



Digitalising health data: great opportunities amid widespread scepticism

Switzerland has work to do if it is to build the population's trust

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This report is based on an online survey of 1,500 Swiss residents, conducted in July 2022. The sample was representative in terms of age, gender and region. Because of rounding, percentages may not add up to 100.

We also conducted expert interviews in August and September 2022 with the following people:

- Adrian Schmid, eHealth Suisse
- Christoph Bosshard & Esther Kraft, FMH Swiss Medical Association
- Sven Inäbnit, Roche
- Stephan Mumenthaler & Jürg Granwehr, scienceindustries
- Susanne Gedamke, Swiss Patient Organisation (SPO)
- Simon Michel & Thomas Kutt, Ypsomed
- Alfred Angerer & Matthias Maurer, Zurich University of Applied Sciences (ZHAW)

We would like to thank all interviewees for their valuable input.



Executive Summary

Executive Summary



Digitalising health data? This is what the Swiss think: A recent representative survey by Deloitte Switzerland shows that almost half the population would not consent to their health data being collected and shared digitally. The proportion is even higher among women and those living in the German-speaking cantons. Given global data breaches this scepticism is understandable but also regrettable: the health sector needs greater digitalisation.



Context: Greater digitalisation of the health sector offers too many advantages to ignore. The huge rise in costs that members of health insurance schemes are likely to face over the next few years illustrates the scale and urgency of the problem. Greater digitalisation promises improved efficiency – better services at the same cost or the same services at a lower cost. However, health data are very sensitive personal data and thus any changes must consider upholding the highest level of protection. The population's mistrust of digitalisation needs to be taken seriously but must not be used as a pretext for failing to act. Current levels of scepticism should instead be viewed as a mandate to shape digitalisation of the health sector in a way that achieves efficiency gains while also ensuring data security and protection. It is also important to understand the roots of this scepticism and how it can be tackled efficiently and effectively.



The attitude of the Swiss population: Apart from family members, people are most likely to voluntarily grant access to their personal health data to individuals with whom they have direct contact in a health care setting, such as attending physicians and experts in health care organisations. Patients in Switzerland reserve their greatest mistrust for private companies and research institutions. However, they express greater trust and would be markedly more willing to consent to access if digital data collection offered an opportunity to improve their own healthcare. The availability of incentives may also increase levels of consent but implementing incentivisation in practice would be far from straightforward.



Recommendations for action: Our findings underpin recommendations for action to increase acceptance of the digitalisation of healthcare. First, to a certain extent, data anonymisation would help to boost willingness to the digital collection and sharing of sensitive health data. Second, incentives may be effective but would be far from straightforward to implement. Third, it is crucial that data are stored, processed, and accessed within Switzerland. Finally, action needs to be stepped up to increase trust, transparency, and data security as well as data governance.



Widespread mistrust, but benefits outweigh concerns

Widespread mistrust, but benefits outweigh concerns



Switzerland has well established data privacy laws and regulations. Even rooted in the Swiss Constitution, e.g., Article 13 (2) which covers the right to privacy, stipulates

1. Every person has the right to privacy in their private and family life and in their home, and in relation to their mail and telecommunications.
2. Every person has the right to be protected against the misuse of their personal data.

Switzerland has so far collected health data on a decentralised basis and often in analogue form. Yet extended digital collection and the opportunity to share data more easily with stakeholders in the health care ecosystem would potentially improve patient outcomes, making healthcare more efficient and bringing down costs.

The COVID-19 pandemic shone a merciless spotlight on how little progress has been made towards digitalising the Swiss healthcare sector. At the very least, this is a missed opportunity both for the healthcare system and for the country as a research hub. Nevertheless, digitalisation is progressing and initial benefits are materialising, e.g., digital management of COVID certificates and vaccination coordination. Switzerland's life sciences sector – a crucial pillar of its economy – relies on having a better data management and improved data interoperability for its research, driven by the digitalisation of the health care sector.

However, such digitalisation is a realistic prospect only if the population is willing to make its sensitive personal data available. That means that citizens have to trust both the ecosystem actors and the processes for doing so. In short, without trust, there can be no digitalisation.

Deloitte Switzerland conducted a representative survey of 1,500 respondents to explore their preferences regarding sensitive personal data collection and sharing.

Degree of digitalisation in the Swiss healthcare sector

In a direct democracy like Switzerland, change and reform rely crucially on citizens trusting both the health care actors and processes. Given the Swiss direct democracy and federal structure where decision making is the remit of cantons, municipalities, and citizens, it is particularly difficult to introduce wide ranging change to the health care service on a national level.

This complex federal structure is especially evident when it comes to digitalisation of the health care sector. Digitalising processes can take time, so Switzerland finds itself lagging behind most other countries. IMD's most recent research¹ demonstrates that Switzerland underperforms other countries in terms of digitalisation and e-government. And as Ypsomed CEO Simon Michel states in his interview, "Switzerland will be one of the last developed countries to make optimal use of digital health data."

Digitalisation is forging ahead in many sectors, including healthcare, but progress requires those involved to consent to having their health data collected and shared digitally. Centrally collected and cross-referenced data are crucial for research purposes, to improve the quality of treatment and to increase efficiency.

However, collection and sharing need to be managed on the basis of trust, confidentiality, transparency, and with citizens fully informed. Where they lack the trust to provide consent, progress will be delayed – or worse, prevented.

Despite a generally positive reaction in Switzerland to the launch of its electronic patient dossier (EPD), the move has also attracted criticism. Meanwhile, the proposal to introduce an electronic identity card (e-ID) was rejected by almost two thirds of voters in a March 2021 referendum. Both reactions demonstrate the Swiss population's significant mistrust of digitalisation of their personal data.²

This scepticism is real and must be taken seriously but need not be an insuperable obstacle. What is more important is to understand the root causes of this scepticism so that they can be addressed without foregoing the benefits of ongoing digitalisation.



