Shaping the health data future – the DayOne Scenarios

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**Foreword**

**Exploring a new way of solving the health data ecosystem challenge**

In both Switzerland and around the world, our health systems face a unique challenge: creating a health data ecosystem that serves both the needs of citizens and patients as well as the needs of industry and innovation. In response to this, the DayOne Health Data Project comprises a unique endeavor to identify the building blocks for a health data ecosystem that achieves this goal.

Presently, data is scattered in heterogeneous silos or caught in proprietary systems and platforms. As a result, our ability to serve the needs of patients is hindered by a lack of interoperability, cooperation and common understanding when it comes to health data. This is holding us back from the patient-centered, and value-based health systems of the future that will allow for the optimization of outcomes which matter most to patients. The need for this in Europe is particularly strong where the cost of healthcare is increasing from chronic conditions and aging against a backdrop of a fractured data and regulatory environment.

In response to this challenge, DayOne is pleased to present this publication which has been created thanks to the enthusiasm and dedication of the more than 50 experts. These experts have jointly contributed to creating the Future Scenarios presented here which are designed to advance our understanding in this field. We were pleased to convene a group with a huge appetite to explore a new way of solving the health data ecosystem challenge.

This task has been conducted by the DayOne Health Data Scenario Project: by creating 4 clusters of overall 10 scenarios where we propose a map Map of the Future that will help us navigate the trajectory towards a prosperous health data future. Furthermore the DayOne Health Data Scenarios may not only guide the industry’s health data ecosystem, but also support each stakeholder to challenge and possibly define new strategies moving forward. This publication also contains some insights from different ecosystem partners whom we have invited to share their view on the health data future. We would like to thank all the authors for their great articles.

The DayOne Health Data Scenarios wouldn’t exist without the engagement of all the contributors mentioned on page 2. Their insights and knowledge were instrumental in shaping the content of this publication. It has been a unique collaborative effort, made possible by the intellectual and methodological guidance of ScMI and Blauen Solutions. This has been a rewarding journey which we are happy to continue, hoping to make a distinct contribution to a broader movement taking place, especially in Europe and other parts of the world, to build the future health data ecosystem that serves both citizens’ needs and the need for innovation in healthcare.
### Table of Content

5  Data will drive healthcare innovation – in which direction?
10 Three essential questions on how to deal with the DayOne Health Data Scenarios
   An Introduction to the DayOne Health Data Scenarios,
   by Thomas Brenzikofer, Basel Area Business & Innovation;
   Alexander Fink, Sarah Ohse, ScMI; Beat Meyer, Blauen Solutions

11 Better data, better healthcare – but how do we get there from here?
   An opinion piece by Randall McGuire, Novartis

12 Who will become the data custodian of choice?
   An opinion piece by Nishant Sinha, Deloitte Switzerland

15 Scenario Cluster 1abc: Government takes over, incumbents remain in the driver’s seat
16 Scenario 1a: Traditional healthcare system – moderate growth
17 Scenario 1b: Resurgence of nationalism – protectionist mindset
18 Scenario 1c: Global authorities – health data as public good

19 Scenario Cluster 2ab: Consumerization of healthcare drives innovation in a buyer’s market
20 Scenario 2a: Patients in control – new business models arise
21 Scenario 2b: Low tech, high literacy – prevention is a business

22 Scenario Cluster 3abc: Cultural change boosts disruptive innovation through democratization of tech
23 Scenario 3a: Reinventing healthcare – in a data-driven one-world framework
24 Scenario 3b: Free market meets regulation – the one-level playing field
25 Scenario 3c: Highly interconnected – in a fragmented market

26 Scenario Cluster 4ab: Big tech is ruling the world, creating an innovation-driven seller’s market
27 Scenario 4a: A completely new vendor landscape – in a corporate-driven healthcare world
28 Scenario 4b: Healthtech drives innovation – empowering established structures
   Scenario descriptions by Thomas Brenzikofer, Alexander Fink, Sarah Ohse, Beat Meyer

29 Health data ecosystems of the future need trust and citizen inclusion
   An opinion piece by Stefano Napolitano and Dominik Steiger, MIDATA Cooperative

31 To remain world leader in innovation, Switzerland needs to steer health data governance
   An opinion piece by Moritz Fegert and Isabel Knobel, foraus

33 A first scenario assessment makes a strong call for change and need for action
   Conclusions by Thomas Brenzikofer, Alexander Fink, Sarah Ohse, Beat Meyer

36 “Data helps us to make better medicines for patients”
   Interview with Greg L. Hersch, Novartis
Data will drive healthcare innovation – in which direction?

In the course of the DayOne Health Data Project 2020, over 50 experts from different stakeholders have worked together to define 10 scenarios that will shape the future health data ecosystem. What do these scenarios mean and how will they impact citizens, patients, healthcare providers, governments, science and business?

The invention of the microscope opened up a whole new world to the natural sciences and laid the foundations for modern medicine. 400 years later, we are facing a similar quantum leap. Thanks to digitization, more and more health data (or data that can be related to health) is being generated, not only in the clinic, but also by all sorts of medical and consumer devices such as mobile phones, wearables as well as embedded or even implanted sensors.

Information technology has developed in step with this rapid growth of health data: from decentralized storage systems and architectures, to powerful analytic tools and the rise of machine learning. The hype around artificial intelligence, or more profane: data science, is big and so are the expectations. There is hardly a medical challenge for which solution is not sought to be digital.

A reality check, however, forces one to take a more sober view of things. Despite millions of little digital helpers to be found in the app stores, the big and disruptive breakthrough is still pending. Not that the methods of data science failed per se. Rather, did the magic fail to materialize due to lack of raw material: data. Although the mountain of health data is now growing in zetabytes from year to year, this resource can only be accessed to a limited extent and made arable.

There are many reasons for this. On the one hand, data is an asset whose value grows exponentially through aggregation. Accordingly, data is stored as a valuable commodity behind firewalls in silos, with the prospect of being monetized as profitably as possible. On the other hand, the information obtained from the data can potentially lead to misuse, which calls for the state to act as regulator.

Ultimately, the question is who has, if at all, the legitimate claim to dispose of the data monopoly? Can the answer be left to market forces? Or should government step in? And if so, what is the right policy? As an acting authority or by creating a regulatory framework that would allow for a democratization and decentralization of the said data monopoly? And how would such a world look and what would it mean for citizens, patients, healthcare providers, innovators, science, governments and business?

In order to be able to give qualified answers to these questions, one must first understand the implications of the health data future, first for the healthcare ecosystem as a whole and then in regard to the different stakeholders. This is only to be explored in a sandbox, considering and weighing up possible scenarios.

It is exactly with this intention, that Basel Area Business & Innovation started the DayOne Health Data Scenario Project in 2020. Together with the project partners ScMI AG and BlauenSolution, we have set up a collaborative process, in which over 50 experts have participated. In a series of workshop sessions the future projections of a total of 20 influencing factors were examined, which led to the definition of 10 scenarios in a comprehensive map of the future.

Thomas Brenzikofer is co-founder of the DayOne Initiative and manages its events as curator and moderator.

Alexander Fink is founder and CEO of ScMI Scenario Management International AG and author of several books on the topic.

Sarah Ohse joined ScMI AG in 2018 after finishing her Master in Business Administration and studying Innovation Management.

Beat Meyer is Founder and Managing Director at Blauen Solutions, a niche Strategic Intelligence Consultancy in the Basel Area.
The scenarios can be clustered into four groups according to two main differentiating features:

- **Technology, Core Dimension 1**: A second – vertical – dividing line can be drawn in respect to expectations on the achievements of digitization: will technology be able to deliver on promise and induce disruption or will it only bring incremental change?

- **Culture, Core Dimension 2**: A first – horizontal – dividing line concerns questions around cultural change: Will the citizen be increasingly willing to participate actively in their health and well-being? Or will they continue to linger in a more passive role, as a mere recipient of care services?

