

Proceedings booklet

# Digital Health @ Worldwebforum

Digital health ecosystems, hybrid care pathways and  
data ethics in healthcare





## TRACK 1: DIGITAL HEALTH ECOSYSTEMS

Abstract: Digital health is a true revolution. It puts patients at the centre, empowers them to manage their health, and enables several actors to use new sources of data, e.g. to personalise treatments and medicines. Despite an estimated potential of more than EUR 100 billion in the EU, there exists no sustainable business model for innovators so far. An ecosystem approach to connect various actors in the health system would address that gap, benefitting (1) patients with digital offerings having higher relevance and value along the full patient journey (2) providers with novel insights and combined digital and non-digital care offerings from linked data sources (3) start-ups with better opportunities to tailor their offerings and reach patients at scale (4) pharma companies for finding best participants for clinical trials, and (5) payors with more effective steering, higher interaction efficiency and better service delivery.

# Unleashing the power of digital health through ecosystems

*by Ulrike Deetjen, Stefan Biesdorf, Giovanni Guilliani and Walter Oberhänsli*

Digital health is revolutionising the way we think about healthcare: it puts patients at the centre, empowers them to track, manage and improve their treatment, making them more informed, independent and demanding. Moreover, digital health data enables healthcare providers to tailor solutions by personalising treatments and medicines, and offers a tantalising look into the future of medical care. Yet so far, it has proved a hard nut to crack.

This document explores what it takes to unleash the full power of digital health to the benefit of patients, payors and providers alike. It describes the burgeoning digital health trend and its potential across European countries, the execution challenges it faces, and the kind of ecosystem it needs for unleashing its full potential. It concludes with ideas on how to establish that ecosystem across countries.

## **The rise of digital health**

Digital health is the face of 21st century wellness. The convergence of information, technology, people and connectivity will improve health outcomes for patients and increase efficiency for health care professionals. We distinguish between “e-health” (centred around the health care professional, e.g., EMRs, Clinical Decision Support) and the more recent development of “digital health” (centred around the patient, e.g., Health Apps for self management of chronic conditions). Exhibit 1 shows the different concepts.

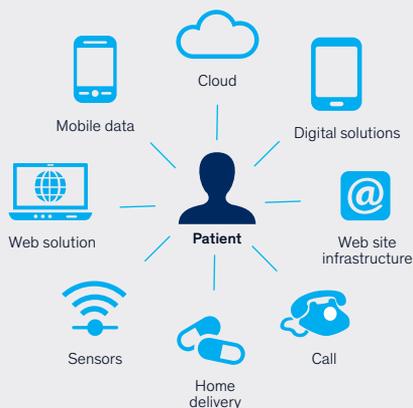
### E-health: centred around the provider



#### National e-Health programs

- Nationally focussed
- Low perceived benefits for providers
- Limited competition
- Fragmented IT
- Change resistance

### Digital health: centred around the patient



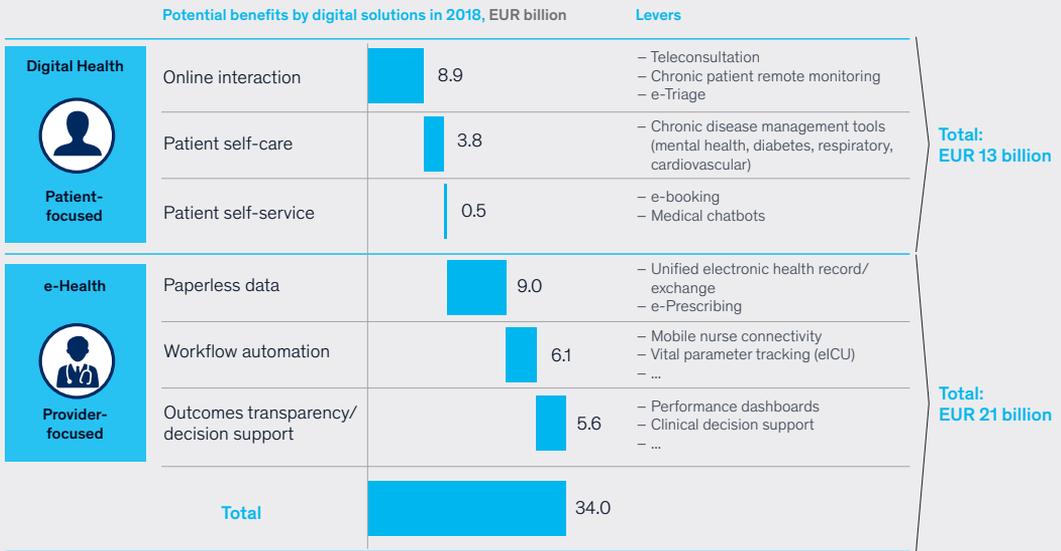
#### Digital health transcends national borders

- Global scale
- Intrinsic interest in connecting
- Winner-takes-all logic
- Modern IT
- No natural owner

Digital health players and new entrants are flooding the market with new, improved solutions. In 2018 alone, users could access more than 250,000 health apps on fitness/wellness, disease prevention/management, specific conditions, medical records management, interactions with health service providers etc. in iOS/Android app stores. These digital services are convenient (easy to use, whenever and wherever) and familiar, as people are now accustomed to using them for other purposes, e.g. banking. As digital offers grow in number and sophistication, users are taking them up, provided that they meet security and privacy requirements – even despite challenges in a rather fragmented landscape of solutions of different quality and suitability for individual needs.

The potential of digital health is estimated at more than EUR 100 billion in the EU, as it may capture between 5 and 10 per cent of a country's health spending – for example through better access to care, better adherence or more efficient triage between care settings. In Germany alone, the potential amounts to EUR 34 billion. One third from “digital health” is centred around the patient, not including the costs for realising this benefit. This finding is based on our scientific review of over 500 academic papers and interviews with experts from different sectors of the health system.

Exhibit 2: Huge benefits through both e-health and digital health (Germany)



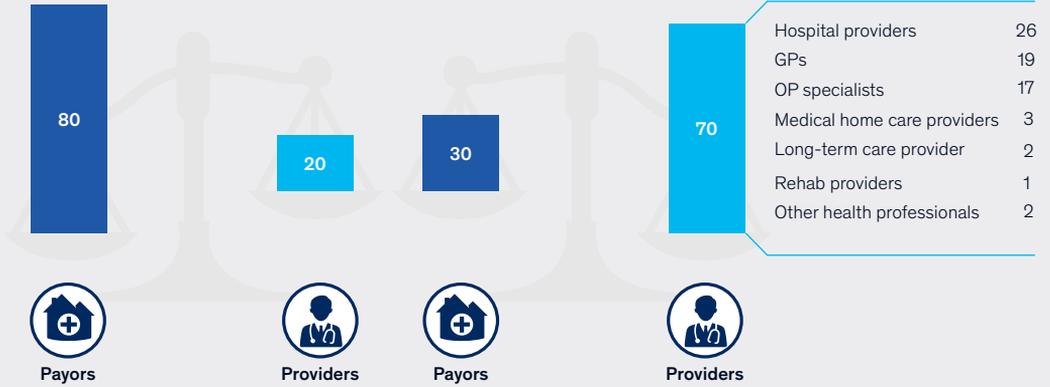
Payors and providers are benefitting from these developments to different extents. Contrary to an analysis by the German telemedicine agency gematik from 2006, which found that nearly 80 per cent of the value accrued to payors and only 20 per cent to the providers, our analysis from 2018 revealed that about 70 per cent of the value was realised by providers – through increased efficiency and focus on high-value activities, partially stemming from better use of data from claims and EMR data. The introduction of EMRs and e-prescriptions is the most important lever, and acts as a crucial enabler for all other levers.