1. IMD World Digital Competitiveness Ranking 2022, <https://www.imd.org/centers/world-competitiveness-center/rankings/world-digital-competitiveness/>
2. SRF (2021) Eidgenössische Abstimmung - Das E-ID-Gesetz wird deutlich abgelehnt. <https://www.srf.ch/news/abstimmungen/elektronische-identitaet/eidgenoessische-abstimmung-das-e-id-gesetz-wird-deutlich-abgelehnt> (in German)

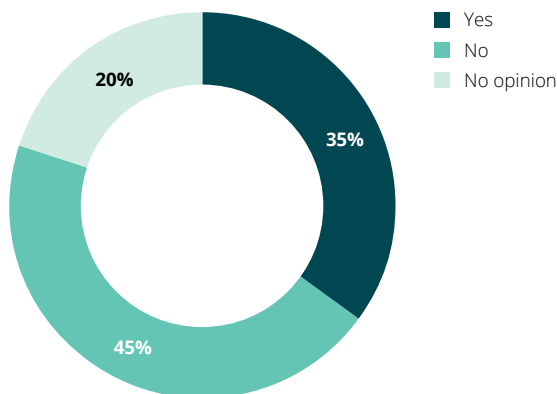


Causes and nature of mistrust in digitalised healthcare

Causes and nature of mistrust in digitalised healthcare

The Deloitte survey, carried out in summer 2022, confirms that the Swiss population generally lacks trust in the digital collection and sharing of their personal health data. There is a high general level of data protection in Switzerland, as Article 13 of the Constitution or the revised Federal Act on Data Protection demonstrates. Yet this does not appear to go far enough to reassure citizens: the survey findings show that 45% of respondents do not want their personal data collected and shared digitally. Commenting on the findings, Patricia Gee, who leads Deloitte's Future of Health in Switzerland initiative, says, "As indicated in the survey, the issue of privacy, including that of your own data, is very important in Switzerland and grounded in local heritage and culture."

Chart 1: Would you agree to your personal health data being collected and shared digitally?



Source: Deloitte Research

Other actors in the Swiss health sector have reached similar conclusions on the basis of the survey findings. As Adrian Schmid of eHealth Suisse states in his interview, "The Swiss want self-determination but are less keen on shared use."

Women and those living in the German-speaking cantons of Switzerland are particularly reluctant to have their data collected and shared digitally (48% and 46% of respondents respectively said "No" to this question). Just 30% of women and 30% of respondents living in the French- and Italian-speaking cantons report that they would be willing to consent to digital collection and sharing of their data (the remaining respondents were without opinion). The over-55s are particularly likely to be unwilling to give consent.

Christoph Bosshard, Vice-President of the Swiss Medical Association (FMH), agrees that the survey clearly demonstrates the population's reluctance to have health data digitalised; respondents prioritise data protection over the benefits of digitalisation. Society as a whole needs to be brought on board, he says: "Digitalisation in the health sector is not just a medical issue; it's also about social values." Agreeing that there is a need for social dialogue, Sven Inäbnit, Director, Governmental Affairs, Quality and Compliance at Roche, adds that the Deloitte findings substantially reflect those of his company's own research.³

It is also clear, however, that opinions are not set in stone. As many as 20% of all respondents answered "No opinion" to this question. This significant proportion suggests there is scope for using more intensive communication to convince those currently undecided about the benefits of digitalised healthcare. This would, though, also require greater transparency about how personal data are handled. Sven Inäbnit believes that the undecided group could be won round with more information while Ypsomed CEO Simon Michel also argues, "It is mainly a question of providing information and explanation." He believes there is still a lack of understanding of the specific benefits of digital applications.

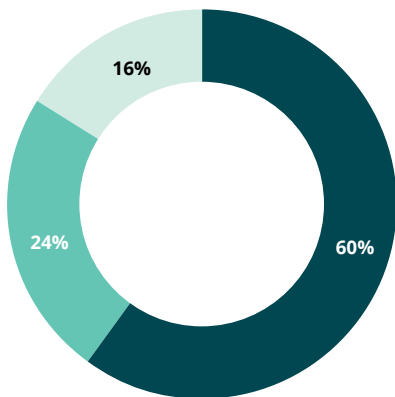
3. See, for example, Pletscher, Mändli Lerch, Glinz (2022) Willingness to share anonymised routinely collected clinical health data in Switzerland: a cross-sectional survey. <https://smw.ch/article/doi/smw.2022.w30182>

No change in attitudes following the pandemic

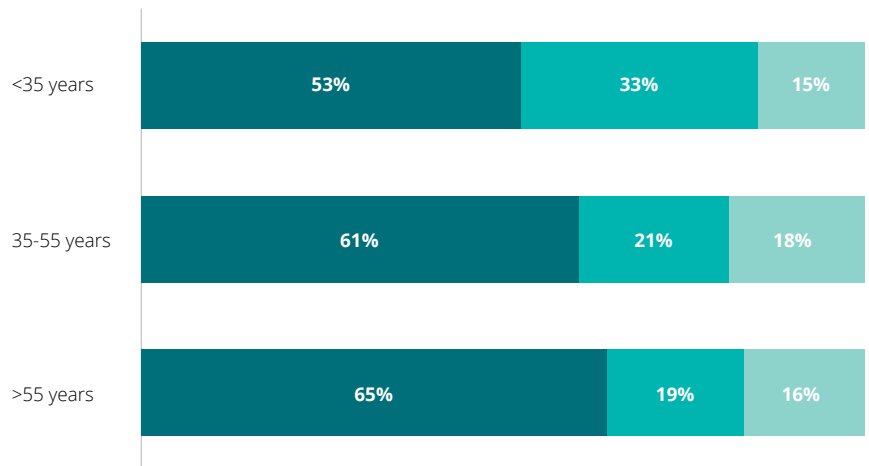
The COVID-19 pandemic laid bare the weaknesses in the healthcare sector but failed to shift the dial on attitudes towards data sharing. Altogether, 60% of the Swiss population say their attitude has not changed, although one in three under-35s are now more likely than before the pandemic to consent to digital collection of their health data, compared with just one in four of the population as a whole.

Chart 2: Has the COVID 19 pandemic changed your attitude about digital collection and sharing of health data?

Overall results



By age group



- No
- I support the digital collection of my health data more than before the pandemic
- I oppose to the digital collection of my health data more than before the pandemic

