy protection, including automated procedures for garnering patient consent for use of personal health data, verifying permission to access and use data, and generating an audit trail recording every access and use of such data. But it is also a legal and regulatory issue. Governments will need to establish guidelines for data integrity and security, processes for shared governance, rules for access and methodologies for anonymization so that data can be shared in the aggregate without violating the privacy of any individual patient.<sup>16</sup> One promising approach to ensure the appropriate balance between the social benefits of sharing and individual privacy is to develop privacy legislation that focuses less on protecting data and more on defining what analyses of the data are acceptable.

**Data transparency.** Artificial intelligence and machine learning make it possible to create new analytical and decision-support tools for clinicians based on algorithms that extract clinical insight from large data sets. However, if clinicians cannot understand the underlying analytics that lead to these algorithms, they are unlikely to put their trust in them.

This presents another critical tension: transparency around how data is being accessed and used by analytical tools is critical in gaining the trust of clinicians for widespread adoption. Yet in order to encourage investment and innovation, creators of such algorithms seek to keep their analytic tools proprietary. To manage this trade-off, new governance and regulatory mechanisms are needed to review, refine and endorse digital tools. Regulators will have to review all necessary documentation prior to granting such digital tools access to the market, ensuring promised contributions to healthcare value are achieved without unwarranted “side effects”.

**Data access infrastructure.** Finally, there will need to be standards and protocols for the infrastructure of data access – where and how information is stored, who controls it and how access to that information is managed. Traditionally, most approaches to these questions have followed some version of a centralized model. Data is stored in centralized data warehouses; in order to access specific data, the data needs to be transferred to the user’s own warehouse. For example, most quality registries that track health outcomes have created their own centralized data warehouses, which are entirely separate from the data captured in hospital information systems.

There are situations where a centralized approach makes sense – for example, there may need to be national databases with critical patient data (demographic data, medications, allergies and the like) for emergency situations. However, there is growing recognition among data scientists that centralization has its limits. For one thing, it is not easy to scale. The large amounts of data necessary to get statistically significant results in precision medicine very quickly encounter storage constraints. The concentration of patient data in centralized data warehouses also creates a single point of failure that makes data more vulnerable to hacking. Finally, exchanging data across jurisdictions adds another, often insurmountable, level of regulatory complexity to data-sharing efforts.

There has therefore been a movement away from models of centralized data storage and access, and a shift towards distributed models. In the latter, data holders keep control of their own data but also have the ability (and the responsibility) to share it for purposes of research, tracking and clinical decision-making, while protecting individual privacy. Under the distributed model, analytical software travels to the data rather than the other way round. Because data always remains behind each institution’s firewall, distribution also has real privacy benefits, because no individual’s entire data is stored within one single place. (See the sidebar, “Two models for distributed data access”.)

## Two models for distributed data access

Industry stakeholders are pursuing a variety of approaches to the distributed access of health information. One approach, developed at the Massachusetts Institute of Technology and known as Opal/Enigma, uses blockchain to create a trusted platform for distributed data analysis without the need of a trusted third party.<sup>17</sup> The blockchain technology allows for the creation of an auditable, tamper-proof record of communications between data and operators. This blockchain record, which includes information on credentials and data operations, is distributed among platform members and ensures that only vetted algorithms have access to data by means of smart contracts. The blockchain's complete audit trail of transactions and authentication and its ability to provide different levels of access to data highlight its advantages over other technologies that support data access.

Another complementary approach is the GO FAIR implementation network, a proposal for the implementation of the European Open Science Cloud. GO FAIR is based on the FAIR data initiative developed by Dr Barend Mons, a molecular biologist and professor of biosemantics in the Department of Human Genetics at the Leiden University Medical Centre in the Netherlands. According to the FAIR concept, all health data should be **findable** (easy to locate, and not only by humans but by automated computer systems), **accessible** (permanently stored with well-defined rules for licensing and criteria for access), **interoperable** (sharing the same semantic and data model so that it is ready to be combined with other datasets) and **reusable** (able to be used in future research and further processed to address new research questions).<sup>18</sup>

GO FAIR has developed a model for the distributed storage and access of data known as the Personal Health Train. As the name suggests, the approach can be likened to a traditional railway network. In this analogy, every health data provider would establish a FAIR data station with which researchers, clinicians and other data users can communicate to get access to data according to explicit rules for access. The analytical tools developed by researchers and other medical specialists – the equivalent of “trains” in the railway analogy – would travel to the data stations, where they would gain access to data for analytical purposes and develop insights from it but without extracting the data or aggregating it beyond each institution's firewall. There is also a linking infrastructure (the “tracks”) over which the algorithms move, regulating access and providing data security.