Despite its potential, the costs for bringing healthcare innovation to life need to be put into the equation. Creating digital health applications and making them available to patients creates costs: for those providing the infrastructure, those creating the applications, those managing them and providing medical expertise, as well as ancillary costs for marketing, legal issues and data protection. To pay for these costs, created value and incentives need to be aligned.

To date, however, few if any digital health solutions receive regular reimbursement from public health systems, and alternative sustainable and adequate revenue streams are hardly available. First important steps have been made, e.g. with the digital care law coming into place in Germany in 2020. In short, it suggests new ways of prescribing apps and financing them through payors based on actual benefit to the patient. However, digital health is still far from realising its full potential today.

Gematik study (2006): Value capture by payors and providers, percent

New study (2018): Share of EUR 34 billion that resides with payors and providers, percent



## Challenges in digital health

There are various reasons why innovation “laggards” continue to dominate digital healthcare, and digital health innovation still has not taken off:

- **There is no sustainable business model for innovators.**

Digital health players cannot create a thriving and sustainable business model from patient-generated revenues via sales in app stores. That said, alternative sources of revenue are only starting to become available for app providers, as first payors are beginning to pay for solutions. In Germany, for example, the app “Tinnitracks” offers two types of therapy to help patients who suffer from tinnitus. After otorhinolaryngologists prescribe the app, most payors reimburse the costs. However, this model at least partially lags behind because of existing incentive structures in activity-based reimbursement schemes<sup>1</sup>.

- **It is difficult to estimate the value for the health system.**

If patients manage their diabetes via an app, how does this impact health outcomes or expenditure? To answer this question, activity data (or “input data”) from digital health apps would have to be linked to outcome data from the health system to evaluate the actual value generated – both in terms of patient well-being and system efficiency. So far, no effective methods for this evaluation and on how to link it to new ways of reimbursement are available.

<sup>1</sup> In November 2019, the digital care law („Digitale-Versorgungs-Gesetz“) was passed in Germany. Among other novelties, it officially enables physicians to prescribe certified health apps which have to prove that they improve outcomes. Those apps have to be reimbursed by public payors. Even though there is still a hurdle because a prescription is needed, the act might unlock new sources of revenue for app developers.

- **Start-ups struggle to capture full value.**

Start-ups typically create point solutions for specific patient needs. They build mobile apps that meet a single need and are easy to understand and offer “specialized stand-alone services”. But since they are not integrated into the traditional care delivery system, they cannot realize full value for either the patient (personalized, specific recommendations) or the health system (cost reduction or quality improvement).

- **Health market dynamics are very complex.**

A “killer app” may not be enough to change behavior in the healthcare space, i.e. technology innovation is not sufficient to convert users. In other markets such as travel, users will use an app that provides an optimal user experience; in the health market, patients are much harder to engage until they know that an app will truly impact their lives in a positive way.

- **Data sources are disparate and disconnected.**

Providers have not yet understood how to bring data and information onto one platform and use them to improve patient outcomes in a measurable way. At the same time, players are reluctant to share their data: e-health players have no embedded incentive to share their data with digital health players.

All players must be engaged and see a benefit in digital health applications. Patients need curated services/apps and the knowledge that their engagement makes a difference. Providers and medical practitioners need to integrate these applications into workflows that create value for them, e.g. through better patient adherence. And payors have to incentivize both sides to use these applications in order to reduce health costs and offer better services to their members.

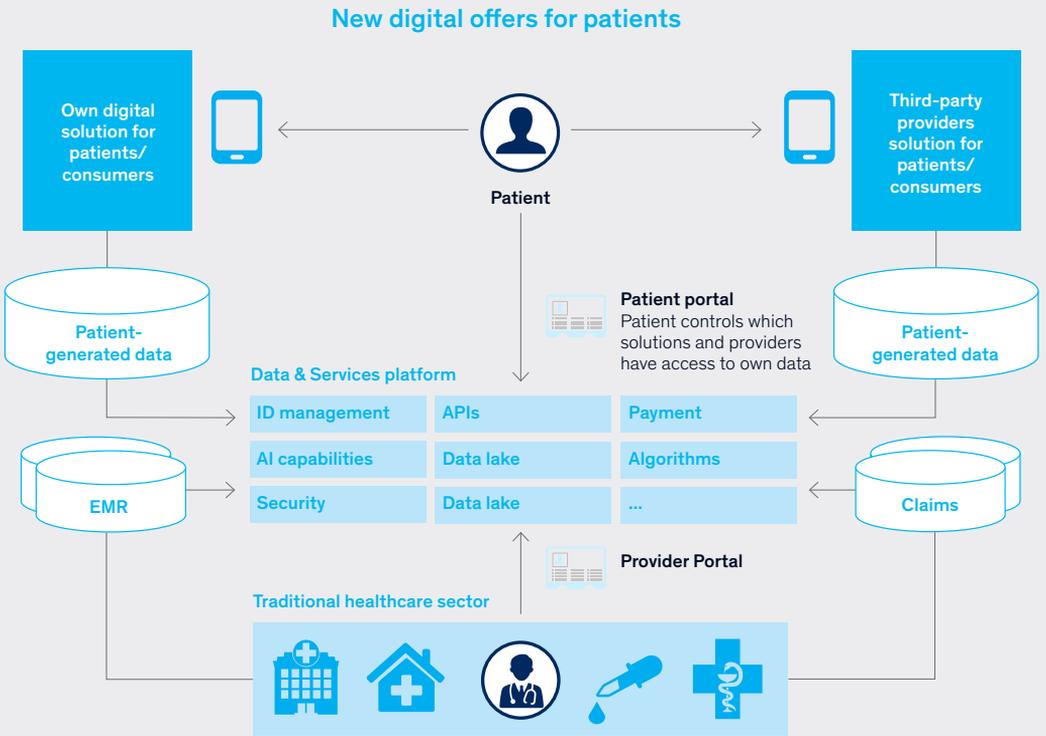
Hence the question is: what will it take to overcome these challenges and unlock the full potential of digital health?

## **Enabling digital health through the ecosystem**

The key to truly unlocking the power of digital health lies in ecosystem approaches that connect different services and solutions into seamless patient journeys. Ecosystems bring together medical data (from the health system) and patient-generated data (from digital health applications). Connecting disparate technology components and data sources enables a powerful patient offer and makes the healthcare system function better. In addition, bringing together these data sources offers new ways of evaluating performance and outcomes, with opportunities for completely new reimbursement paradigms.

Ecosystem approaches help integrate digital health solutions into the existing infrastructure in two important ways (Exhibit 4). First, a central platform with standard data management functions including patient authentication and data privacy, pre-populated with data from the health system (e.g. claims data), and single sign-on across solutions could help creators of digital health applications provide a more contextually relevant experience for the patient. This is the principle of contextual deep linking where customers are forwarded from one app to another while preserving the context of the interaction. Second, patient-generated data fed back into the health system would improve integrated care delivery and system navigation and could be combined to evaluate the effectiveness of specific interventions.

Exhibit 4: Target picture for health ecosystem



Ecosystems create value for all participants in the traditional healthcare sector: they deliver value for patients by enhancing service and convenience by providing standalone or seamlessly integrated digital offerings along the patient journey. They deliver value for insurers by directing patients towards the best treatment option. And they deliver value for all other participants by increasing transparency and efficiency to maximise overall value for the system rather than for individuals (as created by activity-based reimbursement schemes, for example).