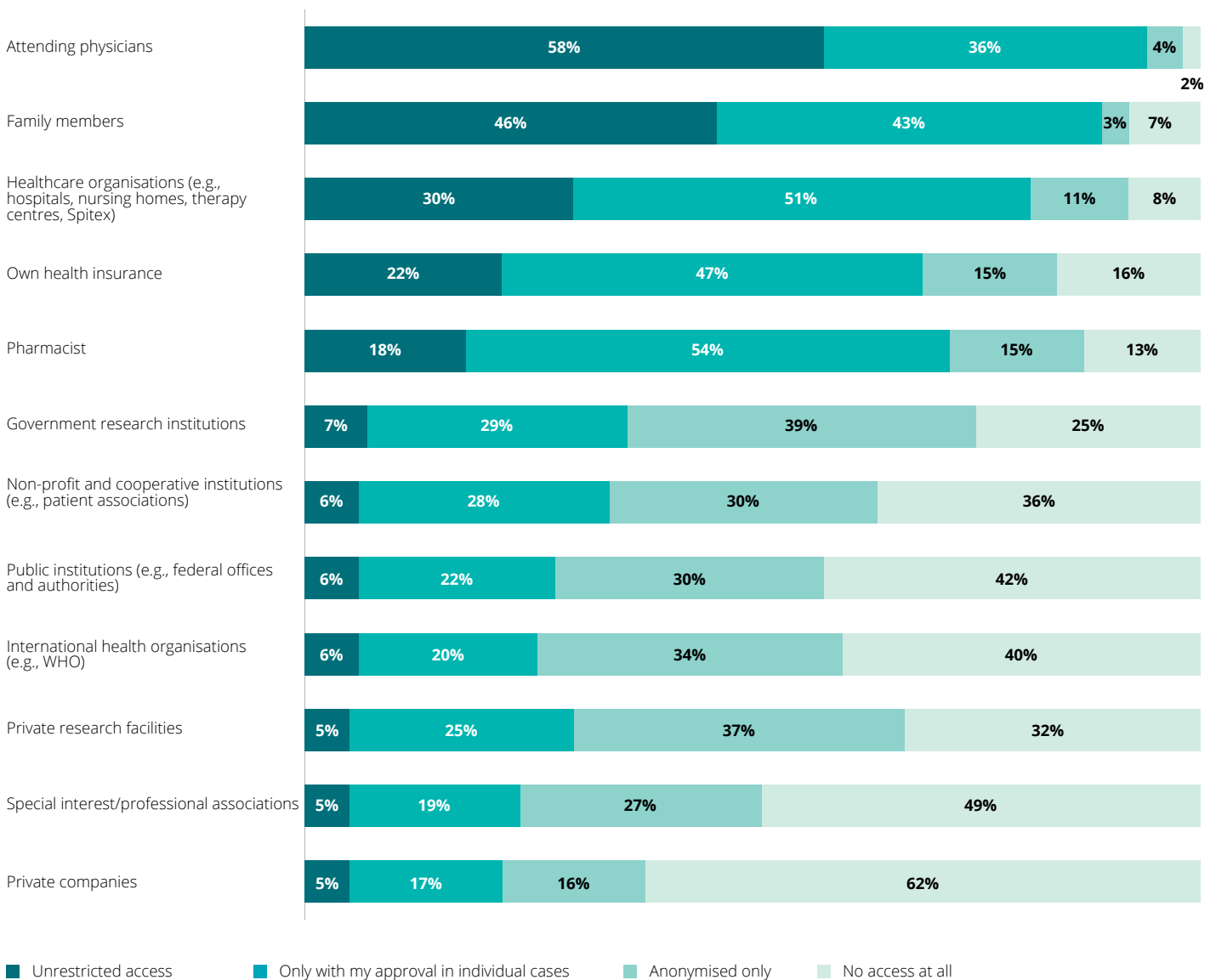
Source: Deloitte Research

Attending physicians enjoy highest levels of trust

Mistrust about data sharing varies widely according to the individuals or agencies involved. Very few people say they would be willing to grant unrestricted access to their personal health data, and even where they are willing, that willingness is confined largely to attending physicians (58% of respondents). The figure is notably higher among the over-55s (70%). However, if consent were also sought in each individual case, the consent rate increases to as much as 94%.

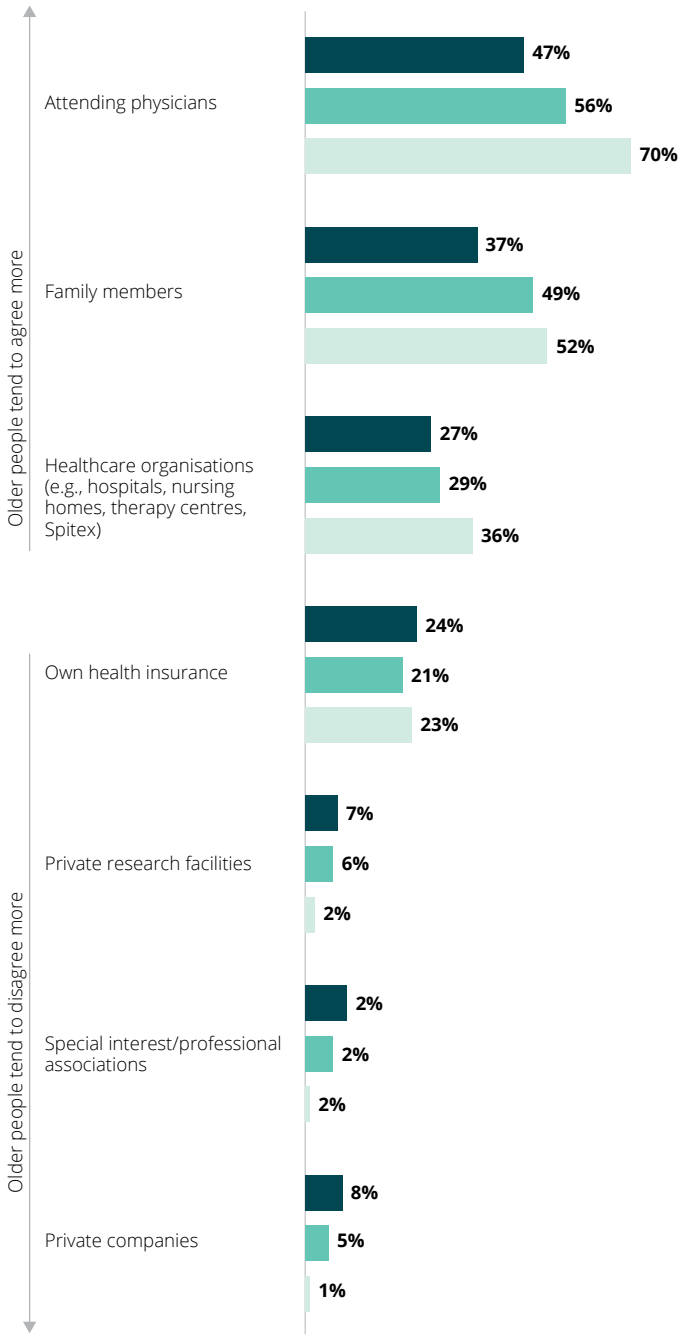
Doctors enjoy by far the highest levels of trust. As FMH Vice-President Christoph Bosshard, who leads on digitalisation within the association, states in his interview, "That's where people clearly feel the issue of digitalisation should be focused." He argues that although doctors' intrinsic motivation is enormous and "we have to digitalise; there is no debate around that", doctors' excessive workloads and the skills shortage means that they are already working at or beyond capacity, with little slack to do more.

Chart 3: If you were free to choose, who should generally have what type of access to your personal health information?