Depending on how the above questions are assessed, the combination of the answers results in four groups:

1) **Stagnation**: digitization does not have a disruptive effect – citizens do not change their behaviour and remain in a mostly passive role

2) **Consumerization**: citizens change their behavior and seek an active role – digitization does not have a disruptive effect

3) **Democratization**: digitization has a disruptive effect – citizens change behavior and seek an active role

4) **Corporatization**: digitization has a disruptive effect – citizens do not change behavior and remain in a mostly passive role
Core dimension 1:
Technological change

A Low level of technology-driven change in healthcare
• Moderate degree of readiness of AI in the healthcare system
• Low personalization of drugs and curative medicine
• Low level of technology-driven change in healthcare services and processes
• Low scope of the data value chain (broadness)

B High level of technology-driven change in healthcare
• High degree of readiness of AI in the healthcare system
• High personalization of drugs and curative medicine
• High level of technology-driven change in healthcare services and processes
• High scope of the data value chain (broadness)

Core dimension 2:
Cultural change

A Traditional culture of healthcare with citizens/patients less in charge of their own health
• Low degree of openness of platforms
• Low degree of openness in the research system
• Low degree of non-professional healthcare (community health workers) + self care
• Low level of culture/process-driven change in healthcare services and processes

B Culture- and process-driven change in healthcare with citizens/patients wanting to be fully in charge of their own health
• High degree of openness of platforms
• High degree of openness in the research system (open science)
• High degree of non-professional healthcare (community health workers) + self care
• High level of culture/process-driven change in healthcare services and processes

Core dimension 3:
Stakeholder

A Strong trust in traditional healthcare provider – new players and stakeholders will not emerge
• Very focused use of genetics and biotechnology
• Low personalization of prevention, early disease detection and monitoring
• Low relevance of non-medical (but health-related) interventions
• Low diversity, no integration of new players from outside of the healthcare system

B Structural change in the healthcare landscape – new stakeholders and players emerge
• Use of genetics and bio technology is becoming a commodity
• High level of personalization in prevention, early disease detection and monitoring
• High relevance of non-medical (but health-related) interventions
• High diversity, integration of new players from outside of the healthcare system

Core dimension 4:
Regulation

A Public-driven system with global regulatory framework leads to high trust in health data
• More multilateral geopolitical power structure
• High data accessibility for citizens
• High trust in health data
• Increasing legal execution of health data privacy
• High regulation of Big Tech
• Moderate monetization of data
• High degree of citizen ownership of health data

B Low degree of global regulatory framework leads to a corporate-driven healthcare system with a high degree of monetization of health data
• Rather fragmented geopolitical power structure
• Low data accessibility for citizens
• Low trust in health data
• Low regulation of Big Tech
• Moderate legal execution of data privacy
• High monetization of data
• Corporate ownership of health data

* = scenario 3b ** = partly scenario 3b
A further division of the scenario groups originates from two additional differentiating features that have proven to be significant:

- **Stakeholder, Core dimension 3**: will new players emerge – or will the traditional providers continue to dominate?
- **Regulation, Core dimension 4**: will we move toward a global harmonization or will we continue to face a fragmented environment?

Again we can define 4 further quadrants:
1) Traditional stakeholders in a weak regulatory and therefore corporate-driven environment
2) Traditional stakeholders in a strongly regulative and therefore ecosystem-driven environment
3) New stakeholders in a strongly regulative and therefore ecosystem-driven environment
4) New stakeholders in a weak regulatory and therefore corporate-driven environment

If we now put these eight quadrants on top of each other, we get the following topography of the map of the future:

**Scenario cluster 1**:

**Government drives innovation (if at all) in a flat market.**

Governmental authorities remain strong or take over. Neither technical disruptions nor changed consumer behavior are driving the market, which is flattening out. Investments are primarily made by the public sector. Regulation overall remains rather weak thus perpetuating the status quo (1a), will increasingly follow national interests (1b), or possibly take on an increasingly global perspective (1c).

In contrast to this we find:

**Scenario Cluster 3**:

**Democratization of tech and data access drive innovation creating an open, ecosystem-oriented market.**

Technological development has a disruptive effect. The citizen seeks to play an active role. Rising public interest leads governments to intervene strongly in the market through regulation. Either with the aim to set global standards facilitating the creation of new and open innovative structures (3a), or to avoid monopolies and facilitate access for new players creating an open market (3b). If regulation remains weak we will still witness a highly cooperative environment in which incumbents and new players will have to follow an ecosystem approach in order to succeed (3c).
Scenario Cluster 2: Consumer behavior drives innovation creating a buyer market.

Technical development has only an incremental effect. Innovation is primarily process-oriented. In return, consumer behavior is changing, with patients and citizens seeking an active role. Rising public interest leads governments to intervene strongly in the market through regulation. Either citizens generally trust their existing providers (2a) or they are open to new players (2b) providing integrated healthcare services.

In contrast to this:

Scenario Cluster 4: Capital and incumbents drive tech-focused innovation creating a vendor market.

Technological development has a disruptive effect. There is no change in consumer behavior. Digitization is largely left to market forces, governments hardly intervene with new regulations. Big tech or healthtech providers will gain the trust of the citizen offering a new breed of health services (4a) or they will continue to boost innovation in the background, as technology providers for the incumbent organizations, which though will become increasingly dependent on them (4b).

The quintessence of the map of the future lies in correlating the 10 scenarios to the key influence factor “health data”, for which six core dimensions are to be considered:

1. Are citizens able to execute on the ownership of their health data?
2. Is the health data infrastructure proprietary and closed or open?
3. How trustworthy is the health data?
4. Is there a strong incentive to monetize on health data as an asset?
5. Who will be able to access health data, a broad range of actors or only closed user groups?
6. Are there standards in place that will facilitate the interoperability of health data?

Given the answers to these questions as of today it becomes clear that the full exploitation of potential change would entail a significant call for action, which would either be advanced (clockwise) through rather tough governmental intervention and regulation, or (counterclockwise) they would develop through market forces through the growing need for ecosystem collaboration. The way to go will probably be somewhere in the middle.
Three essential questions on how to deal with the DayOne Health Data Scenarios

The DayOne Health Data Scenarios are the result of a complex bottom-up approach led by the specialized consultancy ScMI. More than 50 experts contributed to this unique process of three sessions over 18 hours of workshops, building a strong foundation for further use.

Why Scenarios?
Thinking in terms of scenarios is an effective way of assessing future development in complex situations. In contrast to mere trend analyses, which project a single tendency into the future, albeit a dominant one, scenarios depict plausible futures which are as different as possible so that they represent the whole window of opportunities – and risks. And while forecasts are mostly made on the basis of historical data, scenarios gain meaningfulness because their development results from the compilation of the assessments of various stakeholders.

How to develop scenarios
The development of the present scenarios is based on the ScMI method. In a first step, the scenario field is analyzed. This includes identifying the most important drivers and influencing factors. The key factors are then determined on the basis of an analysis of the interdependence between the influencing factors. A set of 4–5 alternative future projections is developed for each of these key influencing factors, which allows the creation of a first draft of different scenarios. These are then refined into the Map of the Future.

What do the scenarios tell us?
It is not to be expected that one of the present scenarios will occur exactly as described. Rather, scenarios are thinking tools. On the one hand, they define the framework within which a topic can develop and thus allow the individual actors to align their strategy appropriately. On the other hand – and this is the active variant – the actors can also consider whether and how the future development can be influenced in a desired direction. The latter is all the more effective if it is possible to promote corresponding activities as an ecosystem effort.

There are three main questions that help the reader navigate through the following description of the DayOne Health Data Scenarios:
– First: How likely is it that this scenario will occur?
– Second: Will the change induced by the scenario have a positive or negative impact – overall and for a given stakeholder?
– Third: What options do individual stakeholders or stakeholder groups have to achieve the occurrence or non-occurrence of a scenario?
Better data, better healthcare – but how do we get there from here?

The digital revolution is poised to leave in its wake a better world. But the “digitized” airplane lacks fuel to fly: data has to be made accessible across silos for the benefit of patients. For this to happen will require a clear vision and political will.

Randall McGuire, Economist, Swiss Public and Economic Affairs, Novartis International AG

Today we stand before a digital revolution. Many aspects of our lives are about to change. The pandemic has given us a glimpse into this new future. Within weeks of the coronavirus outbreak, working in prestigious office towers designed to spur networking and innovation was replaced by much of the population working from home and interacting online.

This experiment had mostly proved that we are just as creative and effective when working from home. The pharma industry overall has rallied to deliver effective vaccines against the novel virus in record time. This was only made possible by massive increases in computing power and advancements in technology over the last years.

Soon we will also see artificial intelligence taking over many of the routine tasks that burden us now. This revolution will leave in its wake a better world and, in healthcare, better and more cost-effective therapeutic outcomes. The pressing question is how do we get there from here?

What prevents Switzerland from having best-in-class healthcare today? Some would argue: data, data, data. It is as if we developed the fastest airplane, but forgot the fuel. Disappointingly, patient care today is very fragmented with little integration among providers. Patient records are often kept in practitioner silos with little collegial exchange. The truth is the left hand is often unaware of what the right hand is doing. Ad hoc collection of data exists, but there is no centralized overall health data strategy. There is little comparison of patient quality and cost-of-care data or tracking of patient outcomes systematically over time. All of which is crucial if we want to identify areas of improvement. Consequently, Switzerland ranks low in comparison with other countries.

Luckily, we need not look far for examples of what we can do better. Top nations in digital healthcare have implemented a number of effective measures that include well-rounded political visions, comprehensive and strategic data-use strategies, systematic and centrally coordinated data ecosystems, integrated care programs and incentive-based compensation. All aimed at creating more value for patients. Let us look at each of them.

To start, we need a political vision that sets priorities and puts patients first. It must be our goal to ensure that patients get the best possible care at the best cost. No healthcare system can satisfy all patients all the time. The political will is to ensure that the elements of quality, access, and affordability of healthcare are all taken into account.

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needs of all patients all the time, and it is therefore crucial to focus on what matters most and creates the most value.