Whatever the specific technical approach, the standards for data access need to encourage the broad sharing of data and ease of use for data analysis. In addition, critical governance questions will need to be resolved as such standards are implemented, including who grants algorithms access to data and how such a model would be scaled and standardized on the international level.

## The importance of effective governance

As investment and interest in health data continue to grow, we must ensure that the development of standards is better coordinated, truly global in scope and focused on the goal of supporting continuous improvements in healthcare value. Given the complexity of the global healthcare industry, we recommend an approach in which leading stakeholders from both the public and private sectors work together to drive the standard-setting agenda for the entire industry. (See the sidebar, “Creating transformative industry standards: The internet analogy”.)



## Creating transformative industry standards: The internet analogy

For an example of how stakeholders can work together to create standards that transform an industry, consider the story of the establishment of the TCP/IP networking standard, which laid the foundation for the modern internet. The development and dissemination of the TCP/IP protocol is the story of a dynamic public-private partnership in which key institutions in government, academia and private industry played an activist role.

The development of the technical standard in the 1970s was funded by government – specifically, the Defense Advanced Research Projects Agency (DARPA) of the US Department of Defense. The initial working group included university researchers from Stanford and industry experts from Xerox’s Palo Alto Research Center. Operational models of the protocol, which allowed it to run on different computing platforms, were developed by the private contract-research firm Bolt, Beranek and Newman, in collaboration with Stanford and University College London.

Once the standard was developed, the US government played a key role in accelerating its adoption when, in 1982, the Department of Defense made TCP/IP the standard for all military computing. And in 1985, the National Science Foundation chose the standard for NSFNET, which became the general networking infrastructure for roughly 2,000 institutions of higher learning and leading high-tech companies. Soon after, major computer companies such as IBM, AT&T and DEC adopted the standard, and smaller companies began including it in DOS and Windows, which would become the key operating software for the then-emerging personal computer. A key step in the dissemination of TCP/IP occurred in 1989 when AT&T agreed to place its TCP/IP code for the popular UNIX operating system in the public domain.

The story of the TCP/IP standard reflects precisely the type of multistakeholder collaboration that we believe is necessary for the development of value-based informatics standards in healthcare.

Standards developed by this public-private partnership should build on many of the existing efforts already underway and be published in an open-source format. (See Figure 6.) What’s more, in order to maintain market confidence in the collaborative effort but also to encourage competition and further innovation, any organization should be able to contribute to further development of the standards, provided that these efforts also adhere to the principle of open publication. Open publication of all

results is an important safeguard against any appearance of unfair collusion or violations of antitrust regulations. (For a discussion of the initiatives that the Value in Healthcare project will undertake in 2018 to accelerate the development of this public-private partnership, see the appendix of this report, “Next steps for the Value in Healthcare project”.)

**Figure 6:** Global Informatics Standards Should Build on Existing Efforts

Source: BCG analysis

Note: “CIMI” stands for the “Clinical Information Modeling Initiative”; PCORnet is the National Patient-Centered Clinical Research Network.