The key to success is patient engagement. Therefore, the patient needs to be placed at the heart of the solution. An ecosystem will only function if patients trust it, experience a superior benefit, and understand the value of sharing their data and engaging with the offers. The patient as fulcrum helps align incentives, as data sharing becomes mutually beneficial: a patient agreeing to share his data also receives the related benefits. A system that does not revolve around the patient will fail – as will a system that only captures value for some of the involved parties rather than creating balanced incentives for everyone.

## Designing the right ecosystem

For this ecosystem to come into existence, certain critical design elements need to be combined. The ecosystem needs an orchestrator that combines different data sources and is in a central position in the health system. It also needs to be clear what value is generated for each of the involved parties in order to align incentives.

### What is needed to establish the ecosystem?

Founding an ecosystem requires a basic infrastructure that allows different parties to exchange data enabled by a trusted party. At the very foundation, it consists of a patient-centric gateway with basic functionalities in partner management, such as authentication and authorization of patients. Furthermore, it contains digital health solutions with standardized, externally documented application programming interfaces (APIs) that allow ecosystem partners to integrate with little effort, and standard workflows for doing so—across the digital and physical world.

Built for scalability (e.g. by using medical cloud functionality and scalable IT foundations such as containerization), the basics are sufficient to start and grow the ecosystem through the dynamics of two-sided markets: a larger number of offers from partners attract new patients, more patients in turn attract a larger number of partners offering their services etc.—as ecosystems grow, the winner will take it all.

Finally, at the next stage of the evolution, further services (such as analytics) may be integrated into the ecosystem foundations. This would allow to even better target patients with relevant offers, understand data (e.g. as a basis for clinical trials) or evaluate the effectiveness of digital health interventions, which forms the basis for enabling sustainable business models for start-ups.

### What design choices need to be made?

Three principle elements should be considered for designing an ecosystem: value in use cases, openness of the system and potential data sources (see Exhibit 5).

- **Value in use cases.**

Customer-facing applications generate one third of the value created in digital health by reducing demand for services. Efficiency gains account for the remaining two thirds of the value (classic e-health). Customer-facing applications are therefore important to build momentum but should then merge with traditional care delivery into a hybrid model to realize their full value.

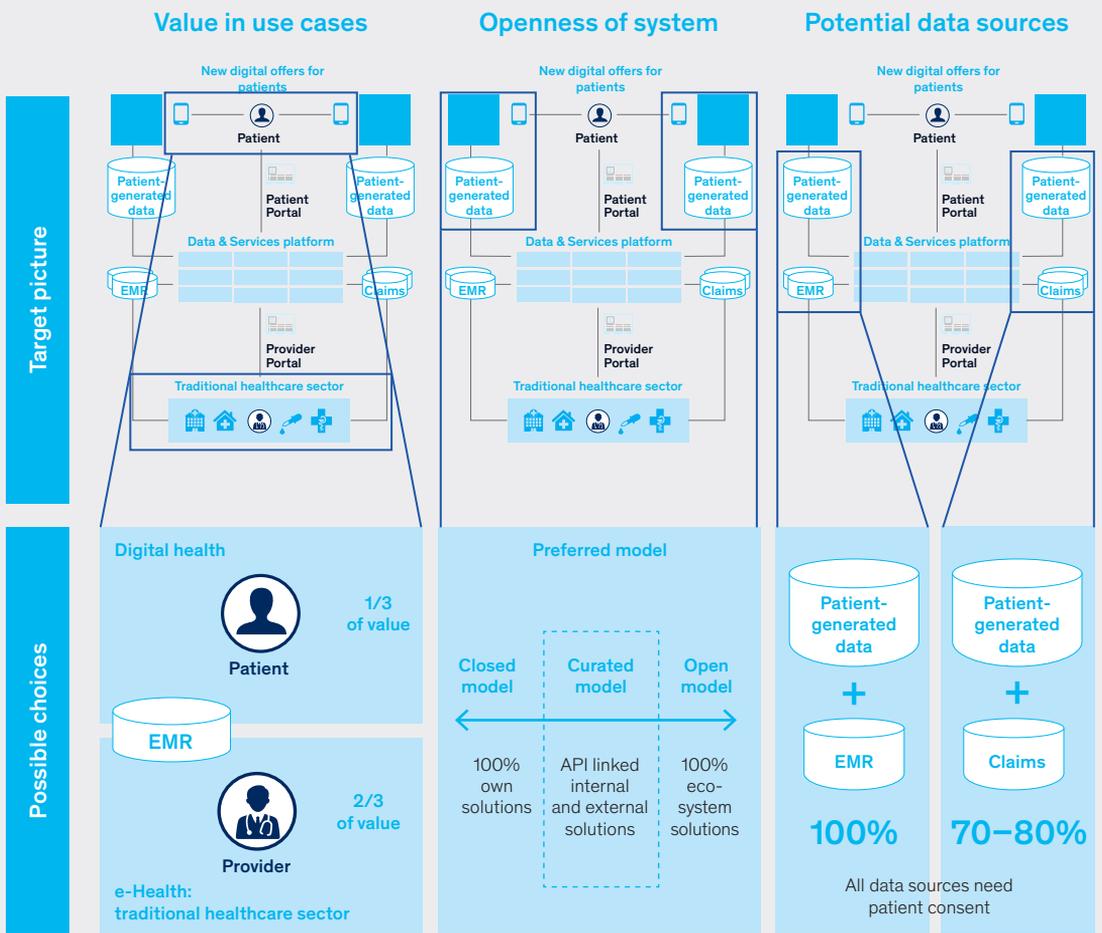
- **Openness of the system.**

Neither fully closed (proprietary applications) nor fully open models work. Closed ecosystems can lack scalability and innovation as they may not cover the full range of patient needs. Open ecosystems may face reputation and trust issues. The solution is therefore a system that curates offers without creating app certification bottlenecks.

- **Potential data sources.**

To incentivize start-ups to join the ecosystem and combine patient activity and outcome data for evaluation purposes, the system must integrate data from the legacy health system. Claims data are a good place to start, as they are widely available and well structured. Similarly, EMR data offer very valuable insights.

Exhibit 5: Critical design choices for ecosystems



## Who uses the data?

Data may be used by a variety of players, e.g. patients, providers, start-ups, pharma companies and payors.

Based on the ecosystems, **patients** benefit from using integrated services with higher relevance and value. This is due to existing data being used to personalise the digital offer and supporting the dialogue with health professionals on data collected in everyday life outside of the medical system.

**Providers** benefit for the same reason—provided that analytical capabilities really support insights rather than just data collection, and reimbursement models incentivise the use of digital health innovations.

**Start-ups** benefit from gaining access to data from the health system, e.g. claims data in the first step. They can use it to better tailor their offers and evaluate the usefulness of the digital health innovation by bringing together activity and outcomes data. Of course, this relies on the prerequisite of patient consent – and the real benefit of this is only created once reimbursement schemes enable payors to select start-ups on that basis and link payment to actual impact on the health system.

Likewise, **pharma companies** may also benefit from this data. Modern medicine requires access to data. That way, they can find the right participants for clinical trials, and develop new drugs by using data from outside the health system (for mental health, dementia, certain types of cancer and other conditions with a high share of behavioural influencing factors etc.). Furthermore, they can present the real-world evidence of how drugs impact health outcomes or even personalise approaches for treatment to improve healthcare in the future.