Next, it is very important to develop a comprehensive data strategy and data ecosystem for secure sharing and use of health data. A data strategy determines which data to collect with which instruments and how to make them available to stakeholders in the healthcare system without compromising data privacy but with optimal interoperability.

With an established strategy, stakeholders can systematically record health data electronically and enter it into a data ecosystem that can then be used for analysis to improve quality of care, patient outcomes and efficiency. Finland, for example, has a very well-developed health data ecosystem. Via a central data platform implemented by the public sector, all relevant stakeholders have access to electronic disease registers, e-prescriptions and electronic laboratory and imaging data. High compatibility of its databases allows for centralized data collection and analysis. To protect data privacy, health outcome and cost data are recorded anonymously. Decentralized data storage adds another layer of security. While the Swiss system is more fragmented than Finland’s, a certain level of centralization seems compelling here too, requiring broad commitment from a range of stakeholders.

Integrated care and value-based compensation provide additional thrust for higher-quality care at lower cost. Research institutes find that, when all providers have real-time access to electronic patient records, errors in treatment and duplication of service decline. Redesigning provider reimbursement away from fee for service or lump sum models in favor of models that pay for coordinated services that depend on real patient outcomes creates real incentives for providers to work together and improve care at lower cost. For more than a decade, France, Sweden and the UK have had good experience using models such as pay for performance, outcome-based pricing and bundled payments for coordinated treatment to incentivize providers, with positive results for both patients and physicians.

Moreover, interoperability of and access to health data spurs increased innovation, leading to better patient options. It is critical to remember that Switzerland does not exist in isolation and that the world of R&D is highly intertwined. We must not miss out when Europe develops a single health data space, and we must maintain Switzerland’s position as a world-leading innovation hub. It is pertinent that healthcare is part of this digital revolution.

Finally, value-based solutions and creative payment models are needed now more than ever for compensating drug and medical device makers for their life-saving and life-altering innovations. New cell and gene therapies that cure rather than just treat disease are already on the market and many more are on deck. Our goal must be to design proper incentives and suited payment models that maximize the ability of makers of such innovations to continue to bend the curve of life and rid humanity of all its devastating ailments.

Needed: An overall data strategy that determines which data to collect with which instruments and how to make them available to stakeholders in the healthcare ecosystem without compromising data privacy but with optimal interoperability.
Who will become the data custodian of choice?

While the focus in the last few years has been on how to store data at scale, the future will depend on how we identify those “nuggets” of quality health data that can help drive value and enhance the customer experience. Organizations will have to change their mindset: not data ownership but data custodianship will be key.

*Nishant Sinha, Deloitte Switzerland*

Nothing is more important than our health. All of us interact with the healthcare system to varying degrees, and we will continue to interact with it throughout our lives. For most of us the interaction with healthcare is limited to interaction with our family GP and at times with local specialists.

Our interactions generate contextual information about us. Our current expectations of the healthcare system have been formed over years based on the idea that the healthcare professionals have the full and complete picture of our health every time and each action is perfectly efficient.

However, those assumptions are somewhat wide of the mark for a variety of reasons including changes in living conditions. The gaps in the healthcare systems become even more obvious in the case of a global pandemic – as we have seen over the last 12 months with Covid-19.

Technology is helping bridge some of the gaps in healthcare but not at the pace one would like. It’s also challenging long held beliefs that are difficult to change. For example, during the first wave of the coronavirus outbreak, multiple contact tracing apps were introduced to identify population at risk. These apps were supposed to be efficient provided a large segment of the population used it. However, the apps failed to attain the expected level of usage and success.

A lot of the resistance to these apps came from concerns over the data they generated and the storage and usage of the data – questions that were not in the common discussion domain before the apps were developed: questions and guarantees around ownership, usage and storage of data and enough safeguards around possible misuse.

Similarly, many people were caught unawares in situations far away from their normal residence. The luxury of having a physician who helped us quickly recover from a normal known illness was increasingly at risk. And so was the access to our data related to health that was generally not “anywhere” accessible.

This experience with gaps around efficiency and efficacy of an individual’s data for proactive healthcare, is leading to broader and active discussion around future health data ecosystems and how technology could lead us to a “surer” future. While technology and data are not the only lever for changing the future, they
Health Data Scenarios are increasingly being seen as key factors driving the change, apart from patients and users demanding a “changed experience”.

Healthcare has been undergoing gradual disruption over the last few years. While the underlying disruption and convergence themes have not changed, the emergence and subsequent response from the healthcare and government agencies to Covid-19 has hastened changes in the last year that were expected to modify the landscape gradually over 4 to 5 years.

Based on emerging technology, there is reasonable certainty that digital transformation will continue to drive much of this change. There has been increasing convergence between life sciences, healthcare and technology leading to innovative digital health solutions. Newer healthtech firms are coming into market with sophisticated and customized digital solutions for individuals and corporates alike.

Healthcare is increasingly becoming more organized around the consumer rather than around the institutions that drive our existing healthcare system – focussing on the value rather than the volume-based incentive. Consumers/patients are beginning to take direct ownership of their health, making them more conscious of the choices that need to be made.

Digital transformation and convergence is manifesting in multiple ways for healthcare. Our expectations and interactions with the online world of apps, search engines and shopping portals have converged to meet the requirements, need and continuous support required for healthcare.

Healthcare is itself shifting from reactive to proactive and predictive – no longer is there a “one size fits all” approach but rather a personalized and uniquely tailored approach for each of us. While these changes are still localized, advances in digital transformation will healthcare in the future to be provided at similar level across regions, countries and continent with ease.

Data ecosystems of future healthcare will be enabled by radically interoperable data, artificial intelligence (AI), and open, secure platforms. Partnerships and data exchanges will emerge to achieve better patient understanding and drive focussed outcome through large-scale analytics. The ability to provide a customized experience and unique offering to each patient and at scale will require organizations to collaborate and leverage data at scale. By 2040 (and perhaps some time before then), streams of health data – together with data from a variety of other relevant sources – will merge to create a multifaceted and highly personalized picture of every consumer’s well-being.

Today, wearable devices that track our steps, sleep patterns, and even heart rate have been integrated into our lives in ways we couldn’t have imagined just a few years ago. It’s expected that this trend around data aggregation and consolidation will further accelerate. The next generation of sensors, for example, will move us from wearable devices to invisible, always-on sensors that are embedded in the devices that surround us.

The future of healthcare data will focus on organizations acting as “data custodians” rather than “data owners” for the patients/consumers. The ultimate ownership of the data and its usage will rest with the patient. The sharing of the data will be driven by the value provided to the user by the provider.

Consumers – armed with this highly detailed personal information about their own health will demand that their health information be secure and portable. Consumers have grown accustomed to transformations that have occurred in other sectors, such as e-commerce and mobility. These consumers will demand that health follow the same path and become an integrated part of their lives. Organizations will have to enhance their analytics and data infrastructure to allow for bi-directional data exchange flows at scale.

While a lot of focus in last few years has been on how to store data at scale, the future of healthcare data will focus on identifying those “nuggets” of quality data that can help drive value and enhance the customer experience. Organizations will increasingly focus on enhancing their analytic infrastructure that allows for consumer health data to be held in an open, secure, accessible, transparent and contextualized environment as a “custodian”. It’s safe to assume that successful organizations of the future will be able to work with the patients/consumers in helping them derive value from their data across the touchpoints thus making them the custodian of choice.

As consumers/patients have taken higher ownership of their health, the focus for organizations will increasingly shift from managing volume to providing value thus transforming the way we think about the health data ecosystem.
Scenario Cluster 1abc

**Government takes over, incumbents remain in the driver’s seat**

In the absence of technological and cultural changes, it is only to be expected that healthcare will develop in an evolutionary way. Governments will drive innovation (if at all) in a flat market dominated by a few players. Due to the lack of incentives, health data remains siloed.

The overarching principle in this virtually driverless first group of scenarios is that nothing disruptive happens. Technology will not be able to deliver on its promise. Digitization of health will enter the famous valley of disillusionment, and progress in data sciences will only be gradual and not lead to disruptive change. Innovation will therefore be – at best – incremental in nature.

Also when it comes to people’s behavior and cultural change, stagnation is the new normal: citizens have no wish to play an active role in dealing with their health, so the expectation is that they are fine with the authorities exerting full control.

The overall economic outlook in this group of scenarios is quite grim, leading to a flat market. The lack of dynamics prompts investors increasingly to pull out, leaving very little, if any, space for new players to enter the field. Market incumbents, despite facing reduced competition, will have to deal with growing pressure on their margins as authorities gain increasing power.

There is one crucial indicator in this scenario: regulation. Considering scenario 1a as pretty much the status quo, there are two directions in which to go. Global authorities gain traction and the leading nations work together towards a harmonized regulatory framework pointing to scenario 1c. If this is not the case and the political trend towards increasing nationalistic tendencies becomes entrenched, authoritarian governments will intervene more strongly making markets more fragmented and harder to operate in on a global scale.

In contrast, and possibly driven by global challenges, such as pandemics and climate change, the need for worldwide collaboration will grow, encouraging supra-governmental bodies to take the regulatory lead. This will favor the development of more open, competitive markets allowing mostly big players to leverage their services and drive consolidation.