Domain		Examples of relevant, existing standardization efforts
Capture	Outcomes	<ul style="list-style-type: none"> <li>• <b>ICHOM:</b> Provides global standard sets of clinical outcomes and PROMs</li> </ul>
	Subpopulation / intervention	N/A
	Metadata	<ul style="list-style-type: none"> <li>• <b>Argonaut:</b> Provides set of metadata that could serve as starting point</li> </ul>
Mapping	Semantic model	<ul style="list-style-type: none"> <li>• <b>ONC Common Data Set:</b> Semantic model should map to ontologies chosen</li> <li>• <b>SMART on FHIR:</b> Provides starting points for semantic model</li> </ul>
	Data model	<ul style="list-style-type: none"> <li>• <b>Argonaut:</b> Provides several relevant FHIR data-model components</li> <li>• <b>FHIR Care Plan and CIMI:</b> Need to align with adjacent efforts</li> <li>• <b>Open EHR:</b> May provide some building blocks</li> </ul>
	Policy & data linkage	N/A
Access	Infrastructure	<ul style="list-style-type: none"> <li>• <b>PCORnet:</b> PopMedNet solution is a distributed network access of data</li> </ul>
	Patient consent	N/A
	Access control	<ul style="list-style-type: none"> <li>• <b>SMART:</b> Provides methods for authorization and authentication</li> <li>• <b>Argonaut:</b> Provides implementation guide of SMART on FHIR</li> </ul>
	Audit trail	N/A

# New directions for leadership

Value-based healthcare constitutes an agenda for health system transformation. As such, it requires transformative leadership. Healthcare leaders will need to play an active role in transforming their own organizations to improve value and deliver outcomes that matter to patients in a financially sustainable manner. However, they will also need to articulate a vision that looks beyond the interests of their individual organizations in order to transform the system as a whole. Finally, government has a critical role to play in enabling value-based innovations and in creating the broader policy and the regulatory and legal framework necessary to make it easier for stakeholders to align on delivering healthcare value.

## Industry leadership

Last year's Value in Healthcare report featured some of the leading healthcare organizations that are actively pursuing value-based healthcare. These include providers such as Kaiser Permanente and the Cleveland Clinic in the US, Martini-Klinik in Germany and Aravind Eye Care System in India; payers such as Humana in the US and Menzis in the Netherlands; medical-device makers such as Medtronic; and pharmaceutical companies such as Novartis, to name just a few.

Many of these organizations have today or have had in the recent past dynamic leaders who understand the opportunity that value-based healthcare represents for their institutions and who have put their organizations at the forefront of the trend. But even these leading companies have confronted obstacles as they have tried to spread the value-based model or sought to form partnerships with other stakeholders. As a result, too many of these institutions have been relatively isolated islands of innovation within the broader healthcare sector.

The leadership challenge today, therefore, is to advance beyond such islands of innovation in order to create fully fledged value-based health systems at the regional, national and international level. To achieve this goal, industry leaders need to look beyond the strategy and interests of their own institutions and start to play an active leadership role at the system level. The champions of value-based healthcare need to start affecting the entire healthcare system. Only when they do so will they create a stable platform for the important innovations they have developed in recent years.

This system-level leadership takes a variety of forms. In some cases, institutions within a particular sector of the healthcare industry are partnering to improve health outcomes at the level of national health systems. In the US, for example, the High Value Health Care Collaborative (HVHC) is a "provider learning network committed to improving healthcare value through data and collaboration".<sup>19</sup> Founded by Dartmouth-Hitchcock Hospital, Intermountain Healthcare, the Mayo Clinic and

the Dartmouth Institute for Health Policy and Clinical Practice, the network brings together 10 US provider organizations across the country to measure, innovate, test and continuously improve value-based approaches to care; rapidly disseminate and facilitate adoption of proven high-value care models; and advocate for policy and payment models that support value-based healthcare.

Similarly, in the Netherlands, seven Dutch teaching hospitals have joined together in an association known as Santeon to improve patient care by fostering inter-hospital cooperation.<sup>20</sup> According to former Santeon Director Leonique Niessen, "We simply believe that one hospital cannot improve quality alone. A single hospital can set up improvement programmes but will need to compare its performance with others to understand where it can improve and which procedures deliver the best outcomes". With some 2,800 employees, of which about 1,800 are doctors, the Santeon hospitals are responsible for approximately 11% of the total volume of hospital-based healthcare in the Netherlands. The association is implementing systematic tracking of health outcomes, inter-hospital benchmarking and continuous improvement of the treatment pathway in key disease areas such as breast cancer.