Finally, **payors** benefit from ecosystems in various ways. By integrating digital health solutions, they can deliver better service to their members (thereby increasing customer retention rates), steer patients through the system more effectively and increase interaction efficiency. Each of these benefits helps reduce costs, and ultimately leads to a better, more efficient health system.

## **Becoming an ecosystem leader**

Ecosystems need orchestrators who create the infrastructure to tie everything together. Successful players will integrate tangible and intangible assets into one seamless solution. Tangible assets include the ability to engage patients, the analytical skills to collate and analyse disparate data sets, and a technology platform that brings together players seamlessly in the ecosystem – often in conjunction with a patient-centric EHR as a basis. Intangible assets include experience in creating an ecosystem, intellectual property and know-how in the health space, and the power of partnerships between players that bring different sets of unique skills to the table.

One natural owner for this would be payors<sup>2</sup>. Payors benefit from ecosystems in various ways. By integrating digital health solutions, they can deliver better service to their members, steer patients more effectively and increase interaction efficiency. Each of these benefits helps reduce costs, particularly in systems where payors also set up the EHR – as is the case in Germany, where several payors develop their own interoperable solutions (e.g. vivy, TK with TK-Safe, AOK).

At the other extreme, large US technology players such as Google, Apple or Amazon are well positioned to set up the ecosystem due to their technological capabilities and closeness to the patient via services within and especially outside of the health system. While current EU regulation limits the possibilities for these players, particularly when integrated into the health system, their ability to use existing infrastructure and provide services with superior user experience should not be underestimated.

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<sup>2</sup> Providers (i.e., hospital or pharmacies) might be possible owners, too. However, most providers lack the size to orchestrate an ecosystem beyond their – typically local – reach. Hence only providers with a national – or even better international – presence might step up into the role of an ecosystem provider. Apart from that, depending on the region, PHI players might be possible owners, too. Last, but not least, health systems might themselves aspire to build and operate an ecosystem.

In the next step, specific measures should be defined to help countries take up digital health opportunities while ensuring – given the cross-national nature of digital health – that innovation scales across country borders. To that end, the EU could invest in the basic technical infrastructure that allows digital health solutions to refer patients and their data from one solution to the next. In a second step, a “hybrid health system” could be launched by enabling patients and their data to be referred to health-care providers in the traditional health system.

Core elements of the technical infrastructure include identity management of patients and solution providers, encrypted data transfer, patient consent functionality and the logging of the referrals and data transfer. High security standards are a must. There is no need to store the data on the technical infrastructure: the data only “travels” on the infrastructure between the digital solutions, thus making data theft less likely, and builds on the local infrastructure in each member state.

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In any case, the opportunity needs to be seized now – a wait-and-see strategy is not an option. Health players should act sooner rather than later and consider developing platforms to enable data sharing in the health system. By doing so, they can enable innovators to build sustainable business models, while acting as a central gatekeeper in the system and maintaining control over data.

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## TRACK 2: HYBRID CARE PATHWAYS

Abstract: Online shopping has not (and will likely never) make offline shopping irrelevant. Similarly in healthcare there will be a co-existence between traditional care delivery and digital care delivery. Today, care pathways consist of disconnected, singular touchpoints, often neglecting the interrelated nature of online and offline. Hybrid care pathways connect touchpoints in both worlds: for example, patients with chronic heart disease using an app for managing their condition might be advised to see a physician based on connecting all available data points. Combining these events into seamless patient journeys has three benefits: (1) efficiency in the health system increases by reducing duplication and delays (2) quality increases due to better condition management and (3) patient satisfaction increases through higher convenience. Core elements for successfully implementing these pathways are a suitable IT and data infrastructure across national health systems as well as outcomes-based payments and novel reimbursement schemes.

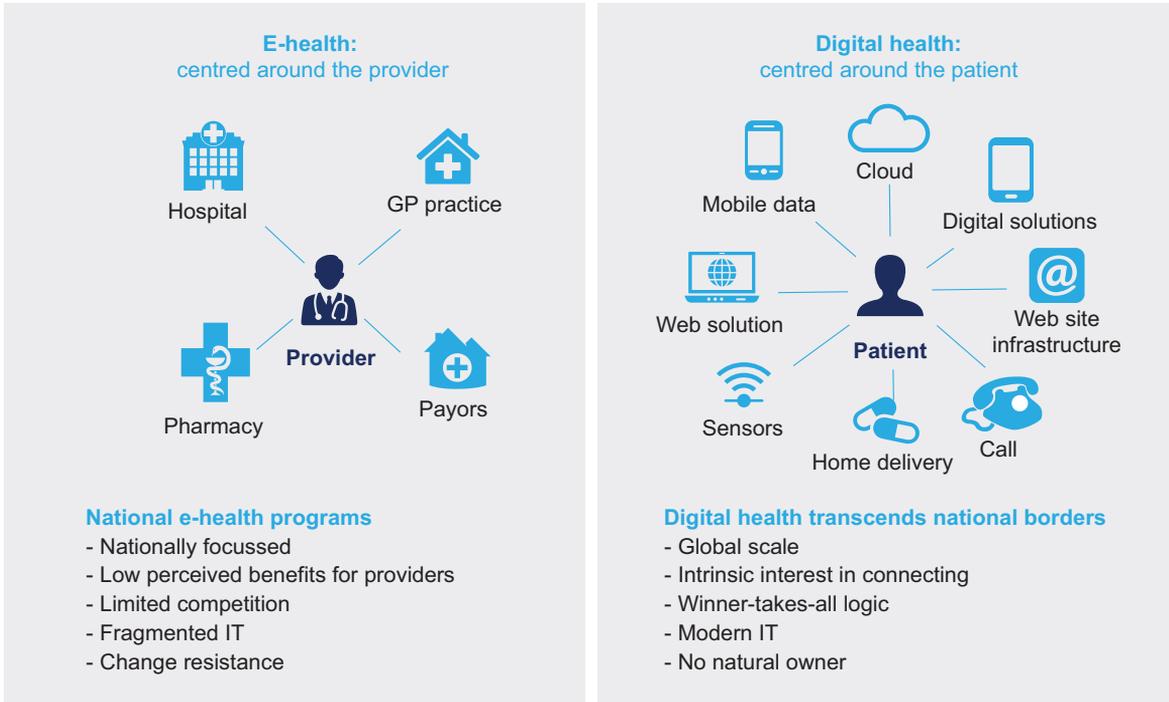
# Living offline and online: The future of hybrid care pathways

*by Kristin-Anne Rutter, Ulrike Deetjen, Stefan Biesdorf and Michael Green*

The healthcare industry's collective mission is to promote individual health and well-being, cure diseases, and care for the communities in which we live, work, and play. Technological advancements have already contributed greatly to this mission, transforming the way in which healthcare is delivered.

In the last century, we witnessed the emergence of IT systems in healthcare. Electronic medical records (EMR) became standard and integrated with other systems, such as radiology or clinical imaging. From 2005 onward, we saw the development of health and wellness applications, driven by the advent of the smartphone. Yet, EMRs remain siloed making it hard to create a complete picture of a patient's care and digital health applications in their current form cater to the needs of patients only to a small extent and remain niche products, because they only cover unconnected singular facets of a patient journey.

Making connections between all these singular facets into seamless patient journeys is one of the challenges that remains, as is connecting different providers amongst each other to fully understand a patient. Furthermore, connecting information on different medications to learn about potential side effects and connecting new digital health services into regular care to improve management of chronic conditions and find help in acute cases also remain challenges.