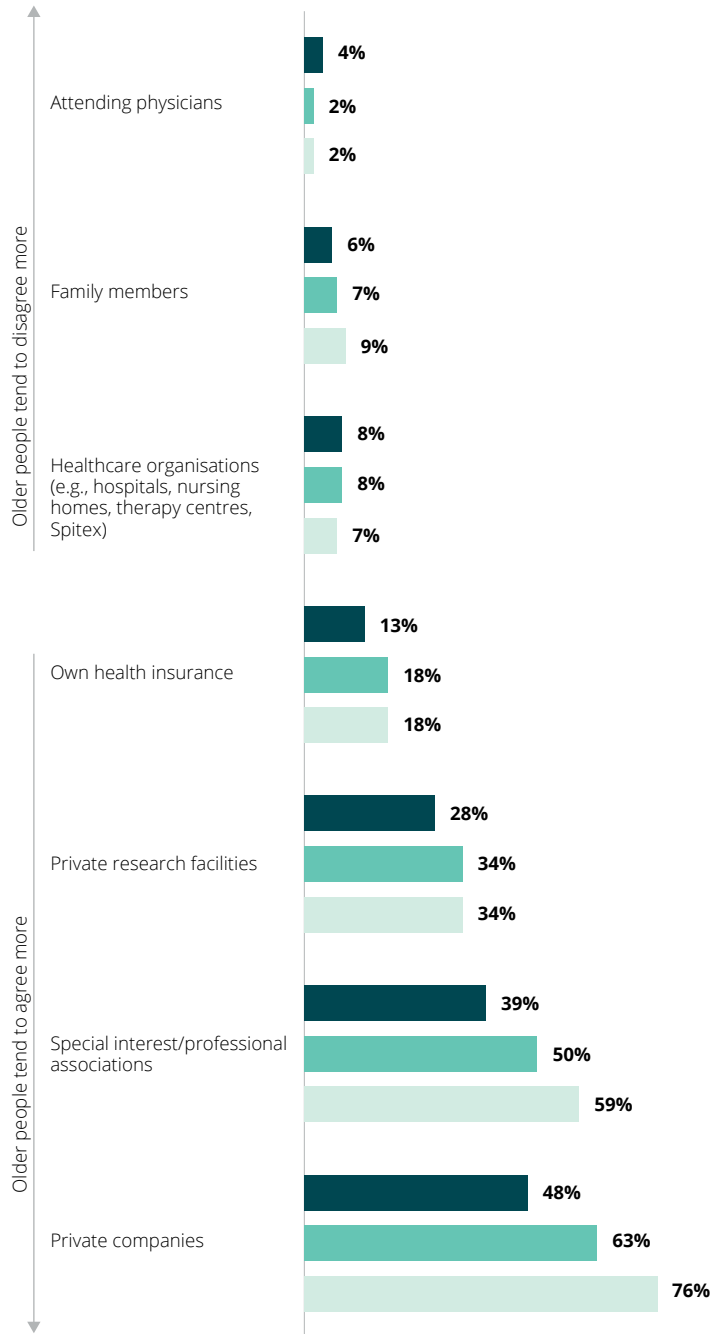


Source: Deloitte Research

Breakdown by age of the provided survey answer "unrestricted access"



Breakdown by age of the provided survey answer "no access at all"



Legend: <35 years (dark teal), 35-55 years (medium teal), >55 years (light teal)

Source: Deloitte Research

The more direct the personal contact an individual has with a health sector stakeholder, the greater the trust that individual is likely to have in the healthcare sector as a whole. Alongside family members (89%), most respondents (81%) say they would be willing to share their data with medical professionals in hospitals,

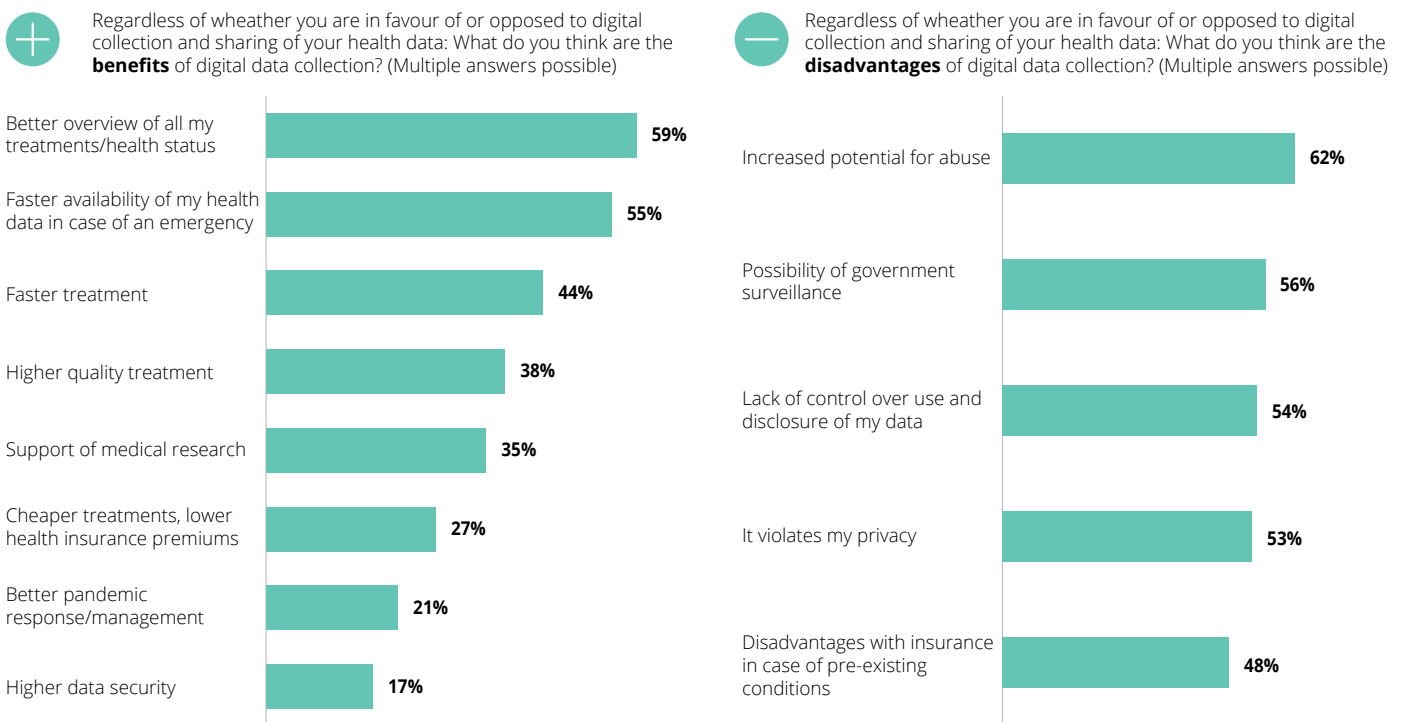
nursing homes, therapy centres and the care provider Spitex. There is also a relatively high level of willingness to share data with individuals' health insurance providers (69% of respondents) or their pharmacist (72%).

Potential disadvantages seen more than advantages

Respondents believe the collection and sharing of health data involves potential disadvantages and advantages. The most commonly cited disadvantages include increased scope for abuse, lack of control over use and disclosure, and the threat of government surveillance.