In other situations, organizations are working through their industry trade associations to accelerate the development of the critical enablers for a value-based health system. For example, MedTech Europe, a European trade association representing medical technology industries, has been instrumental in developing a value-based purchasing framework for medical technologies in accordance with the February 2014 directive of the European Union on public procurement. And the European Federation of Pharmaceutical Industries and Associations (EFPIA), under the leadership of Novartis CEO Joseph Jimenez, has played a central role in the "Big Data for Better Outcomes" initiative of the EU's Innovative Medicines Initiative (IMI). The IMI's HARMONY Alliance brings together 51 partners to battle haematological cancers using big data analyses and the FAIR data sharing principles described above. In the US, the American Medical Informatics Association (AMIA), the US professional association of clinicians, scientists, researchers and other health informatics professionals, recently issued a position statement urging the US National Library of Medicine to "focus research on the basic science of data standards, including development of granular data specifications to enable a 'periodic table of elements,' approach to biomedical data standards".<sup>21</sup>

Some institutions are taking a critical next step: cooperating across traditional boundaries between sectors so that providers, payers, and pharmaceutical and medtech companies can use their combined influence to transform health systems. The Atlanta Heart Failure Pilot described in these pages is one example. The 80-plus international healthcare institutions that provide financial sponsorship to ICHOM to support the creation and implementation of outcome standards relevant across all stakeholder groups is another.

Given the fact that healthcare is a highly regulated sector in which government and public policy play a central role, it can sometimes be tempting for private-sector stakeholders to wait until government takes the lead. But these examples make clear that there is a great deal that active and committed stakeholders can do – even in the absence of a fully articulated policy framework for value-based healthcare. Indeed, industry leadership can actively shape the decisions and actions taken by governments and public policy-makers.

## Government leadership

In the end, however, health systems remain largely national in their funding and organization, so reshaping the health system will also require transformative leadership on the part of national governments. One of the key lessons of the Atlanta pilot is that strong leadership by elected officials can play a critical role in convening industry stakeholders based on the shared goal of improving healthcare value. Demonstrating such leadership, however, requires elected officials to be visionary, to look beyond the current election cycle and lay the foundation for progress over the long term.

Government leaders and policy-makers also have an important role to play in changing the legal and policy framework governing health systems so that incentives are in place to facilitate cooperation on the aims of value-based healthcare. In last year's report, we identified five critical steps for governments and policy-makers to take:

1. Mandate health outcome tracking
2. Balance the trade-off between patient privacy and data sharing
3. Enable cooperation, coordination and partnerships along care pathways (while protecting against conflict of interest and focusing competition on value)
4. Encourage new longitudinal payment models
5. Enable all actors (including pharmaceutical and medtech companies) to become more accountable and contribute more actively to value-based healthcare.

Governments are doing a great deal already. For example, in 2016, the member countries of the European Union adopted a common regulatory framework (known as the General Data Protection Regulation, or GDPR) for ensuring the protection of personal data, including health data; full application of the framework will go into effect in 2018.<sup>22</sup> And, in January 2017, the health ministers of the 35 member countries of the Organisation for Economic Cooperation and Development (OECD) recommended that countries develop and implement health-data governance

frameworks that secure privacy while enabling health data uses that are in the public interest.<sup>23</sup>

But much more needs to be done. Currently, only about half of the OECD countries regularly link their existing health data sets to monitor healthcare quality or have national policies in place to address how data from electronic health records can inform clinicians, monitor disease outbreaks, conduct research and improve patient safety.

In addition to specific policy goals, governments have a more general role to play: to set an ambitious vision for national health-system transformation and to promote the kind of cooperation and public-private partnerships necessary to make value-based healthcare a reality. (For an example of what this transformative government leadership looks like, see the sidebar, “Transformative leadership: The case of the Netherlands”.)

## Transformative leadership: The case of the Netherlands

In a relatively brief period of time, the Dutch health system has begun to emerge as a global leader in national health system transformation according to the model of value-based healthcare. The country has some 200 quality registries that track health outcomes in key disease areas, and data from these registries is broadly shared with providers, specialist medical societies and payers. Leading Dutch clinicians are active participants in international efforts to develop standards for comparing local outcomes against international benchmarks. Provider institutions such as the Santeon network of seven Dutch teaching hospitals and Diabeter, an innovative diabetes clinic and research centre (recently acquired by Medtronic), have reorganized care delivery around value-based principles. And the nation's private insurers have introduced value-based payment pilots for some key procedures and conditions.