Only by forming seamless patient journeys, high numbers of patients can be provided for digitally. Viewed from the eyes of the patient, fully hybrid care pathways have three main benefits. First of all, they can greatly improve efficiency in the health system via quicker diagnoses, treatment and administration. For example, combining insights on medication data and previous medical history can reduce unwanted side effects. Second, they also may affect quality of care through better condition management and adherence as well as provide insights into less understood conditions. For example, for diseases such as dementia, it is estimated that the socio-economic context of the patient beyond the confines of the medical system contributes about 50 percent to understanding the disease. Third, they may improve patient satisfaction and convenience in managing health and wellness.

### Why hybrid care pathways are hard to realize

To understand the difficulty in setting up hybrid care pathways, it is useful to distinguish between “e-health” (centred around the health provider) and the more recent development of “digital health” (centred around the patient or person). Exhibit 1 illustrates the different concepts.

Over the past decades, many countries have invested heavily in national e-health programmes with modest returns and big execution challenges. These have tended to rely on medical professionals as agents of change. Yet, rather than being agents of change, they have often shown high change resistance in accepting new systems. For example, only an estimated 25% of German hospitals are using EMRs, while 75% still use paper<sup>1</sup>.

<sup>1</sup>“Pushing water up a hill – the trials and tribulations of the German hospital market”, M. Hotopf, L. Murray, Healthcare Business International, Aug 2019

Digital health is different. Digital health is driven by change agents who have experienced the convenience of digital services in their everyday lives or in other industries. Other industries developed an obsession with customer needs much earlier, using the new opportunities that smart phones and an 'always on' mindset entailed. Customers also demand change from the health system to cater to their needs – using symptom checkers for quick medical questions to embracing appointment finding and booking apps to access a convenient consultation.

To summarize: while much of the value is in e-health, demand for change comes through digital health. For realising maximal value, it is important to bring both e-health and digital health together, which would include innovative services from diagnosis to appointment booking or management of chronic conditions, designed from the patient's perspective. These become even more valuable through seamless integration with offline health services (e.g. traditional physician appointments) – and, in turn, create value for the health system through improving efficiency and quality.

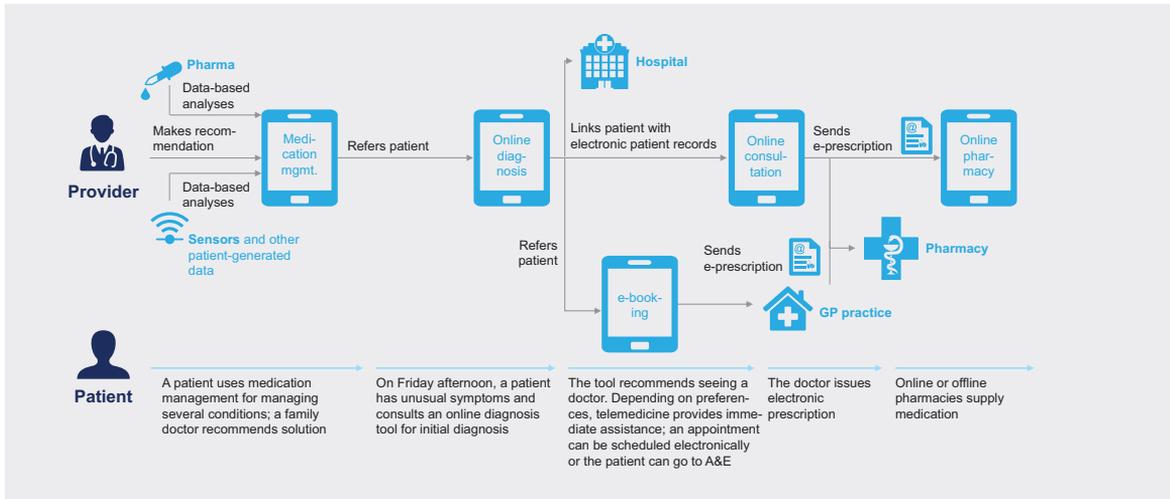
### **Integrating e-health and digital health into seamless journeys**

The vision for hybrid care pathways is simple: a patient with chronic heart failure uses an application and a set of digital monitors to managing his or her condition. Upon experiencing symptoms or detection of an abnormal observation, he or she consults a diagnosis app to find out what to do. If required it automatically connects to a telemedicine consultation, which can recommend going to the accident and emergency department (A&E). When the patient arrives at A&E, all the data for this specific occasion and general information on the patient's medication is already there, as is information on his or her compliance with taking beta blockers and information from his or her blood pressure monitor.

However, bringing these traditional data sources and new patient-generated data together to enable hybrid care pathways as well as enabling smooth handovers into seamless journeys is not yet possible. Connectivity in today's health system centres around claims and reimbursement. Traditional care providers form part of a prescribed network of services: the GP refers the patient to the specialist, the specialist prescribes a drug or a treatment, the pharmacy or hospital provides the drug or care. Each step is regulated, with clear guidelines and standards that define how information flows.

Yet, outside these standard channels (and sometimes within), data inefficiencies plague health systems: data on health is highly protected and often locked up in legacy e-health systems or data access is controlled by technical and commercial constraints of e-health providers. There may not even be a common language that data is stored in. Consequently, it can hardly be accessed by innovative players to improve their services. Moreover, integrating these services – at least enabling digital health at scale beyond point-to-point solutions – into seamless patient journeys remains practically impossible due to a lack of interoperability standards and technical platforms. An efficient, well-designed customer journey that spurs patient engagement should connect digital health offers into a 'string of pearls' (Exhibit 2).

Exhibit 2: 'String of pearls' logic for hybrid care pathways



The 'pearls' (different digital services and innovations) already exist, but we have yet to string them together. To realise the value created by each individual solution, we need to connect all offers into seamless patient journeys.

## Data is the basic foundation

In the e-health world, there are three main categories of data in health systems: electronic medical record (EMR) data and claims data.

**EMR data** is the information gathered by a physician during the examination of the patient, including treatments applied and drugs prescribed. This data resides in the IT systems of the healthcare professional, be it in the GP's practice or the hospital. It is very useful, but since it's kept in fragmented places, it is hard to use outside the setting in which it was generated (i.e. a GP can only see the EMR information he created himself, but not the information from another GP).

**Claims data** is the information that GPs and hospitals pass along to payers for reimbursement purposes. This information is highly standardized, as it has to be accepted and processed by different payer organizations. Then again, it is less rich than EMR data, as it only contains the necessary data for reimbursement. In addition, claims data comes with high data latency: information often reaches payers several months after it was created. Such data can hardly be used for treatment and diagnostics.

**Patient-generated data** is a new data category created through digital health. These data sets consist of activity information (e.g. pills taken, physical activity) and vital parameters (e.g. blood pressure, blood sugar readings) or general information on everyday life. Given that this data is not only collected during the treatment of a patient but every single day, this real-world data allows a new perspective on the patient for health providers and the scientific community. As an estimated 30 to 50 per cent of out-comes depend on patient behavior – particularly for some less-understood conditions, such as dementia – bringing these insights into clinical settings will be a critical driver of improving population health and advancing the way in which care is provided.

A key challenge to stringing the pearls together is the required coordination beyond point-to-point connections of single actors. It requires a way to connect digital services within each other and exchange data to form a real end-to-end patient journey, but also to link them with the traditional care sector.