Respondents are less likely to cite the benefits of digital collection and sharing of health data. This may be the result of low awareness of the specific uses for this data and the benefits these uses may bring.

Chart 4: Advantages and disadvantages of the digital collection of health data



Source: Deloitte Research

More than half of all respondents hope that sharing data will improve their overview of their own health status and ensure faster availability of their data in a health emergency. They are less likely to mention higher quality treatment (38% of respondents) or faster treatment (44% of respondents).

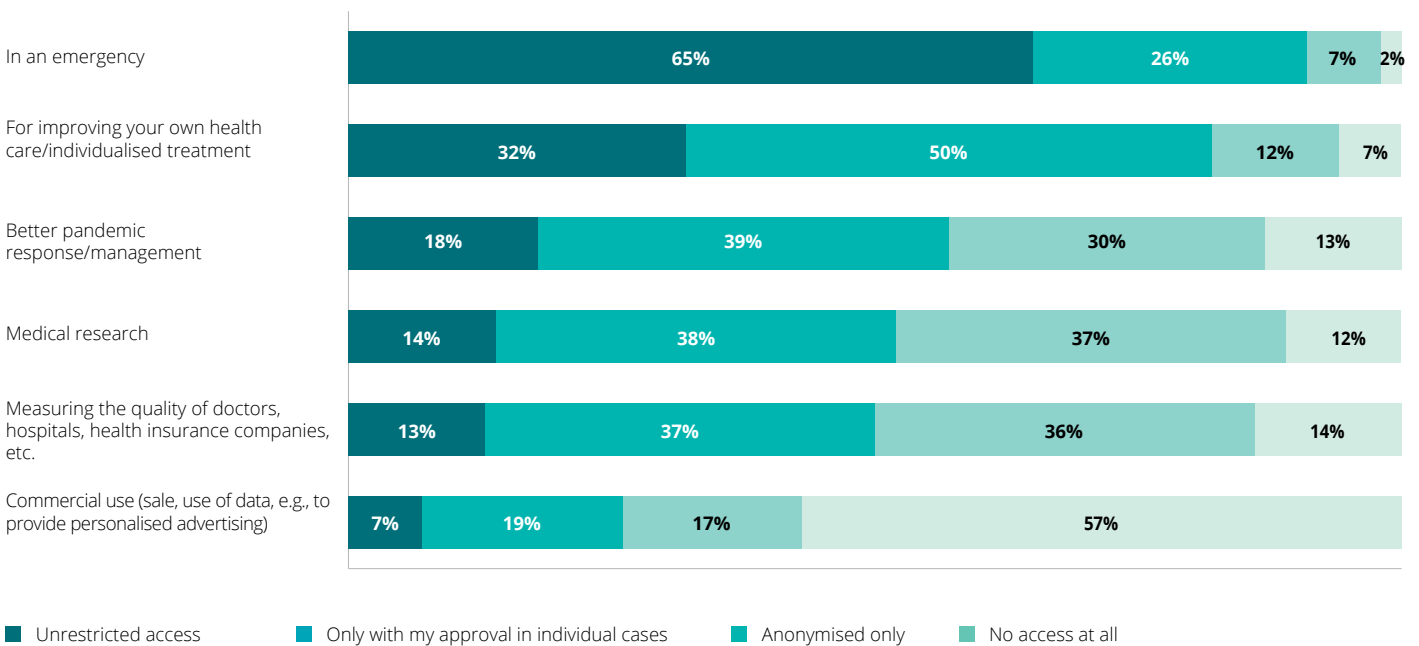
Only 35% of respondents mention the benefits of data sharing to support medical research. Jürg Granwehr, who heads the Pharma Law department within scienceindustries, describes the figure as “very sobering”, adding that it “provides little incentive to share data”.

This low level of perceived benefit should not, however, be seen as a general disapproval of research institutes. A study commissioned by Roche⁴ indicates that 71% of the population and 81% of those with chronic conditions would be willing for researchers to use their health data, provided those data were anonymised. Simon Michel, CEO of Ypsomed, argues that, “In most applications, it is possible to strip out personal information from data.” This reflects the findings of the Deloitte survey: only 12% of respondents report that they would be unwilling to make their data available for medical research under any circumstances. Anonymisation therefore seems to be the crucial factor.

4. Pletscher, Mändli Lerch, Glinz (2022) Willingness to share anonymised routinely collected clinical health data in Switzerland: a cross-sectional survey. <https://smw.ch/article/doi/smw.2022.w30182>

Crisis of trust in health companies

Chart 5: If you were free to choose, for what purposes would you make your health data available?



Source: Deloitte Research

Private sector healthcare companies do not enjoy high levels of trust among the Swiss population. In fact, Swiss nationals reserve their greatest scepticism for such companies. Overall, 62% of respondents would not be willing to share their health data with private companies under any circumstances (Chart 3), while 57% would not consent to sharing their data for commercial use (Chart 5). Alexander Mirow, Life Sciences partner at Deloitte Switzerland, comments, “In the eyes of the respondents, making money from health is seen as a sensitive topic and needs to be handled mindfully.” There is wide agreement among the experts that the findings reflect a general lack of popular trust also in pharmaceutical companies: as Sven Inäbnit of Roche argues, “We need to correct the impression that only the pharmaceutical sector profits from using health data.” The health sector as a whole – including individual patients – would, he says, benefit from using digital data. Ypsomed CEO Simon Michel argues in a similar vein, “Digital health reduces the cost burden on the health sector.”

Unfortunately, the reputation of the pharmaceutical sector does not always extend to its use of data given the Interpharma’s Gesundheitsmonitor 2022⁵ reflects a general widespread popular trust and good reputation of the pharmaceutical sector as a good employer and driver of innovation. This is highly surprising: the pharmaceuticals industry already considerably outperforms other sectors in terms of privacy, data protection, and data security. As Sven Inäbnit emphasises, “Protecting our patients’ health data is part of our DNA.” Nevertheless, it is clear that the population as a whole does not yet adequately appreciate that research purposes require only aggregated data and not information on individuals. Stephan Mumenthaler, Director General of scienceindustries, says, “The life sciences sector’s interest is confined to aggregated health data. But even aggregated collection requires trust and confidence that people’s personal data are being protected.”