A key factor in the rapid dissemination of value-based healthcare in the Netherlands has been the increasingly active enabling role played by the Dutch Ministry of Health, Welfare and Sport, which oversees the national health system. The ministry sees its leadership role as being three-dimensional. First, it strives to set the national agenda for value-based healthcare. For example, the ministry has set the ambitious goal that by 2021, health outcomes will be fully transparent to the public for 50% of the national disease burden.

The ministry also helps to ensure the key enablers for value-based healthcare are implemented. For example, it has sponsored an initiative known in Dutch as “MedMij” (the English translation would be either “With Me” or “My Med”), which aims to create a secure digital environment by 2020 that will allow all Dutch patients to access their personal health record and be able to add information to that record from personal devices such as wearable health technologies. The Value in Healthcare project is also conducting a pilot project with the ministry to convene local stakeholders in order to develop recommendations for strengthening the Dutch health informatics infrastructure and to create a high-level roadmap for its future development.

Finally, the ministry encourages changes in clinical practice by highlighting the best examples of innovative healthcare organizations and introducing new contracting practices to encourage increased cooperation among industry stakeholders.

As a result of all these efforts, Dutch healthcare is rapidly evolving in the direction of a more innovative, more value-based and more globally connected health system.

## Global leadership

Although health systems will remain largely national in scope, the ultimate benefit of value-based healthcare will be realized on the international level, as health systems benefit from accessing data about health outcomes not just in one country but across the entire world. Thus, transformative leadership is also necessary at the global level.

As is the case with industry leadership, this global leadership will take a variety of forms: for example, global networks of quality registries tracking outcomes for specific conditions or diseases, or international consortia such as ICHOM. Increasingly, international organizations are themselves playing a leadership role. For example, in 2017, the OECD launched the PaRIS project. The OECD is a global leader in collecting, reporting and benchmarking health system performance and healthcare quality indicators. But there is a critical gap in the organization's reporting system in terms of patient-reported outcome metrics, which are central to value-based healthcare. The PaRIS – Patient-Reported Indicators Survey – project aims to fill this gap by developing standardized patient surveys that deliver a patient-centred view of health system performance. The OECD is partnering with ICHOM in this multi-nation effort.

These examples suggest that healthcare leaders in both the public and private sectors are, indeed, stepping up to the challenge of health system transformation. But we all need to do more. The global healthcare sector is at a crossroads. Growing complexity is leading to more frustration, increased fragmentation and lower productivity. Value-based healthcare offers a compelling alternative vision, and rapid advances in information technology provide an opportunity for system-wide transformation. To realize the vision, senior leaders must take responsibility, not only for the health and development of their own institutions, but also for the health and development of the entire healthcare system at the regional, national and global level. In fact, it is only through a system-wide transformation, as described in these pages, that the long-term health of their own institutions – not to mention the long-term health of their patients, customers and citizens – will be assured. Now, more than ever, is the time for collective action.

# Appendix: Next steps for the Value in Healthcare project

In the third year of the Value in Healthcare project, we will be undertaking a variety of initiatives to encourage and support the kind of collective action necessary to make value-based healthcare a reality.

## Creating a network of value-based healthcare pilots

In 2018, the Value in Healthcare project will be applying the lessons from the Atlanta pilot to additional pilots for health system transformation around the world. Among the pilots currently under consideration are:

- **Ontario Type 2 Diabetes Pilot.** Diabetes is a serious chronic disease that is reaching near-epidemic proportions. According to the International Diabetes Foundation (IDF), roughly 415 million adults suffered from diabetes in 2015 – and nearly half of those cases went undiagnosed.<sup>24</sup> We are working with the provincial adviser Health Quality Ontario to define a potential pilot. The goal: to reduce the prevalence and rate of complications of type 2 diabetes in Ontario by 2021 – the 100th anniversary of the discovery of insulin by Frederick Banting and Charles Best at the University of Toronto.
- **Singapore Coronary Artery Disease Pilot.** We are also in active discussions with the three healthcare clusters in Singapore to organize a pilot focusing on coronary artery disease, one of the leading causes of death in that country. The plan is to create an integrated approach to treatment that encompasses primary care, acute hospital care and community-based care services.
- **China Value-Based Healthcare Pilot.** When it comes to creating a value-based health system, we believe that China has great potential to leapfrog the legacy health systems in other parts of the world.<sup>25</sup> In June 2017, at the Annual Meeting of the New Champions in the Chinese city of Dalian, we began preliminary discussions with provincial officials and other local stakeholders about the possibility of launching a pilot focused on type 2 diabetes or breast cancer. And, in November 2017, we published the Mandarin Chinese translation of our first-year *Value in Healthcare* report to support these ongoing discussions.

Over the long term, we hope to create a global platform for accelerating the development of value-based healthcare around the world. For example, the World Economic Forum could serve as a convenor, bringing together all participants in global pilots for an annual workshop in which they share methodology, learn from each other's experiences, and develop approaches for scaling local pilots to the national and international level. The Value in Healthcare project will be exploring this and other possible roles in 2018.

## Accelerating the development of informatics standards

In 2018 the project will also focus on accelerating the process of global standard-setting for health informatics. The standard-development initiative we envision is a long-term effort that over time will need to consist of four major work streams:

- The **measures library work stream** will establish a definitive use-case by developing the complete set of data and metadata categories necessary to track health outcomes, key population segments and segment-specific interventions for a selected group of diseases or conditions.
- The **semantic model work stream** will develop the semantic model, mapping the different domains of the measures library to existing ontologies.
- The **data model work stream** will develop a common data model for the structured exchange of data on patient care pathways and outcomes – that is, a time-based series of data on all interventions and observations during treatment and the subsequent health outcomes, so that specific outcomes can be linked to specific interventions
- The **data access work stream** will detail use-cases suitable for a distributed-access architecture, pilot the approach, and establish standard levels of patient consent and technical solutions that allow patients to control access to their data (including requirements for access control and audit trails).

In 2018, we will focus primarily on the data model work stream – for the pragmatic reason that this work stream is most likely to yield a proof-of-concept within a year and to achieve rapid global uptake. The objective will be to enable online and distributed capture of standardized data and metadata from individual providers, for the purposes of comparison, by developing a reference implementation based on existing global outcomes measures. Initial deliverables will include:

- An open-access, HL7-FHIR-compatible, general-format data model for the standardized recording of health outcomes
- An open-source reference implementation using existing global standard outcomes measures
- Documentation of testing and verification of the data model and reference implementation.



The reference implementation is crucial because it will demonstrate the intent of the data model, show how it can be integrated into clinical workflows, and highlight the potential benefits of its use. To select the most appropriate reference implementation, several criteria need to be evaluated:

- The project will need to be global in scope, with measures that are broadly accepted by the international clinical community
- There will need to be opportunities for rapid uptake by provider organizations in order to test and verify the functionality of the data model and to integrate it into existing informatics systems
- A neutral third-party organization will be needed to facilitate multistakeholder collaboration and support the open publication and documentation of the resulting code.

Given these criteria, a strong candidate for the reference implementation is one or more of the ICHOM health-outcome standard sets. These standard sets have been defined by global teams of leading doctors, outcomes researchers and patient advocates, and are in use at hundreds of healthcare providers around the world. What's more, in October 2017, ICHOM, in collaboration with ICON, a global provider of outsourced drug-development services, launched the world's first global patient-outcomes benchmarking platform; this platform would be an ideal testing environment for the functionality of the data model.<sup>26</sup> ICHOM is also partnering with key international organizations such as the OECD to encourage standardization and international comparability of the resulting data. Finally, ICHOM provides an institutional mechanism for open publication of the code and supporting documentation, from which other organizations can freely adopt and adapt the data model for their own uses.

Additionally in 2018, we will identify key collaboration partners for the three other work streams described above, as well as defining the governance model, the resourcing and financing requirements, and the activities and milestones for implementation. At the same time, we will continue our work with leading stakeholders to further refine and implement our value-based informatics framework.

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