When it comes to the health data ecosystem, there will be little change in the current status: data, although valuable (mainly for the authorities and incumbent players), will continue to reside in the existing silos, with very little need for interoperability. Ownership by the citizen is simply not or – as in authoritarian regimes – cannot be an option. Moving to scenario 1c, however, data will be increasingly perceived as a public and trusted good, as it is regulated globally, making its monetization more difficult.
Scenario 1a: Traditional healthcare system – moderate growth

Everything remains as it was:
- A low level of innovation preserves traditional structures and players in healthcare processes
- In a treatment-based healthcare market, a low degree of regulation leads to a corporate-driven system with a lack of trust in highly monetized health data
- The rare areas where data-driven healthcare innovation is implemented are controlled by a few companies in narrow value chains

Global disintegration over the coming years up to 2035 continues to inhibit the creation of a worldwide regulatory framework. Data cannot be used in an efficient way to drive innovation in healthcare systems. This is mostly felt in research and by healthtech start-ups, limiting their access to the large amounts of data needed to achieve scientific validation. On the other hand, big tech can exploit its power and keep its systems closed. In addition, the overall low degree and fragmented nature of regulation will raise the barrier to new business entries, protecting the existing players in the markets in accordance with the global power blocs.

Healthcare processes will experience a relatively low degree of innovation, keeping the traditional structures and players in place. A stagnating cultural dynamic does not provide any input for change. Citizens (patients) continue to delegate responsibility for their health to the care organizations they are familiar with. Healthcare largely remains a volume- and treatment-based market focused on medical interventions. Prevention in the form of continuous health monitoring and personalized medicine will only play a marginal role. Even though breakthrough innovations in the field of genetics and biotechnology might arise, their implementation will be limited to the traditional healthcare system.

Health data does not play a significant role. A low degree of global regulatory frameworks leads to a corporate-driven system with mistrust of highly monetized health data. The few areas where data-driven healthcare innovation is being implemented are largely controlled by a few companies in narrow value chains. This leads not only to limited trustworthiness but also to a fragmented data structure, defeating any opportunity to grasp the bigger picture. In these traditional structures, citizens do not seek control over their data.
Scenario 1b: Resurgence of nationalism – protectionist mindset

Back to the future:
- Protectionism leads to drastic de-globalization, including in research and development
- National players shape healthcare, which leads to huge differences between countries
- Traditional systems and actors remain in charge, while citizens hardly seek to be in charge of their own health
- Healthcare innovation is incremental and occurs only at the national level as a result of protectionism
- Data is mainly powered, owned and evaluated by national authorities

Protectionism has stopped globalization by 2035, leading to a stagnant economic environment shaped by separated power blocs. Overall, the degree of multilateral collaboration is low, and binding legal or technological frameworks cannot evolve. Big-tech companies are able to use their power in order to keep their systems closed, although national decision-makers are able to ban them from their regional economy. Research takes place in closed national systems with limited applicability. The decreasing economic dynamic causes private investment volumes to decline. Depending mostly on government spending, the research environment and technological advances differ fundamentally from one region to another. Market entry barriers can be very high, depending on the region, making it impossible to scale business models and protecting mainly the big national players.

Healthcare systems are not only fragmented but mostly unable to embrace new approaches. Innovation is becoming more and more unprofitable and cannot be scaled. In line with the high costs of technological innovation, the healthcare sector is still shaped by traditional players, services and processes following a treatment-based approach. Therefore, personalized medicine and advanced diagnostic procedures do not play a significant role.

Health data is owned by national companies, which are able to profit from moderate transparency and thus monetize data in narrow value chains. As citizens do not care about being in charge of their health, they are not keen to own their data and view traditional actors, who work closely with governments, as their gatekeeper. The players are strongly incentivized to act in the national interest. While legal involvement is moderate, data is fragmented. The health data is only standardized – if at all – on the national level and lacks trustworthiness.
Scenario 1c: Global authorities – health data as public good

In a collaborative regulatory effort, governments shape a global health market:
• Political authorities become more active and engaged in healthcare processes
• This serves to bolster trust, but also inhibits advances and innovations
• Since data is viewed as a public good, value chains are organized by the state and only involve a few players

A stagnant or even recessive economy shapes the world in 2035. Hopes pinned on innovation are lost in many fields. Technologies such as AI remain largely theoretical concepts and are only partially put into practice. Multilateral power structures lead to a harmonization of legal frameworks, which consequently force big-tech companies to comply and give up some of their business areas – the companies in question have to split and lose some of their market power. Governments are more active and set frameworks for corporations, even serving intermediaries in some cases. Research takes place in closed systems and does not lead to significant new practical insights, while being rather unprofitable and attracting little investment from only a few key players.

The healthcare sector continues to offer traditional services following standard processes. In line with the low levels of technological and cultural change, innovation is mostly incremental. Players are only able to bring new treatments and services if they are implemented as a continuation of the given system, which is treatment- and volume-based. The personalization of medicine and new diagnostic procedures as well as value-based approaches will not happen. There is a low level of non-medical, preventive interventions.

Data is viewed as a public, national good, the use of which is highly regulated and oriented towards a common purpose, leaving little space for monetization. Although citizens have guaranteed access to their data, they do not participate actively and let the traditional players retain control, governed by political authorities, who have become much more active and engaged in the healthcare sector. Value chains are organized by the state and only involve a few players. The existing data is quite trustworthy, but there is a lack of transparency because only players associated with political authorities gain access.
Scenario Cluster 2ab

**Consumerization of healthcare drives innovation in a buyer’s market**

While technology only progresses gradually, citizens want to assume an active role in managing their health. This behavioral change will lead to process and business model innovation, potentially adding new players to a changing healthcare landscape.

The main characteristic in this scenario is the fact that technology is unable to deliver on the promise while citizens’ behavior changes radically: they want to be fully in charge of their health. As the big hopes in data science and artificial intelligence fail to materialize, it is not technological progress that will revolutionize medicine, but consumerization.

The overall economic environment is stagnant. The lack of technological progress will lead to a decrease in private investments in the healthcare ecosystem. Nevertheless, the market approach to healthcare prevails as governments focus mainly on their regulatory role. The political climate is quite friendly and collaborative, leading to worldwide harmonization of regulation.

This trend is strongly supported by the overall trend of consumerization driving healthcare innovation: firstly, the healthcare business model will have to embrace outcome and value-based concepts; secondly there will be a clear need to implement integrated care models around citizens’ needs; and thirdly, smart preventive services will need to be offered.

Whether the stakeholder landscape changes or not is the one crucial question dividing this scenario group into scenario 2a and 2b. In the former the incumbent providers are expected to be able to adapt to new customer demands. In the latter the healthcare market will be disrupted by the emergence of new players.

Consumerization will turn healthcare into a buyers’ market. In order to match the changing customer behavior, there will be a push towards a more liberal market order and deregulation. The downside is to be seen in the breakdown of the solidarity principle in the healthcare ecosystem, leaving an ever greater disparity between the health-literate and health-illiterate population, which will reflect inequality not only in income but also in health behavior and natural disposition.

As regards the health data ecosystem, it comes as no surprise that this scenario group is mainly enabled by one characteristic: The patient-centered use of data. Citizens being fully in control of their own health data will organically lead to more trust and open, participatory infrastructures. On the other hand, economic stagnation will stimulate consolidation among providers which, although operating in a liberal market, will have little incentive to go beyond proprietary data standards, hence restricting the health data value chain to only a few players.
Scenario 2a: Patients in control – new business models arise

Citizens assume responsibility for their health:
• While technological innovation lags behind, change is driven forward by a progressive culture
• With citizens and their needs taking center-stage, the healthcare system will have to adapt
• Health data is regulated to enable patient-centered usage, offering open accessibility but limited monetization opportunities

The lack of scientific advances does not stimulate innovation. The hype around artificial intelligence does not pay off. This delusion is matched by overall stagnant economic development, causing investment in healthcare to decline. In stark contrast to the dehyping of tech, a progressive cultural change arises around citizens’ needs and the wish to assume control over their own health. This development puts pressure on governments to enable a citizen-centered approach in the usage of health data and to engage in multilateral harmonization of laws to limit the power of big tech companies. Only a few healthtech players will be able to overcome the high market barriers, and the incumbent healthcare providers will mostly remain in place.

Healthcare providers will have to adapt to progressive cultural change. As citizens want to take charge of their health, they also want to be in the driving seat when it comes to deciding what serves them best when they are far more directly involved in terms of not only responsibility but also costs. Due to the marketization and consumerization of health, value-based business models will be on the rise as well as integrated care concepts. While remaining focused on interventional rather than preventive medicine, innovation will be mostly driven by process-specific or commercial developments rather than technological advances. The market will be more liberal, leading to increased health inequality.