5. Bieri, Kocher, Venetz, Bohn (2022) Gesundheitsmonitor 2022. https://www.interpharma.ch/wp-content/uploads/2022/06/LV-IPH.01.22.001-%E2%80%93-Gesundheitsmonitor-2022_d_V02.pdf (in German)

Recommendations for action: Squaring the circle – tackling widespread mistrust to drive forward digitalisation

April May June July August September October November December



Recommendations for action: Squaring the circle – tackling widespread mistrust to drive forward digitalisation

The survey findings reflect significant concerns on the part of the Swiss population about the digital collection and sharing of their sensitive personal data. These concerns are justified and need to be taken seriously, but if tackled adequately, they should not impede digitalisation. The survey findings demonstrate clearly that reluctance is reduced if the digital collection and sharing of their data is linked to specific purpose and use cases. For example, one respondent in three would have no reservations if sharing data improved their own healthcare and facilitated more individualised treatments. In the scenario where individual consent would be obtained in every case, this proportion rises to one in two. As many as 38% and 37% (Chart 5) respectively would require their approval in individual cases for medical research or for use of their data to measure the quality of the healthcare providers. Meanwhile, 37% and 36% respectively would consent to these use cases provided their data were anonymised. “The patient must have ultimate control over their data,” says Susanne Gedamke, CEO and appointed delegate of the Board of Trustees at the Swiss Patient Organisation (SPO).

Professor Alfred Angerer, Head of Healthcare Management at ZHAW, argues that digitalisation requires will, ability and need. The cost in both financial and quality terms of not making crucial data available must, he says, be made clear: “It is a disaster for citizens that we do not have an effective EPD” he argues, adding that Switzerland has the ability to tackle the technological challenges. Angerer envisages a time-limited think-tank along the lines of Germany’s Health Innovation Hub, which operated until the end of 2021.

The rapid advance and growing hyperconnectivity of the digital health care ecosystem poses new challenges to the embedding of existing regulatory frameworks (e.g., data protection, product liability, reimbursement of new technologies under the mandatory social health insurance scheme, etc.). Most of these frameworks are not specifically tailored to individual emerging use cases and changing technology as well as the connected data risks or even to the healthcare sector as such.

Policymakers should push for increased public discussion between the regulator, industry, and research and education representatives. These should provide regularly revised opinions, position papers or guidelines and standards on the various aspects of ongoing digitalisation. This would allow organisations to gain a good understanding of the regulator’s intention while actively managing public expectations.

On the other hand, organisations must consider data risk management as a core design element of their corporate strategies and proactively foster and communicate it. The investment would generate a ‘win-win’ situation: organisations will be able to win patients’ trust by demonstrating corporate transparency and integrity while actively mitigating any emerging risks before they become significant.

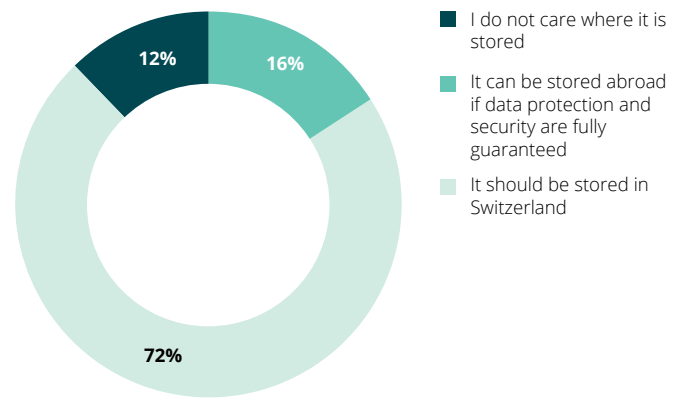
Based on the survey, we believe that the following four strategic measures will drive greater acceptance of healthcare ecosystem digitalisation:

- Anonymisation helps to some extent
- Data storage and monitoring in Switzerland is essential
- Trust, data security and transparency about the use of data
- Data ethics and clear demonstration of benefits and purpose to all stakeholders

Deep dive on our recommendation: Data storage and monitoring in Switzerland is essential

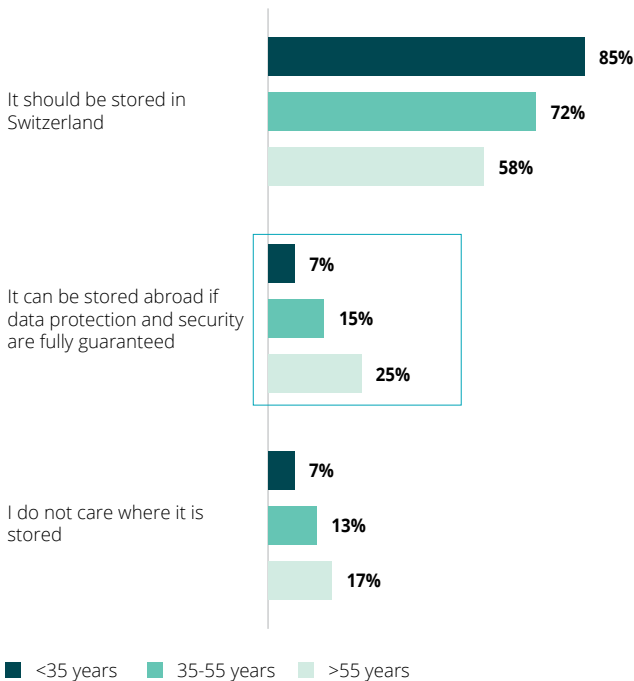
Unsurprisingly, 72% of the population insist that their data should be stored within Switzerland. This rises to 77% of respondents in rural areas and 85% of the over-55s. Doctors and hospitals are the most frequently cited preferred responsible for the storage of data (67%), rising to 76% among the over-55s. The under-35s, by contrast, would prefer to have their data stored by their health insurance provider (45%).

Chart 6: If digital data are collected: How important to you is the location where your digital health data are stored?