## **Driving change for hybrid care pathways**

National health systems may not be in the best position to drive this change. Health systems are national by design and therefore pursue national e-health projects. As a consequence, this would not only save costs but also prevent health systems from developing innovative solutions without a proven track record. This can be compared to drug development, where the risk stays with the pharma companies and health systems only reimburse those who prove to be effective.

In contrast to national health systems, digital health has clear change agents and no borders. The clear returns from scale will create a strong ‘winner takes all’ effect, which will eliminate less-successful offers. It’s the acceptance of the patients that makes the difference: digital health solutions that attract the most patients will accumulate most data<sup>2</sup> and will – supported by built-in AI functions – provide a superior solution.

In order to enable hybrid care pathways, countries or national organizations should invest in the basic technical infrastructure that allows digital health solutions to refer patients and their data from one solution to the next and between digital and physical touchpoints. National health systems should not think about developing digital health solutions themselves, but rather include (certified and tested) digital health solutions that already exist.

Core elements of the technical infrastructure that should be invested in include

- identity management of patients, healthcare staff and digital solutions
- encrypted data transfer based on standard APIs and clinical terminology
- patient consent functions
- logging of referrals and data transfer

High security standards are a must. There is no need to store the data on the technical infrastructure: the data only ‘travels’ on the infrastructure between authorized digital solutions, thus making data theft less likely and building on the local infrastructure in each member state, always in compliance with overarching regulation such as the GDPR. In Canada for example, Infoway is building a national digital health platform that will connect an alliance of solution and service providers with personal health data using a standardised identity, trust and consent framework. The right, expandable infrastructure has almost limitless potential. If grounded in a stable technical platform (technology infrastructure, analytics capabilities and specific offerings), the model can create a foundation across different countries and thereby even help create a cross-national digital health system. This is already the case in Finland and Estonia: Since January 2019, Patients from Finland can visit a pharmacy in Estonia and get prescription drugs using their electronic prescriptions issued by their Finnish doctor.

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<sup>1</sup> For example, Flatiron’s solutions are based on more than 2.2 million active patient records to power their Oncology solutions

In addition, a mechanism to certify apps is required. Certification would include an assessment of potential health risks, data privacy, security and the ethical use of patient data (i.e. to prevent single players from accumulating or monopolizing data). Furthermore, a regulatory framework that allows digital health solutions to use the technical infrastructure is required: only those solutions which are without risk to the patients' health and comply with necessary security and data minimization safeguards should be allowed to connect to the infrastructure. In the UK for example, the National Institute for Health and Care Excellence published its first "evidence standards framework for digital health technologies", covering this balance. To avoid creating obstacles to certification, evaluating standards may also be established via distributed certification mechanisms (e.g. open-source requirements).

Lastly, the right commercial and policy conditions have to be created. These conditions should ensure that players who control data are mandated to share with authorized third parties. Some countries start implementing first steps towards this idea, for example with the digital care law in Germany.

Realizing the full potential hybrid care pathways will rely on introducing outcome-based payments into current reimbursement schemes and combining activity data (from digital health solutions) with outcomes data (from e-health solutions and the traditional health system). By doing so, there would be clear competition between different services and an incentive to steer the patient to the best solution possible for his or her individual situation.

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The online and the offline realm can hardly be separated in today's world anymore. Hybrid care pathways are a necessity in today's and tomorrow's health system, and they help improve efficiency, speed, and quality of care as well as patient satisfaction, provided basic privacy and security standards are met.

Because of the traditionally huge skepticism in healthcare systems when it comes to integrating digital offerings, purely digital care pathways have to be established first. These will then be used by many patients. Due to the high demand from patients, interest of traditional providers for being part of those digital pathways will increase – and thus hybrid care pathways will emerge.

Ultimately, just as digitization leads to a melting of industry boundaries, creating successful hybrid care pathways also goes beyond the healthcare realm. Patient-centric infrastructures should be linked to broader initiatives surrounding the single digital market. Done successfully, this would be a further step towards strengthening and empowering citizens to take advantage of opportunities created by digitization in all aspects of everyday life.

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### TRACK 3: DATA ETHICS IN HEALTHCARE

Abstract: Healthcare has always been a ‘data rich’ industry, but has also struggled with an enormous level of fragmentation across IT systems and standards. As a result, pooling large amounts of data for research purposes has mostly remained an unfulfilled dream. Digital health start-ups are now generating a ‘new class of data’; specifically, sensor and/or patient-generated data. This information is fundamentally different from the data in the healthcare system today. Not only is the level of fragmentation lower, but it can be shared in real time, thus enabling new interaction models – digital and non-digital – between patients and doctors. These possibilities raise new ethical questions and challenges in terms of existing consent models. Individual actors cannot solve these issues on their own – instead, a healthcare network with benefits for diagnosis, treatment, and research requires system-level solutions.

# Health data ethics – finding the delicate balance between ‘can do’ and ‘should do’

*by Nikolai Jannik Podlesny, Florian Niedermann, Ulrike Deetjen, Deborah Peel  
and Ioannis Tarnanas*

Healthcare is an intrinsically ‘data rich’ industry. Today, broad data from traditional sources, such as electronic medical records (EMRs), claims, and government statistical offices, is being supplemented by new kinds of patient-specific data: genomic variances, continuous data streams collected by patients themselves or their wearable devices, or social media. The digitization of this data is creating new possibilities to make healthcare more patient-centred, whilst streamlining providers’ work and increasing the insights available for diagnosis, treatment, and research.

In fact, the ability to combine genetic knowledge with information on a patient’s medical parameters, behavior, stress factors, and fitness activities is often referred to as ‘the Holy Grail of medical care’. Like the original Holy Grail, however, the personalized combination of genetic and day-to-day knowledge can pose dangers to the unwary. The potential for misuse of such highly intimate data is significant, and, as a result, it raises serious ethical questions. In essence: not everything that can be done should be done – and any approach to capturing the value of data in healthcare must consider not only utility but ethical concerns.

This dynamic is already evident in today's patient-centered digital healthcare applications, which represent steps towards such fully personalized medical care. As such, they promise a range of benefits, including convenience, individualized treatment, and the ability to predict success more accurately. However, these benefits also raise privacy and ethical questions – and the growing number of news reports on security breaches, data leakage, and de-anonymization incidents shows just how justified these concerns are. In short, when it comes to medical data, drawing the line between 'possible' and 'advisable' is essential. Companies that understand the advantages and risks can craft solutions that earn consumers' trust and a competitive advantage in the process. The specific form that these solutions should take remains to be determined and will likely evolve along with the capabilities of digital health technology. However, it is clear that they will involve system-level coordination of access to patient data paired with flexible yet robust mechanisms for managing consent under changing circumstances. Such a combination will equip the industry to continuously recalibrate the line between reaping all the benefits of digital health advances and protecting patients' privacy.

## **Advantages of digital health**

The latest digital health solutions promise continuous advanced insights into patients' behavior and activities in order to improve triage and make treatment more convenient. These innovations cover a wide range of applications, starting with drug intake diaries to monitor adherence to drug treatment and analyze side effects. Furthermore, consumer wearables with ECG functions and screening tools for atrial fibrillation can track health parameters around the clock. A further application is telemedicine, an increasingly common way to counter the lack of medical coverage in rural areas by leveraging digital communication channels between physicians and patients. The ultimate achievement in digital health is large-scale genome sequencing, which has recently been achieved nationwide for one Nordic country. The resulting insights offer a whole new level of understanding of personal risk, thus making truly individualized treatments possible and building a solid foundation for research on the distribution of rare diseases.