Having full control of their data will increasingly become a basic need for citizens so that they can be in charge of their own health. Data will be stored decentrally and collected at individual points on behalf of the citizen or patient, enabling them to consent to the specific use of the data. As data science does not drive innovation and the monetization for health data is low, there is little incentive for new players to enter the market, creating only narrow health data value chains among incumbents and building proprietary standards.
Scenario 2b: Low tech, high literacy – Prevention is a business

Staying healthy is the overarching consumer trend:
- Innovation is consumer driven and focuses on processes, not on technology, regulation is supportive of this trend
- In a stagnant economic environment citizens take control of their health, shifting expenses from interventional to preventive medicine
- This strong cultural change in consumer behaviour disrupts the traditional healthcare landscape, allowing for new players to enter the field

The solid governmental environment drives a high level of global harmonization of regulation, limiting the power of big-tech companies. Overall stagnant economic development and a lagging and fragmented research system lead to technologies such as AI remaining largely theoretical concepts unable to stimulate innovation in the healthcare system. On the other hand, these adverse conditions provide opportunities for small companies focusing on efficiency and cost gains as well as serving the behavioral change of citizens towards consumerization of health.

Healthcare systems will change quite disruptively, driven by one dominant factor: the shift in focus from a treatment- and intervention-based medicine towards a more holistic concept of early detection of health issues and smart preventive measures. Since the incumbent healthcare players will mostly remain in traditional structures, they will not be able to meet the new consumer needs. New providers driving the cultural change by offering a wide range of innovative demand-centered healthcare services will step in, taking an increasing share of the healthcare market that is poised to become far more liberated.

The active patient and citizen becomes increasingly health literate, in doing so, they can rely on trustworthy data governed in favor of their citizen-centered usage. This will also require regulation of the data infrastructure towards open platforms. On the other hand, the lack of data monetization and overall economic incentives will leave the health data highly fragmented in terms of standardization and the broadness of the value chains in which they are used. This may lead to lock-in situations, especially for people with low incomes and opportunities to improve their health literacy, leading to a two-class healthcare system with only one section of the population being able to make full use of their purchasing power.
Scenario Cluster 3abc

Cultural change boosts disruptive innovation through democratization of tech

Fundamental changes in healthcare systems are arising from the conjunction of two main driving forces: culturally, the people’s wish to be in charge of their own healthcare; and technologically, the breakthrough of data science in revolutionizing medicine built on a more or less egalitarian ecosystem.

This scenario group can be seen as the home run, so to speak. All the indicators are in positive territory: the economy is strong, people are willing to drive change and technological innovation in data science is surging. It comes as no surprise that in these scenarios we face a future of healthcare in which hardly a stone will be left unturned. So it takes some imagination to get an idea of what healthcare could look like in 2035 according to the playbook of these three scenarios.

The main difference from scenario clusters 1 and 2 is the potential for health-data-driven technology to change healthcare. This allows for completely new concepts ranging from personalized medicine to next-generation diagnostics and early interventions. Medicine can and will be reimagined, as new and disruptive business models arise that favor value-based approaches, preventive measures and the inclusion of non-medical interventions.

The boost in technology is only one side of the coin. A progressive culture is the other. The fact that people want to be in charge of their own healthcare will put pressure on incumbent players and governments to regulate for change. Therefore, the stakeholder landscape is expected to change allowing for new players to emerge. Whether vertically integrated platforms, open science communities, citizen-driven cooperatives or networked conglomerates, they will share one common denominator: they will need to pursue an ecosystem approach to succeed in this very dynamic market.

The crucial indicator in these three scenarios is the question as to how active a role governments will want or need to play. If they succeed in setting up a globally harmonized regulatory framework that not only standardizes data but also makes it trustworthy, we will find ourselves in scenario 3a. If people only drive the healthcare revolution on a national or regional (EU) level, we will find ourselves in scenario 3b. If governments are reluctant to intervene, we will be faced with scenario 3c.

The correlation between the degree of regulation and the data ecosystem we are looking at in these three scenarios is obvious. Scenarios 3a and 3b only differ with regard to the trustworthiness of data. In terms of building an ecosystem with an open infrastructure that provides for broad value chains by establishing standards, they are largely the same. Data will be owned by citizens, allowing only a low degree of monetization. In contrast, monetization is the big thing in scenario 3c, where infrastructure remains mainly proprietary.
Scenario 3a: Reinventing healthcare – in a data-driven one-world framework

Utopia for real:
- Harmonization of both technological and legal standards provides a growth framework for data-driven healthcare services and business models
- Patient and citizen empowerment will lead to the emergence of new players embracing value-based approaches, including preventive measures and non-medical interventions
- Through strong regulation, governments enable an egalitarian health data ecosystem that is accessible to all stakeholders and controlled by citizens

Global development has taken a positive turn: with multilateral power structures accelerating globalization, an overall positive economic development is established. Innovation is happening, especially in the digital sector. Due to harmonized political aims, the standards for disruptive technologies such as AI are quite high. The global framework favors cooperative structures across silos, organizations, geography and disciplines, especially in research, and has a positive influence on the healthcare systems which are ready to embrace innovation. Since market barriers – with the exception of established regulatory and ethical standards – are low, we will witness the emergence of new players.

Healthcare services and processes have changed dramatically. Not only has the emergence of new technologies led to several new treatments based on enhanced diagnostic and monitoring tools. Citizens are also changing their attitudes and are actively engaged in the process and becoming increasingly health literate. Value-based approaches will be the new de facto standard of healthcare, which will be personalized and not only treatment-based but also have a strong focus on prevention. This will open up the field for new services offered by diverse providers.

The emergence of a strongly public-driven and regulated data ecosystem ensures the creation of a very broad and inclusive value chain, where trusted and standardized data can be shared and integrated around the needs of citizens or patients. Data ownership lies with the originator of the data. Non-proprietary and dedicated data platform providers will come to function as intermediaries and offer citizens a certain ease of health data management, ensuring the free flow of data between stakeholders while citizens remain in control.

Map of the Future

- Low level of technology-driven change in healthcare
- High level of technology-driven change in healthcare
- Traditional culture of healthcare system
- Culture- and process-driven change in healthcare services

Democratization of Tech and Data access
create innovation
creating ecosystem oriented market

Health data

- Citizen ownership of data (Ow)
- Open infrastructure (Inf)
- High level of trust in data (Tr)
- Strong monetization of data (Mn)
- Broad data value chain (VC)
- High standardization of data (Std)

Map of the Future

- 3a
- 1a
- 2a
- 3b
- 4b
- 1b
- 2b
- 3c
- 4a
- 1c
- 3a
- 1a
- 2a
- 3b
- 4b
- 1b
- 3c
- 4a

Ow
Inf
Tr
Mn
VC
Std

- does not apply
- applies partially
- applies
- applies

Health Data Scenarios
Scenario 3b: Free market meets regulation – the one-level playing field

Ecosystems around citizens’ needs:
- With data-driven technologies thriving, progressive cultural change embraces innovation while regulation focuses on diminishing big-tech monopolies, lowering market barriers for new players.
- The healthtech sector will focus on citizen or patient-centricity, building efficient ecosystems around their needs. New business models arise around value-based healthcare, prevention and non-medical intervention.
- Health data, owned by the originator of the data, will be freely exchanged through open platforms, which will only be partially regulated on a global scale, making the trustworthiness of data a challenge.

New technological breakthroughs in medicine focusing on data science and profiting from an innovation-friendly climate brings disruptive change to healthcare. Effective regulation, albeit still mostly on a national or regional level, facilitates open markets. Entry barriers are low. Competition is high. New players emerge. Citizens are empowered to take charge of their health. To meet patient demands in this very dynamic business environment, building on collaboration in a predominantly egalitarian ecosystem is key to success, favoring a new breed of decentralized intermediary platforms and accelerating research and development.

Technology will enable a more holistic approach to medicine, inventing not only new, digital and data-driven treatments, but also changing processes and the provider landscape. Ecosystems will be built around patient needs. Value-based and personalized health business models, including non-medical interventions and preventive care, are on the rise, making use of advanced diagnostic tools as well as health monitoring. Traditional players will only be able to adapt if they find ways to collaborate and integrate with the new innovative healthtech providers.

Health data is owned by the individual originators of the data and managed through dedicated platforms that empower citizens to play an active role and take responsibility for their own health. All stakeholders will have consented access to health data if, in return, they provide value through services. This leads to an egalitarian health data ecosystem with open standards and infrastructure providing for a highly diversified value chain. Due to a lack of global harmonization in regulation, trustworthiness in health data will remain an issue.
Scenario 3c: Highly interconnected – in a fragmented market

The new era of data liberalism:
- In a technology-driven and competitive healthcare market, healthtech companies gain importance, but collaboration with incumbent providers is still their main access to market
- Lack of regulation leaves capital and market power to shape the healthcare system, enabling technological innovation in line with the demands of the digitally empowered patient
- Different business and data models coexist. The ownership of health data can be both with the patient and with the provider, who position themselves as custodians of the data, leading to a fragmented system

The economic development overall is positive but unequal. Separate power blocs make it impossible to harmonize regulation. Governments are mostly reluctant to intervene. Collaborative efforts, especially in science and research, nevertheless help to advance innovation. Data-driven technologies, including AI, reach a high level of maturity and are widely implemented in the healthcare system. Faced with low regulation, big tech and healthtech companies become key players. By opening their platforms they can profit best from the collaborative innovation structures. Cooperation through consortia and joint ventures are key to success.