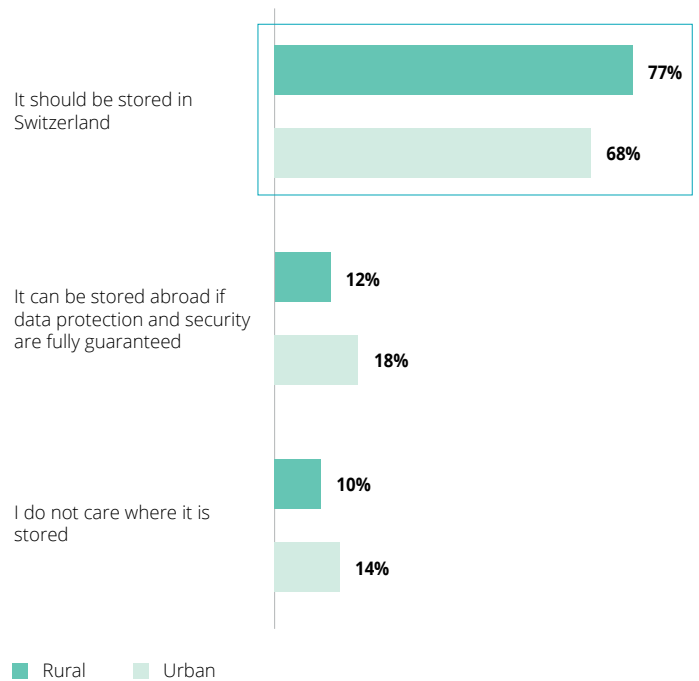
Source: Deloitte Research

Breakdown of response by age group



Source: Deloitte Research

Breakdown of response by living location

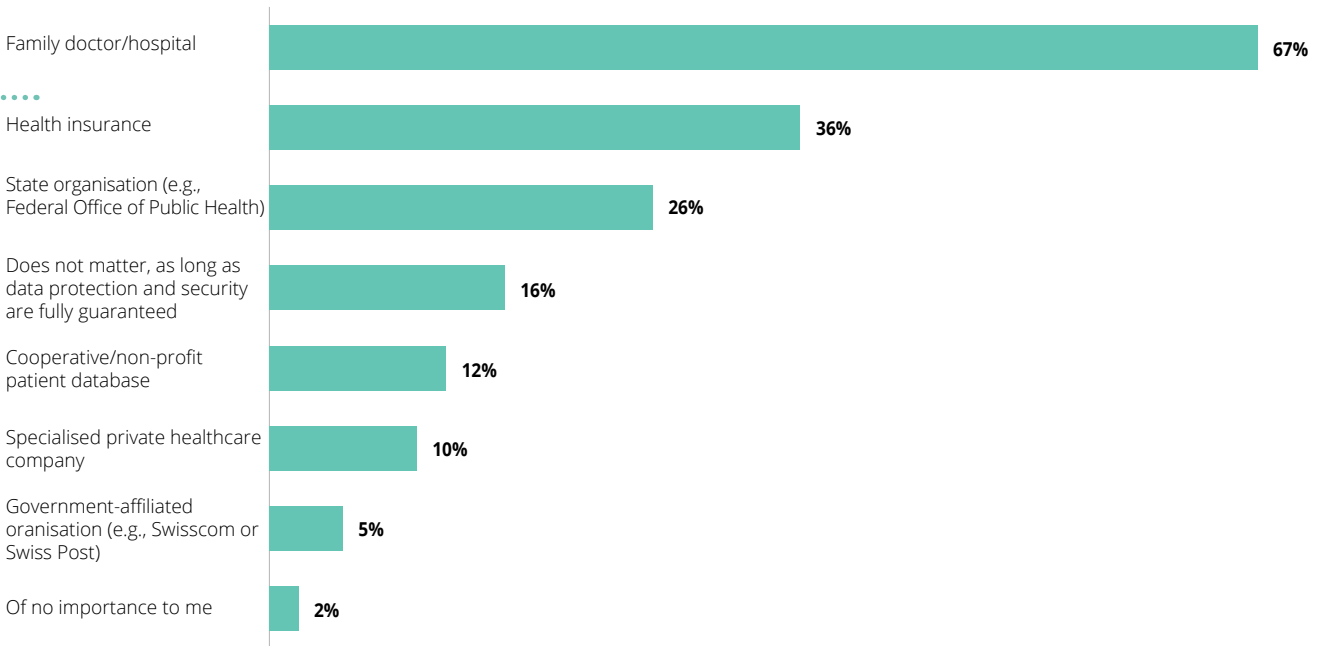


Digitalising health data: great opportunities amid widespread scepticism

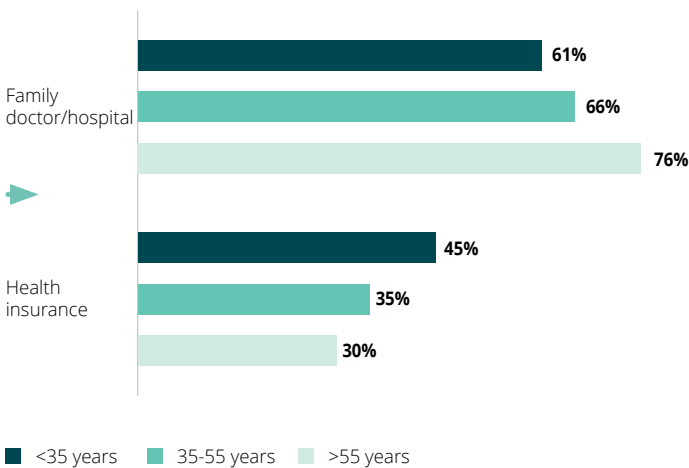
Very few respondents would be happy for their data to be stored by companies affiliated to the Confederation, such as Swisscom and the Swiss postal service (5%), by state organisations (26%), by cooperative or non-profit patient databases (12%), or by specialised

private healthcare companies (10%). The overwhelming majority of respondents (85%) believe that the agency collecting health data needs to be monitored, and for more than half, that could only be done by a government body.

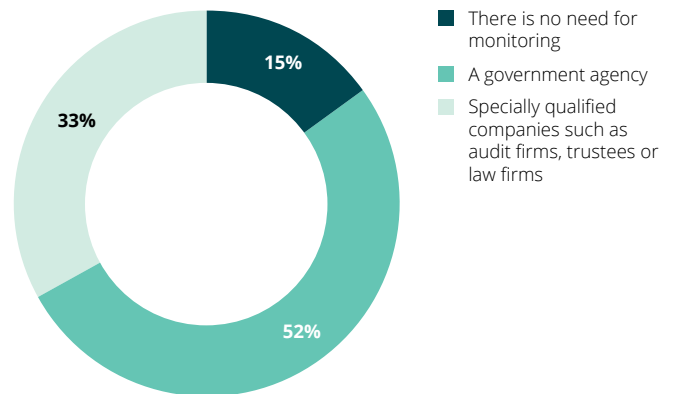
Chart 7: Data storage and monitoring
If digital data is collected: Who should be responsible for digitally storing your health data? (Multiple answers possible)



Age



Who should monitor the organisations that store your health information?



Source: Deloitte Research

Deep dive on our recommendation: Trust, data security and transparency about the use of data

The survey findings demonstrate clearly that it will take more effort and considerable patience to build the trust of the Swiss people to a point where they are willing to have their health data collected digitally and shared more widely. As Sven Inäbnit of Roche notes, “Greater willingness to share data is crucial.”

Trust in digital health services means that patients need to trust professionals. As Adrian Schmid of eHealth Suisse argues, “The data transfer channels then become much less important. If my general practitioner is in favour and I trust him or her, then I’ll consent.” Healthcare professionals (HCPs) could therefore take on the role of digitalisation ambassadors – trusted individuals who take the lead in convincing individuals and benefitting the system as a whole. But while HCPs have a crucial role to play, they also have substantial responsibilities and accountability, he adds, and must be both willing and able to take the lead in this way.

Susanne Gedamke of SPO thinks, however, that HCPs are holding up digitalisation. One reason, she believes, is that many cannot afford the costs involved in setting up the necessary IT infrastructure. Another is that they are not yet required to provide digital health data to hospitals or nursing homes. Achieving change here will require appropriate support structures, know-how and networks.