The proliferation of digital tools also provides a way for patients to take control of their medical information. One of the guiding principles of many digital health initiatives is self-determination: letting patients own their data and decide who has access to it for processing and analysis. Whilst digital patient access for electronic medical records and claims data is commonly established in the US, this level of transparency and accessibility is still rather atypical in Europe. However, privacy and security remain important issues when considering the breadth of applications for which the data is used and the consequences of putting it in the wrong hands or misusing it. Helping patients make informed choices in the face of constantly evolving technology, treatments, and privacy threats is one key aspect of the ongoing process of setting ethical boundaries on the use of health data.

## Data is the basic foundation

In the e-health world, there are three main categories of data in health systems: electronic medical record (EMR) data and claims data.

**EMR data** is the information gathered by a physician during the examination of the patient, including treatments applied and drugs prescribed. This data resides in the IT systems of the healthcare professional, be it in the GP's practice or the hospital. It is very useful, but since it's kept in fragmented places, it is hard to use outside the setting in which it was generated (i.e. a GP can only see the EMR information he created himself, but not the information from another GP).

**Claims data** is the information that GPs and hospitals pass along to payers for reimbursement purposes. This information is highly standardized, as it has to be accepted and processed by different payer organizations. Then again, it is less rich than EMR data, as it only contains the necessary data for reimbursement. In addition, claims data comes with high data latency: information often reaches payers several months after it was created. Such data can hardly be used for treatment and diagnostics.

**Patient-generated data** is a new data category created through digital health. These data sets consist of activity information (e.g. pills taken, physical activity) and vital parameters (e.g. blood pressure, blood sugar readings) or general information on everyday life. Given that this data is not only collected during the treatment of a patient but every single day, this real-world data allows a new perspective on the patient for health providers and the scientific community. As an estimated 30 to 50 per cent of out-comes depend on patient behavior – particularly for some less-understood conditions, such as dementia – bringing these insights into clinical settings will be a critical driver of improving population health and advancing the way in which care is provided.

## The challenge of unclear ethical boundaries

The stakes in terms of both opportunities and privacy concerns are even higher when it comes to genome sequencing. This technique offers a unique perspective on gene-disease correlations and the probability of a patient contracting a particular illness. At the same time, however, not all patients – even those committed to self-determination – want to know their likelihood of getting cancer by age 55. Furthermore, the extent of genomic insights is unlimited, posing the risk of an entirely new scale of personal data exposure or security incidents. After all, while an individual's behavior or stress might change over their lifetime, biometrics and genetics stay the same.

The lifelong nature of this risk also requires new thinking about concepts such as consent. Patients usually provide explicit consent for the processing of their genomes. Given the lack of an expiration date on genetic testing, the question 'What is a reasonable time for consent to be valid?' arises. Consent may be interpreted within its original context, but it may also take progress and social or technological change into account. One area of concern is specificity: for example, if an individual once consented to their blood being shared, would the sharing of genetic data derived from these blood samples also be permitted? Could a person who consented in the past to their blood being used have understood or predicted the eventual

consequences of sharing genomic data, especially as the time and cost required for sequencing have declined so dramatically?

Medical data insights clearly become especially valuable in situations in which the data they are based on is difficult to obtain or preserve, such as in cases of dementia. But how can physician confidentiality be guaranteed in a digital world? What steps can be taken to counter modelling errors, such as overfitting and fallacies, as well as misinterpretations, such as those that occur through casual inference, in order to protect against outliers in advanced medical analytics?

### **What can go wrong**

These ethical questions may seem abstract, but a growing number of news reports document very concrete incidents of personal data exposure and re-identification of anonymous patients. Moreover, such problems are not entirely new: one of the most prominent occurrences took place in 1997. Using a data set released by the Massachusetts Group Insurance Commission to improve healthcare and controlling costs, an MIT graduate student was able to identify the data for Massachusetts Governor William Weld by crossmatching a voter list with other shared data sets. Today, high-profile cases are in the news regularly.

In 2016, Australia's federal Department of Health published de-identified medical billing records of about 2.9 million Australians on an open data Web site as part of its policy on accessible public data. Individuals were later re-identified through a process of linking the unencrypted parts of the record with known information about them.

Most recently, insufficient security standards exposed 737 million medical images of US patients – including personally identifiable information (PII) – making them publicly accessible. It is clear that companies dealing with data cannot take privacy standards lightly, especially those related to anonymization techniques and security best practices. In addition to the ethical implications of mistakes, companies may face severe legal penalties for getting this wrong.

### **Privacy: Not just essential, but a competitive advantage**

In light of recent privacy incidents and the increasing complexity of data compliance, ensuring proper data privacy is widely acknowledged as a necessity, if an inconvenient one. But while it is important to recognize that data privacy is enforced by regulations (HIPAA, BDSG) and the latest legislation (US CCPA, EU GDPR), companies with convincing answers to the underlying ethical questions can also secure a competitive advantage.

According to the latest Bitkom survey, 75 per cent of German Internet users believe their data is not safe with technology companies. The list of recent cases of privacy gone wrong, breached defenses or data leaks has eroded consumers' trust. Furthermore, whether by mistake or through indifference, some private data has been exposed to third parties, e.g. for tracking purposes.

Nonetheless, we know customers reward trust with loyalty, and one way to foster such trust is to address the so-called privacy paradox: users favor privacy, but do not actively choose the relevant settings to ensure it. Supporting the user through 'privacy by design' or 'privacy by default' initiatives can build trust and a competitive advantage.

Today's tech giants currently do not have this trust. According to a new survey from Rock Health, only 11 per cent of people were willing to share their health data with a company like Amazon or Facebook. Instead, people are more likely to trust the federal government, insurers, pharmaceutical companies and especially their physicians – all entities that have not been implicated in as many recent privacy incidents.

### **German health apps: privacy statistics<sup>1</sup>**

- In 80 per cent of all German e-health apps, user credentials could be read during transmission
- When it comes to protecting PII, many medical apps have shortcomings
- Roughly 38 per cent of the apps did not follow proper security best practices, such as implementing SSL encryption for their server communication
- Health data could be captured in more than 52 per cent of total cases for all apps

### **Key challenges to ethical data usage**

It seems abundantly clear that leveraging data in the health ecosystem comes with risks. But what form do these challenges to companies take? Pitfalls lurk in three main areas: data distribution, privacy compliance, and complex regulation.

**Data distribution:** A variety of data providers exist, forming a landscape of scattered and isolated data. Existing business models are often at odds with a patient-centered ecosystem, as data ownership is claimed by organizations rather than maintained by the patients themselves. Key challenges will involve consolidating existing data pools, winning patients' trust as a cross-border data broker, and enabling a network centered on self-determined patients. A single organization may not be able to achieve all these goals – but a consortium of dedicated players is in a good position to do so.