Digital medicine is empowered by both technology and cultural changes. Healthtech companies, along with their medical providers, will be eager to shape their services around citizens wanting to take control of their health. This will lead to a fundamental change in medicine. Treatments become personalized and preventive measures through next-generation diagnostics and health monitoring allow for early intervention and non-medical interventions. The healthcare business model will remain mostly service-oriented and treatment-based and not become value-based.

The health data ecosystem will be mostly shaped by market power. This leads to a heterogeneous and proprietary world, where services and procedures are only integrated if they serve a given purpose. Ownership of health data does not lie fully with the citizen, but providers will have to position themselves as data custodians, since data sharing is needed in order to fulfill customer needs. Nevertheless, healthtech companies will be able to aggregate and monetize the data, although transparency will be required. Infrastructures and systems remain proprietary and therefore fragmented, albeit providing for different industry partners on a common platform.
Scenario Cluster 4ab

Big tech is ruling the world, creating an innovation-driven seller’s market

Technology makes a big leap forward. Healthcare is becoming increasingly data-science-driven. Incumbent providers and regulatory bodies will not be able to keep pace with the accelerating innovation power of the capital-fed healthtech players.

For the incumbents of the traditional healthcare industry this scenario group paints a doomsday – or a strong need to adapt: Disruption will find – or rather buy? – its way into the industry. The perceived and, to some extent, validated potential of innovation through data-driven approaches unleashes strong investment establishing new players, as well as big tech and big pharma with a war chest that enables them to be part of the game.

Neither on a global nor on a national level will governments succeed in sufficiently regulating health data. On the one hand, it is simply not in their interest, because they do not want to inhibit a prosperous business environment. On the other hand, the “power from the people” that is needed to do so will not manifest itself, because there is little cultural change as citizens are mostly satisfied by the healthcare innovation they are being offered.

The lack of cultural change will not force incumbent players to change processes and business models. They will implement new technologies in the given treatment-based structure. Furthermore, they will not be able to play a key role in the development of new, digital-based medical and non-medical interventions due to the lack of investment capital (healthcare providers) or their incapability to embrace a bolder approach to innovation as they are afraid of cannibalizing their own business.

This gives way to big tech companies and an emerging new breed of healthtech players to increase their footprint in the market and eventually take over. The extent of their influence on and in the healthcare industry is exactly the dividing line between the two scenarios of this group. In Scenario 4b, the incumbent players will remain in charge of the patient-facing part of healthcare. While big tech and healthtech companies will be delivering the technological backbone of digital medicine creating new forms of dependency for the healthcare system. In Scenario 4a, we will probably witness the convergence of big tech and big pharma along with new healthtech players, resulting in a completely new breed of providers.

As for the health data ecosystem, there is only little change to the status quo despite all the revolutionary technology. The main innovation will concentrate on the need to open up the value chain so as to bring a variety of contributing partners into the system. Standardization will also have to increase in order to make health data interoperable and harness the value of the data. Otherwise, ownership and infrastructure will remain proprietary and lack transparency, hence diminishing trust in the data.
Scenario 4a: A completely new vendor landscape – in a corporate-driven healthcare world

The Uberization of health:

- The infusion of medical knowledge results in pharma, biotech, big tech and healthtech companies merging to create healthcare conglomerates that dominate the market
- Traditional healthcare structures and providers will remain in place, assuming the role of value-added distributors of the innovation advanced by the health conglomerates
- The health data ecosystem will be owned by the health conglomerates while allowing a diversity of players to take part in their ecosystem

In the corporate healthcare world, resources flow to the areas where the highest profit is expected. Robust economic growth, thriving technological innovation and strong investments by private and corporate capital will lead to a broad portfolio of new digital health services. Citizens will make wide use of them albeit without changing their behavior. They are happy to remain passive beneficiaries. This will enable big tech companies to expand into the field, relying on their proven business model: offering services in return for data. They will strongly buy into the market through mergers and acquisitions, creating a new corporate vendor landscape and disenfranchising the existing ones.

Innovation will still stem from medical know-how. This gives the traditional healthcare provider a strong role, mainly at the interface with patients, although heavily dependent on the corporate innovation backbone of tech. Eventually they will become disrupted altogether and vertically integrated into big corporate healthcare conglomerates. For the citizen, trusting in the regulatory power of their governments and not striving for progressive cultural change, this leads to digitally improved and more cost-effective healthcare services – although at the expense of a strong lock-in situation.

To be part of the digitally revamped healthcare, citizens are forced into sharing their data. The corporate world will mostly take control of health data with low regulatory intervention from governments. “Owning” the health data ecosystem will be the key strategy to market domination and therefore interoperability (standards), integration of a variety of players (open value chains) and strong incentives (monetization) – the key requirements of any given platform. Meanwhile the lack of ownership, transparency and portability on the customer side is offset by the efficiency and cost-effectiveness of the services.
Scenario 4b: Healthtech drives innovation – empowering established structures

Incumbent healthcare players prevail:
- Digital technologies continue to be based on medical know-how. The trust of citizens will remain with incumbent providers
- Healthcare systems will be shaped by traditional structures, but healthtech companies will establish themselves as new stakeholders in the role of empowering innovation
- Citizens will be willing to share their data with healthtech companies through trusted healthcare providers in return for value – be it monetary or in the form of a service

The global economy is growing albeit mostly in traditional structures: The world remains divided into separate power blocs, and regulatory frameworks are designed on a regional level leading to a fragmentation of legal standards, while research takes place in closed silos. But disruptive change is taking place in technology. Data-driven concepts will celebrate their breakthroughs and allow for new services to emerge. These will be carried out by a new breed of healthtech players, which will become established stakeholders in the ecosystem, albeit mostly empowering the same unchanging traditional structures.

Incumbent healthcare stakeholders will remain the gatekeepers for innovation, on the one hand as trusted providers to the citizen and on the other capable of assuming regulatory certainty for the new services offered in the vastly advancing field of digital medicine. Healthcare will remain treatment-based. Even though closely tied to existing players, the healthtech players will gain influence and market power through their proprietary platforms and create new dependencies for healthcare providers, as they will have an empowering influence on the innovative data-driven approaches to medicine.

The legal ownership of data is in corporate hands, monetization is high. Citizens are willing to share their data, as they receive the services they need, despite experiencing lock-in situations. The regulation of health data continues to be moderate, leading to a health data ecosystem which consists of corporate and proprietary platforms and infrastructures, while allowing for a diversity of players to integrate with them. The “ownership” of the health data ecosystem in terms of acquiring the right to its orchestration will become crucial for players to dominate the market. This role will most likely be assumed by big tech.
Health data ecosystems of the future need trust and citizen inclusion

Health data ecosystems face a particularly challenging environment, which makes the value creation process far more complex. There are significant hurdles to overcome regarding the need to regulate, break up silos and ensure interoperability. This requires the inclusion of citizens.

Stefano Napolitano and Dominik Steiger
MIDATA Cooperative, Zurich

Digital health is part of a broad phenomenon of digital transformation that has already profoundly shaped our society, economy and lives by drastically changing the way we interact, communicate or consume services. Compared to other industries, the adoption of digital solutions in the healthcare sector has generally been rather limited, missing opportunities to introduce much needed improvements in terms of efficiency and effectiveness. However, the growing pressure exerted by spiralling healthcare costs has been exacerbated by the Covid-19 crisis. Healthcare seems to have finally broken the resistance to digital and accelerated moves towards a digital transformation, which is generating high hopes and expectations: it is estimated that the global market for digital health will grow to between 500 and 1000 billion dollars by mid-decade.

Digital transformation offers firms unprecedented opportunities to enhance their ability to gather, share, and analyze data. Data has therefore become an economic asset, fuelling AI and data analytics technologies and enabling innovative business models.

The data economy derived from this transformation is characterized by the emergence of data ecosystems that, in contrast to the traditional proprietary “data silos” model, support the interconnection and interoperability of different data systems, enabling the sharing and re-use of data produced by various sources. At the core of such data ecosystems are new forms of partnership and networking between different actors and the existence of data platforms that provide the required technical foundation and data governance.

Health data ecosystems are not different, but they emerge in a particularly challenging environment which makes the value creation process far more complex. While digital health approaches clearly have the potential to address unmet needs in various contexts, such as prevention, early detection, disease management and rehabilitation, there are significant hurdles to overcome to truly unlock the potential:

• Access to health data, such as health records and clinical observations, is highly regulated, with strict rules in terms of privacy and consent, data anonymization and data re-usage.
• Health data is highly fragmented. Obsolete business models and a considerable regulatory burden have encouraged the formation of disconnected data silos, generating major obstacles to data aggregation and data interoperability.

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Health data is highly diverse. It is not just about electronic health records – highly meaningful data come from personal devices and sensors, and from personal environmental and behavioral data.