More intensive and clear communication of the specific advantages of the digital collection and sharing of health data could go a long way to creating change. As Adrian Schmid of eHealth Suisse argues, “People do not like a lack of transparency. They want to know what the background processes are.” He adds that rights of access would need to be granted individually, with individuals also having the right to withdraw their consent, as is the case with the EPD.

Transparency and information could be secured via four different stakeholders:

1. Solution providers of tools for data processing: they would have to demonstrate technical measures are put in place to build trust in technology that they are adhering to data security and data protection principles. This could include, for example, ISO certification including appropriate safeguards, such as encryption, access management, retention, segregation, backup, and recovery and incident management. The limitation of purposes for which personal data may be used is an important issue. For example, a cloud provider shall not use stored patient data to analyse potential online shopping patterns of patients.
2. Healthcare organisations: need to clearly articulate the benefits of digitalisation and data sharing in terms of better and easier care, lower costs, greater efficiency and interoperability.
3. Healthcare professionals: they are pivotal as they need to understand their own benefits as well as the benefits to patients of digitalisation.
4. Patients: they need to understand the value they get and the beneficial impact on their own daily routines and health by data sharing.

Role of politics

Our interviewees say politics should play a significant role as well. Switzerland needs to bridge the divide between a centralised digital health ecosystem and the current patchwork of arrangements represented by a federal decision-making system. Every agency needs to be on board if the Swiss people are to build trust in digital healthcare. The primary challenge is to politicians: for Stephan Mumenthaler of scienceindustries, the political debate should focus on quality rather than cost. Christoph Bosshard of FMH also argues that politicians and government currently go much further in measuring quality data of service providers such as physicians, the care sector and hospitals than the results suggest they can legitimately do; they therefore need to acknowledge the survey findings.

Adrian Schmid of eHealth Suisse says Switzerland needs a national investment offensive if it is to bring its outdated IT infrastructure up to date. The country's federal health sector lacks the central leadership to drive forward digital data sharing. However, case studies such as from Denmark demonstrate that such data sharing would bring about a qualitative improvement in healthcare. Annieck de Vocht, Healthcare Sector Leader at Deloitte Switzerland, says that cantonal responsibility makes implementing and financing data sharing more difficult: "Switzerland's cantonal system has its advantages in several areas, but poses a challenge for the central coordination of digital health data."

Nevertheless, this is a nettle that Switzerland can and must grasp. There are plenty of possible solutions, but implementing them requires political will and cooperation from service providers across the health sector. National politicians will be the primary driver and must take action, argues Alfred Angerer: "The Swiss Confederation needs to set out a vision for where it wants to go."

If it does, then the Swiss people's trust in digitalised health services can be built. As Angerer puts it, "Digitalisation is not a fair-weather project: it is the only way in which we will be able to maintain our high standards in health, quality and costs in future. The question is not whether we digitalise; it is when."



Case study: Denmark leads the way

Denmark leads the way

Apart from the recommendations for action described in the last chapter, it is worth taking a look at Denmark, which is a flagship for progress towards digitalised healthcare. The most recent rankings compiled by the International Institute for Management Development (IMD) in Lausanne put Denmark at the top of the table.⁶ The country is a pioneer in particular of data sharing with state institutions (e-government), including the healthcare sector.

Switzerland is a similarly sized and similarly prosperous country with a comparable population, so Denmark should be an obvious example to follow.

Simply copying will not fit the bill

However, Matthias Maurer, Deputy Director of the Winterthur Institute of Health Economics at the Zurich University of Applied Sciences (ZHAW), points out that emulating Denmark is not quite as straightforward as it might seem. He has spent many years conducting comparative research into different healthcare systems and policies and has visited Denmark frequently, developing familiarity with the framework in the process. He sees a fundamentally different conception of statehood in the two countries as the main reason why the Danish model cannot simply be transferred to Switzerland. In the nation state of Denmark, health is managed and financed nationally. The country has no health insurance schemes: the state is responsible for financing health services and meets the cost out of tax revenues.

Denmark's centralised structure is not, however, the key difference between the two countries. More relevant is the fundamentally different conception of the role of the state in the two countries. As Maurer notes, the Danish population "sees the state as something good and supportive and have considerable levels of basic trust in it." The Swiss population, by contrast, is much more sceptical about the role of the state: "That became very evident during the COVID-19 pandemic", adds Maurer.

Making an early start with digitalisation

Denmark created the foundations of a digital health sector early on. Around 40 years ago, it started collecting comprehensive data on the entire population from cradle to grave. The cornerstone of this database is a unique personal identification number that every Danish citizen uses to identify themselves in their interactions with government agencies. This makes it easy to link and share data between agencies and service providers.

Maurer argues that the situation in Switzerland is different: the system actually prevents different data being linked and shared. And where data are available, he says, sharing is frustrated on

the pretext of data protection rules. Maurer says, "The shortage of data means we lack transparency"; this increases inefficiency and makes it more likely that medical services are duplicated or even triplicated. Motions have recently been laid before the Swiss parliament on introduction of a unique patient indicator, or master patient number; but the cantons would have to join forces to implement such a system. "We've hardly made any progress", adds Maurer.

6. <https://www.imd.org/centers/world-competitiveness-center/rankings/world-digital-competitiveness/>

Mandatory but with an opt-out

Digital collection of personal data is mandatory in Denmark. Citizens can opt out of their data being used for secondary purposes, such as research, but few actually exercise this right. By contrast, Switzerland's electronic patient dossier (EPD) has a dual opt-in system: both individual patients and doctors may decline to create an EPD.

The advanced level of digitalisation in Denmark does not mean, however, that administrative simplicity is achieved at the expense of individual privacy. The statutory requirements governing who is authorised to access health data are highly stringent. Individual citizens can see in detail who is making use of their data, when and for what purpose, and can make a complaint if they suspect unethical access. As Maurer argues, "Denmark is an example of how to manage data protection meaningfully yet remain open to data sharing that will benefit the entire healthcare sector," he says.

Responsibility for governance lies with the independent Danish Health Data Authority⁷, which also defines interfaces and IT standards and drives development and improvement. One key advantage of the Danish system is that virtually all Danish hospitals are state-run. Individual hospitals may use different IT systems for internal purposes but these systems are linked to a universal database that stores health data centrally.

7. https://sundhedsdatastyrelsen.dk/da/english/health_data_and_registers



Contact

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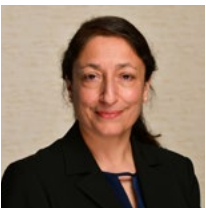


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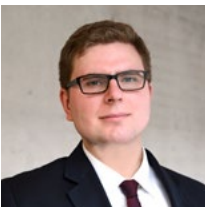


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