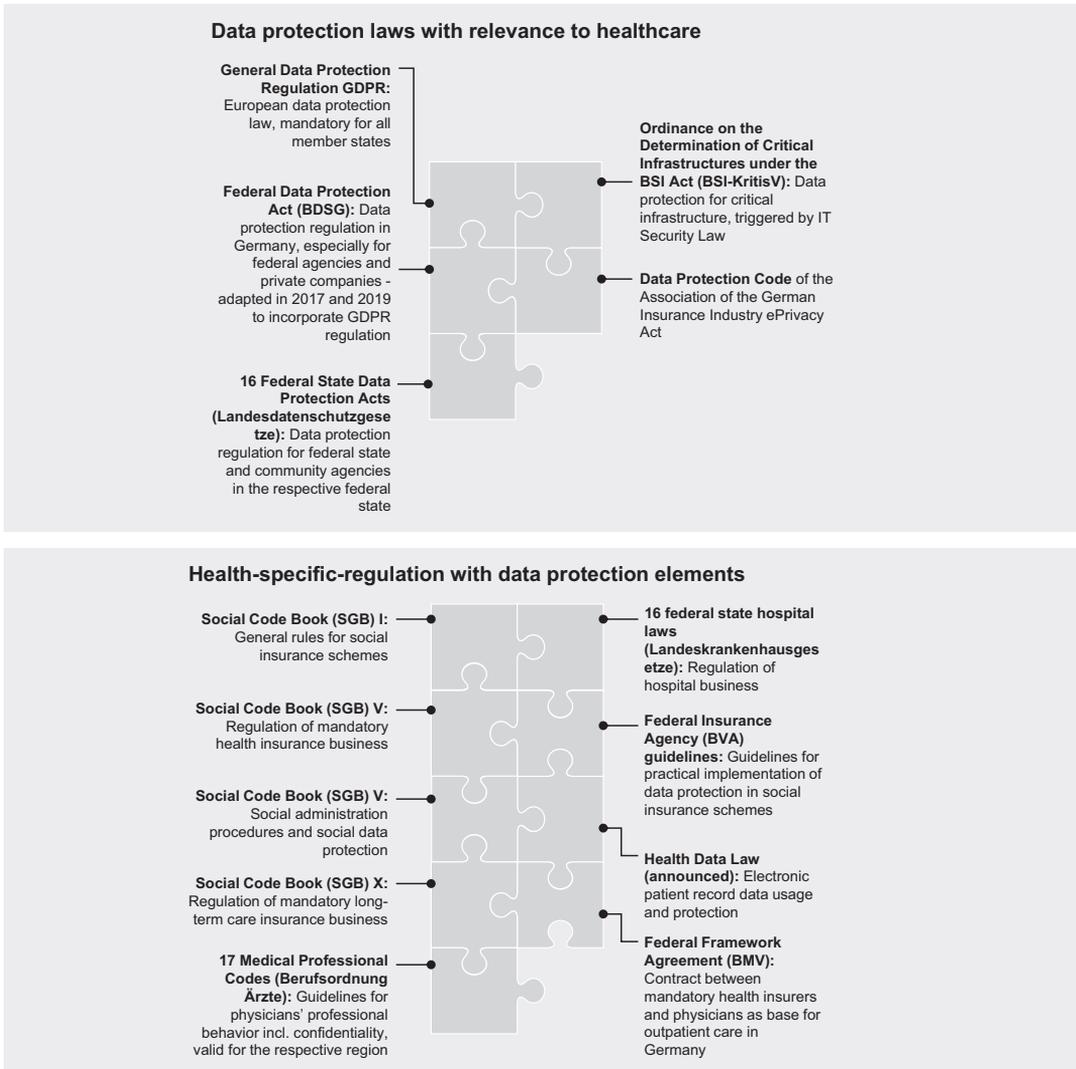
**Privacy compliance:** Empowering patients to practice self-determination is important, but so is protecting them. Privacy assurances (in the sense of privacy by design) should be at the heart of any setup. To allow some data to be used to support medical research, companies should also implement proper anonymization techniques to thwart unnecessary or non-consensual re-identification attempts.

**Complex regulation:** Regulation in healthcare is significantly more advanced than in other industries. However, privacy rules, in particular, are spread across various acts, amendments and directives, thus creating legal uncertainty and making assessments counterintuitive and challenging (for examples in Germany, see Figure 1). The industry is looking for regulatory guidance on ethical questions, such as those provided by the US Presidential Commission for the Study of Bioethical Issues.

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<sup>1</sup> <https://www.eprivacy.eu/medical-app-studie>

Exhibit 1: Selection of existing regulations for health data protection in Germany



Individual players clearly cannot resolve all these challenges alone – instead, they must work with one another and with various authorities. Therefore, it stands to reason that overall coordination in the healthcare system is required. A network approach with a central coordinating mechanism could help to establish the basic infrastructure for ethical data use in the healthcare system, while still taking advantage of new opportunities from patient-generated data and its combination with existing structured data. The role of the coordinating mechanism would be to authenticate and authorize different players in the system, determining who has access to which data and putting the patient in control of these decisions.

In addition, it is important to find answers to the aforementioned ethical questions. To that end, we need mechanisms for explaining to patients how their data is being used. These mechanisms must ensure that not only data is not used against patients' wishes, but also that consent given at a specific point in time in specific circumstances does not stand in the way of beneficial use to the individual patient and larger populations.

A transparent mechanism with meaningful defaults and understandable explanations would allow patients to get involved, yet not burden them with ethical decisions beyond their immediate situation. As described in the health network in Track 1 and hybrid care pathways in Track 2, this mechanism could be attached to the electronic medical record. Since, in many cases, patients already control these records, this approach would be highly convenient and accessible.

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Technological advances in healthcare offer tremendous opportunities in terms of previously unimaginable health insights, triage abilities, and predictive power. But they also raise fundamental ethical questions about data privacy and more. New solutions and networks should enable self-determination, meaning patients themselves – not organizations – own and control their data. Cross-border solutions in consortiums should put patient trust first, minimize exposure risks to personal data, ensure data integrity, and genuinely protect patients' data against misuse. Providing privacy by design and consolidating various isolated sets of health data could be a game changer for the greater public good and pay off in terms of consumer trust and loyalty. Furthermore, it would create greater accountability and relieve individual healthcare providers and companies of the need to draw the continuously shifting line between expediency and ethics on their own.

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## Health data ethics – finding the delicate balance between ,can do' and ,should do'

### A comment from Jens Gunter Greve, YUVEDO

Since Thomas S. Kuhn, we have known that scientific knowledge does not proceed linearly, but rather through periodic revolutions that bring about a paradigm shift in scientific thinking that was valid until then. These revolutions are often initiated by personalities from outside the field. Such a paradigm shift is the replacement of established hypothesis-driven research and evidence-based medicine as the sole standard by data-driven research and real world evidence. Applying Thomas S. Kuhn's theory of science to the medical and technological revolution that has been going on for about a decade means that Big Data, Artificial Intelligence and Machine Learning are the (non-subject) influences that lead to the transformation of the medical-scientific business and can bring about the great breakthroughs. From this follows that the two poles 'can do' and 'should do' are under a – possibly unspoken – imperative 'must do'.

In view of demographic trends, the explosion in healthcare costs and the endless suffering caused by major diseases such as Alzheimer's, COPD, Cancer, Parkinson's, Diabetes, Depression and Obesity, it is no longer a question of 'if' data collection, but only of 'how'.

Restrictions to the right to informational self-determination, which is recognized as a basic and human right, must be prevented by all available means of anonymization etc. However, where people are deprived of their freedom of action and their right to self-determination by serious illnesses and where better symptomatic and causal therapies could be discovered through data collection and analytics, which could maintain or restore these freedoms of the affected persons, the rights to life and physical integrity also represent a high, perhaps the highest of all values. The balance between data protection and data use must be weighed up on the basis of individual case groups. However, the duty of care of the state for its citizens also includes the responsibility to enable the most effective research into chronic and fatal diseases. Restricting the collection of data in a manner detrimental to its purpose is just as out of the question as an unrestricted obligation to disclose health data.

\* See the fundamental work of the science theorist Thomas S. Kuhn 'The structure of scientific revolutions', 1962

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