Strong use cases in digital health therefore need to build upon solutions that allow interoperability and that can deal with personal data in a sustainable way. A crucial component in such solutions is the credible inclusion of citizens, who as patients and data owners can collect, aggregate and exert their right to portability and consent to data re-use.

When looking at the diversity of data sources, from hospital-generated data, down to personal smart devices, data aggregation is easiest at the individual level. Data ecosystems should be designed in a way that generates the right incentives to ensure the involvement and participation of citizens. Such incentives can hardly be of a monetary nature, as the information collected by a single individual does not carry enough information to be considered sufficiently valuable for a direct monetary return – not to speak of the ethical problems in the context of health data. Rather, principles of inclusion, transparency, trust and purposefulness are key elements to encourage such participation. Most importantly, only by creating meaningful use cases is it possible to generate attractive value propositions for the end users, which in turn will fuel overall value creation.

In Switzerland, a solution that embodies the above principles is offered by the MIDATA Cooperative. MIDATA operates a platform for encrypted health data that provides a dynamic consent management system, enabling data owners to retain full control over their own data and autonomously decide how and under what terms data can be further used and accessed.

The adoption of standard frameworks and semantic protocols (such as FHIR, Snomed CT or Loinc) allow MIDATA to easily address interoperability issues, while facilitating the integration of third-party systems in the data platform. While the cooperative and not-for-profit model of MIDATA establishes the foundation for a trust-promoting framework, the value creation for the end user is closely connected with the incentive to take part in projects or initiatives that are relevant to end users. In this way, MIDATA offers a unique model for value creation through use cases, which promotes the active participation of citizens, the collection and aggregation of meaningful data and their consent for further use. The cooperative runs various use cases in health research, healthcare and public health that leverage the capabilities of smart devices and empower citizens and patients. In the “MitrendS” use case concerning multiple sclerosis, it provides an app, a study onboarding process and explicit consent management, with researchers having the possibility to combine novel real-world data and patient-reported outcomes with standard clinical observations in order to identify trends, predict disease trajectories and potentially identify optimal treatment strategies.

In the “Corona Science” use case, a citizen science approach delivers data about Covid-19 symptoms and general well-being. In “Aider les proches aidants”, an integrated support system for family caregivers is being developed. Such use cases are being developed with a broad range of stakeholders in health research, healthcare and public health with the goal to establish the foundations for a growing digital health ecosystem that serves the needs of society and the individual citizen.

MIDATA enables users to gather health-relevant and other personal data from various sources and store it in a secure place. While benefiting from meaningful use cases, users can actively contribute to medical research and clinical studies by granting selective access to their personal data.
To remain world leader in innovation, Switzerland needs to steer health data governance

A new study by the think tank foraus and Sensor Advice argues that Switzerland should position itself at the forefront of health data governance, notably by supporting multilateral efforts, joining the EU health data space and promoting health data literacy and citizens’ inclusion.

Moritz Fegert and Isabel Knobel

The potential of digital technologies for public health could have hardly ever become more apparent than during the current pandemic: from the research into new vaccines, the development of drugs and medical devices to the surveillance of virus outbreaks and management of vaccination data. Digitization is rapidly changing our health systems, and data-based technologies are modifying the way we understand health and how we deal with it. They have the potential to provide more people worldwide with access to affordable health services and can help achieve the United Nations goal of Universal Health Coverage by 2030.

However, on the way to realizing these unprecedented opportunities, there are a number of challenges and risks to be addressed. They all come down to the way health data is being handled. Throughout our national participatory process leading to our recently published study (see information box), we have asked stakeholders and interested citizens in Switzerland: how should the use of health data be regulated nationally and internationally so that everyone can benefit from it? What kind of health data governance is needed? And what is the role Switzerland should play?

Our analysis has made clear that there is a significant need for action in the area of health data governance – and that Switzerland should make it a priority in both its domestic and foreign policy. If our country is to secure its leading place in research and innovation, and if we still want to have a say in how our personal health data is being used in the future, we need to take action now. To this end, and based on our findings, we suggest that the Confederation and the cantons follow three promising paths, allowing Switzerland to play a more active role in health data governance:

1. Support multilateral efforts in International Geneva

At the international level, Switzerland should contribute to the development of a legal framework for handling health data in cross-border contexts. In times of geopolitical polarization, a commitment to digital cooperation and the support of multilateral legislation, e.g. in the form of international health data regulation approved under the auspices of the World Health Organization, is more important than ever. These efforts include strengthening International Geneva as the hub for global health data governance.

Moritz Fegert and Isabel Knobel are the co-authors of the study “Health Data Governance. What’s in it for Switzerland?”. The publication is the result of a national participatory process carried out in 2020 by foraus, the Swiss think tank on foreign policy, and Sensor Advice, a specialist in health consulting and discourse research. The project was supported by Fondation Botnar. The qualitative analysis of its outcome has led to the formulation of 12 broad-based recommendations for better health data governance in Switzerland and beyond. The study is available for download at www.foraus.ch and www.sensoradvice.ch.
Dedicated initiatives and platforms are currently emerging, like the International Digital Health & AI Research Collaborative (I-DAIR), which enables research collaborations in the field of digital health and promotes the inclusive, fair and responsible use of health data and AI-powered technologies.

2. Join the EU’s health data ecosystem
At the regional level, Switzerland should join the European Union in its efforts to build up a common health data ecosystem. Our like-minded neighbor is a pioneer in the field of data protection and the regulation of digital technologies, notably with its General Data Protection Regulation (GDPR). With the European Health Union, the Digital Single Market and the European Data Space there are even more ground-breaking projects in the EU’s pipeline, which will also directly affect Switzerland. In the context of the Covid-19 crisis, the EU has raised the priority of EU-wide health and data-related policy initiatives such as the EU4Health program or the European ‘1+ Million Genomes’ Initiative, aiming at making at least 1 million sequenced genomes available in the EU by 2022. Switzerland should make use of this political momentum and participate in the EU’s plans for a joint space that allows the cross-border exchange of health data. It will not only benefit patients but will also help academia and the private sector to keep its place at the forefront of innovative research and development.

3. Foster national dialogue and promote health data literacy
At the national level, Switzerland should promote an institutionalized dialogue with all relevant parties in the healthcare system. An inclusive consultation process is needed to counter political fragmentation and develop a broad-based yet effective national digital health strategy. Especially important here is the inclusion of the public. Citizens and patients are playing an increasingly active role in managing their personal health. It will thus be key to enabling them to understand, collect, manage and use their health data. This so-called health data literacy can be promoted through national information campaigns and targeted educational services.

In the context of the two workshop-formats PoliTisch and Policy Kitchen, more than 140 stakeholders and interested citizens discussed the challenges and opportunities of dealing with health data.
A first scenario assessment makes a strong call for change and need for action

What is the current state, what is expected and what is preferred? Following the scenario assessment by the participants in the DayOne Health Data Project, it is clear that the right health data ecosystem capable of meeting citizens’ future needs has yet to be invented.

Silicon Valley investor Paul Graham is quoted as saying that the easiest way to get to new ideas is to live in the future and invent what is missing. In this regard, a lot of invention is needed to build the future health data ecosystem. This is clearly demonstrated by a preliminary scenario assessment. Scenarios 1a and 1b were unanimously perceived as representing the current state. And an equally unanimous view was that scenario 3a – which can be seen as the most utopian – was considered the most desirable. As to what can realistically be expected, the participants were quite undecided, but tended strongly towards the scenario group 4ab.

Before we dive deeper into these findings, it is important to state that the assessment is not based merely on the finished scenarios. We dug deeper and asked for participants to evaluate the projections of the 22 key factors. The answers were then condensed to arrive at the present result. This method is relevant as it guarantees that all factors describing the scenarios are taken into consideration and examined as a basis for the assessment.

While the creation of the 10 scenarios for a future health data ecosystem has allowed us to explore different potential paths of development, the assessment evaluates which one of these scenarios is favored. In this regard the results are nowhere near representative, but they are indicative. The assessment is clustered in three
dimensions. First, we want to find out to what extent the scenarios show similarities to the present situation. Second, the scenarios are ranked on the basis of the likelihood that they will occur in the period up to 2035. And last but not least, we ask which scenario is the most preferred and poised to provide the most favorable outcome.

The evaluation of the present situation shows that, given the assessment of the 22 key factors, the greatest similarity is to be found in Scenarios 1b, 1a and 4b. Participants agreed that, in the current state, innovation is evolving incrementally in most cases, bringing only gradual change to the healthcare system with a rather strong government influence, mainly on a national level and within traditional structures, and there is very little appetite for behavioral change. Accordingly, the least coincidence with the present situation is to be found in the “opposite” scenario 3a, where citizens want to take ownership of their health, and innovation is to be found in both technological disruption and strong structural change.

The assessment of the expected future of the health data ecosystem in 2035 leaves more room for interpretation. The highest ranking is given to scenarios 4a and 4b. This means participants are more or less confident that the corporate world will shape the future driven very strongly by technological innovation and private investments. Regarding the health data ecosystem, there will be only moderate structural change. Nevertheless, it should be pointed out that the scenario group 2 also has some attraction making at least some cultural change not completely implausible, albeit less accentuated.

That behavioral change has to be considered as a driver for innovation, at least to some extent, can be confirmed in an analysis of the expected changes on the level of the individual assessment of the key influence factors. It becomes apparent that the expectation of change varies considerably for different areas. When it comes to economic factors, participants expect a shift towards a more corporate-driven innovation, adding new and highly innovative as well as influential stakeholders to the ecosystem and accelerated by an earnings-oriented research system. At the same time, a rather traditional regulatory approach is expected, which might be unable to keep pace with technology advances, allowing these new players to exert their power and keep the health data ecosystems quite proprietary in nature. On the other hand, participants also expect consumers to become much more active in the future and take greater responsibility for their own health. This leads to the possibility that personal and corporate ownership of health data could co-exist in a fragmented system. In this regard, consumer behavior and cultural change have the potential to significantly influence the healthcare system – and our projected future.
Given the expectation that both technological innovation and consumer behavior will shape the future health data ecosystem, it is no great surprise that the most preferred scenario is a combination of the two, landing us in the scenario group 3, in particular, scenario 3a. This result did not differ much from stakeholder to stakeholder (although it has to be pointed out that the number of assessments is far from representative). Nevertheless, it can be stated that a major shift towards a combination of cultural and technological disruption is seen as positive. Breaking up given structures and establishing a new stakeholder landscape is not perceived as a threat by participants, but rather as an opportunity. Change is deemed to benefit both better healthcare outcomes for patients and a flourishing ecosystem environment for business to thrive.

The analysis of all three assessment dimensions shows considerable differences. While the present healthcare system is considered rather traditional and stagnant, change is expected to be quite significant in the 15 years to come. Both technological and cultural impulses are perceived to be capable of transforming the health data ecosystem, leaving the question open as to how this development will evolve: more towards a citizen-centric system or towards big corporations? In spite of this uncertainty, there is little doubt about the ultimate goal: a completely transformed system that allows for holistic growth – in fact, quite the opposite of what we observe today. This makes it clear that a strong and active push for change will be needed in order to shape the future of the health data ecosystem in this direction.

This brings us to the very last consideration. Namely, the question as to what trajectories can be envisioned based on the scenarios presented here in order to arrive at the desired health data ecosystem in the future. Basically, this boils down to the question as to whether the public sector should drive the development and impose regulatory measures that will first empower citizens, democratize tech and then facilitate innovation in a highly egalitarian albeit business-driven ecosystem. Or should governments be more reluctant to intervene and show confidence in the market forces that will shape the appropriate health data ecosystem? A fairly old question, to which the answer can be found either by following the usual ideological imperatives or, in a more pragmatic way, by stress testing the four scenario groups with hands-on healthcare challenges and evaluating the possible results in order to formulate calls to action. This is exactly what the DayOne Health Data Scenario Project will continue to explore in its 2021 edition, together with a consortium of experts and thought leaders.
“Data helps us to make better medicines for patients”

Making data findable and interoperable, using it to learn more about diseases and treatments, all while safeguarding data privacy. How does Novartis approach health data? Thoughts captured in a curated interview with Greg L. Hersch.

Greg L. Hersch, PhD – Digital Program Head Process Excellence & Innovation, Data & Digital, Global Drug Development

Pharma companies make drugs. Why care about health data?
Quite simply, because data helps us to make better medicines for patients. The force of innovation driving Novartis relies on knowledge and curiosity, or in other words, science. The role of data is expanding and has become core to designing new types of medicines and technology-enabled platforms that the industry may not have dared to imagine only a decade ago – such as gene therapy for children, RNA-based medicines and even digital therapeutics. This requires a re-think on how we build evidence and operate in the most data-driven way, along the path for developing these new medicines from ideas to product to patient bedside.

How do you make use of the research data you have?
We have over 2 million patient-years from clinical studies in our systems. This is a huge amount of data – 20 petabytes, equivalent to 40,000 years of music. Now, if we make this data from different sources findable and interoperable, and apply AI-based algorithms, we can find new patterns and correlations between diseases, symptoms, biomarkers and treatments. However, it does not stop there. Imagine how anonymized health records that capture the complex reality of thousands of patient journeys can be compared with data obtained during our clinical studies, helping us not only to plan our studies based on the real-world context, but also to interpret our findings.

So sharing data across organizations would allow even more insights?
Targeted generation of health data in the controlled environment of clinical research comes with time and considerable investment. Any data access model needs to provide an appropriate economic incentive to continue generating that data, with high quality and respect for privacy. We believe that this can be done. Our contribution to the European public-private partnership “HARMONY” provides an example. It aims at gathering, integrating and analyzing anonymous patient data from a number of high-quality sources in the field of blood cancers.

This rationale is even more true for data that is collected in the normal flow of our healthcare systems, with the right controls in place to safeguard patient privacy. The world collects real-world

Greg Hersch is a Digital Program Head in Global Drug Development at Novartis, with global responsibility for creating new digital technologies that enhance drug development and accelerate medicines to patients.

Born in Los Angeles, California USA, Greg received his PhD in Biochemistry from the Massachusetts Institute of Technology (MIT). Greg was a leader in the Healthcare practice of the Boston Consulting Group (BCG), where he worked from 2006 to 2015, while stationed in Boston, Paris and Czech Republic. He began working at Novartis in 2016, where he was the Head of Strategy and Program Management for Novartis Operations, and has since held various positions in Global Drug Development. He lives in Reinach, Baselland, along with his wife and two children.
health data every day, but the potential of that data to improve the human condition is mostly untapped, and the value is lost. Consider the rapid and dynamic insights made available during the Covid-19 pandemic. Data surrounding the volume and location of infections became available on a real-time basis, which enabled us to mitigate risks to our employees and patients in a meaningful way. In the same way, thorough analysis of health insurance claims could help us to rethink our understanding of disease and identify factors that could limit patients from gaining the full therapeutic value of our medicines.

You work in drug development yourself. What new ways of using health data in building evidence on your medicines are you pursuing?

Clinical trials can represent hope for patients where the standard of care is leaving a significant unmet need in their lives. For example, a few years ago before CAR-T therapies were approved to treat certain cancers, very ill patients relied on clinical trials as a means to access these therapies. However, we know that patients face significant barriers when trying to find a clinical trial that is appropriate for them. A patient’s medical record is sacrosanct – and protected by numerous privacy laws. So it isn’t possible to simply contact patients or their physicians when a clinical trial might be a viable option. But we can work with advocacy groups and other not-for-profit entities to create ways for patients to express interest in clinical trials and share health data to see whether they might be eligible.

What does that look like in practice?

In practice, we can offer digital avenues of patient engagement – on Google Search, for instance. However, we are also exploring ways how we can work with other pharmaceutical companies to develop a secure portal that allows patients to submit their data to a third party, and efficiently match all available clinical trials for that patient in a way that protects the identity and data of the patient. This could involve technology such as artificial intelligence to assist in matching, or even security-oriented technology, such as blockchain, to ensure the fidelity and security of patient data. This is just one hypothetical example, and it is part of our jobs to explore all of these ways to make clinical trials more accessible to patients in a responsible way, and in partnership with their physicians.

When it comes to health data, privacy and security are widespread concerns

Autonomy of the individual is key, as is transparency in how we use health data. Whenever we process personal health data, we follow strict data privacy rights procedures and comply with governing laws. In many cases we go beyond the locally relevant laws. Nonetheless, public debate on how as a society we want to use health data will be necessary.

If you could make a wish, how should the Swiss health data ecosystem develop?

We do not want to make a wish – we want to build. It is our perception that de-personalized real-world health data should be accessible to legitimate actors in the healthcare system. For research, policy analysis, potential value-based reimbursement and more. It all starts with a change of mind, dialogue and trust building.
DAYONE is on a mission to help shape the future of health.

Shaping the future of health means making the best use of digital technologies and fostering a strong collaborative environment for a future rooted in precision medicine and personalized healthcare. The Basel Area has a strong healthcare ecosystem with numerous established and world-leading medtech, biopharma and diagnostics companies and research institutes.

The DayOne initiative supports collaboration and innovation by encouraging hands-on participation. We enable multi-stakeholder contribution across several disciplines and industries that can work together to serve healthcare needs. Our unique approach puts the patient at the center.

The topics we cover delve into their needs, and we include patients in our panels and programs. These include Value Based Healthcare, Patient-led Innovation, Future Health Data Scenarios, Fem Tech, and Decision Support Systems among others.

DayOne is the Healthcare Innovation initiative managed by Basel Area Business & Innovation, and is located in the Switzerland Innovation Park Basel Area Novartis Campus.

Get in touch
We welcome you to join us
www.dayone.swiss
Impact

2,000+ healthcare innovators in our community

23 digital health companies accelerated

48 million CHF valuation of companies

115 employees in companies accelerated

26 experts representing the whole healthcare ecosystem

10+ events per year

All figures since 2020

We welcome support from industry and foundations in the form of sponsorships and funding to help us create more impact in the region.