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Health Data Governance: What‘s in it for Switzerland?

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fondation BOTNAR

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Executive Summary

Health data has the potential to improve our health systems and make them more efficient. Thanks to the support of digital technologies for the analysis and the use of health data, it is possible to produce new insights. Based on data, doctors' diagnoses are already more precise and diseases can be identified earlier. Research is able to develop increasingly effective drugs and customised therapies. Through contact tracing, the state is able to contain a pandemic such as Covid-19 in a targeted manner, provided sufficient information is available about the course and the spread of the infections. When used correctly, health data offer endless possibilities of improving public health. The declared goal of the UN agenda of providing more than one billion people worldwide access to healthcare services by 2030 is within reach.

However, in every situation where there is potential, there are also challenges and risks to be met. Health data are sensitive and may be misused. Having more and better data means having more knowledge and thus, more power. A risk is that some actors may benefit from the use of health data more than others. In view of all this, the question of the governance of health data arises. **How should the use of health data be regulated nationally and internationally, in order for their potential to be fully exploited and so that everyone can benefit from it? And what is the role that Switzerland can play in all this? *What's in it for Switzerland?***

This study presents **12 broad-based recommendations for action for better health data governance**. They are the result of a national participatory process carried out together by foraus and Sensor Advice in 2020. In the context of the two formats PoliTisch and Policy Kitchen, a total of 140 stakeholders and interested citizens have discussed the challenges of dealing with health data and the solutions developed. The analysis shows how a great need for action is felt, both at a national and international level, to improve the handling of health data, and not just at the regulatory level. **A coordinated approach is required, from all parties, on five different governance dimensions**: political, societal, ethical/legal, financial and technical.

In political terms, we need more and better cooperation between all parties in Switzerland, under the leadership of the Confederation. There is no common thrust in foreign health policy. Thanks to Geneva's international vocation, Switzerland has the opportunity to position itself as a hub for global health data governance. By promoting initiatives and platforms, it could significantly contribute to further international digital cooperation. Moreover, it could play an important role as mediator in the development of an **ethical/legal** framework for handling health data on a multilateral level.

At the same time, Switzerland's foreign policy's focus should be on the European Union. Our big neighbour is a shining example in the field of data protection, and a pioneer in the regulation of digital technologies. For Switzerland, the integration, in the medium and long-term, into the European health data ecosystem would be an important driver for innovation. Research and the economy depend on "big data" and unhindered cross-border data transfers. This is also where the greatest **financial** risk lies: Switzerland can remain competitive and continue to conduct innovative research and development only if it is not isolated.

Technical standards and infrastructures are necessary, in order to be able to exchange health data as barrier-free as possible. At the national level, the Confederation is on the right track, promoting initiatives such as the Swiss Personalized Health Network. However, there is still a lot to do in relation to data infrastructures, as shown by the odyssey of the electronic patient record.

Also at the level of **society**, there is an urgent need for action. Here, the biggest challenge is data literacy. Hardly anyone knows what health data is collected, let alone how it can be managed and used. In order to strengthen data literacy, more transparency and exchanges with the population are needed. Our participatory formats have clearly shown that there is interest in such exchanges, and that the population is willing to deal with the issue of their rights in relation to health data. ●

1. Introduction

The digitalisation of health systems offers new opportunities to achieve Universal Health Coverage by 2030.

Digital technologies are changing our health systems at all levels: from the research of new vaccines, drugs or medical devices to treatment methods and healthcare services in our everyday life. They open up new and partly still unknown possibilities, changing the way we understand health and how we deal with it. Data-based digital technologies have the potential to provide people everywhere in the world with access to health systems and improved medical care.[1] For the international community, the digitalisation of health systems offers new opportunities to achieve the goal of Universal Health Coverage by 2030 (*Sustainable Development Goal* n°3) as well as, for example, to combat infectious diseases such as Covid-19 more effectively. The potential of digital technologies for public health was also recognised by the Federal Council in its Swiss Health Foreign Policy 2019-2024, adopted in May 2019.[2]

Health data and thus, all information that, whether directly or indirectly, describes the health condition of an individual or a population group, play a central role in the application of new digital technologies. Health data can help research to find new insights and make informed decisions in the treatment of patients, for example through the early detection of diseases.

At the same time, personal health data is extremely sensitive and is associated with the risk of misuse and discrimination. This contrast between usefulness and risk of misuse of health data represents a challenge for the parties in this field, especially since the exchange of data today often crosses borders. This leads to the question of the governance of health data. In this study, we present 12 recommendations for action aimed at better health data governance. They are the result of a national participatory process involving both stakeholders and interested citizens in Switzerland. Within the framework of our PoliTisch and Policy Kitchen formats, we asked how the handling of health data could be improved nationally and internationally, and what role Switzerland should play in all of this, briefly: *Health Data Governance: What’s in it for Switzerland?* ●

2. Project and Methodology

The project aims at discussing the governance of health data and new digital technologies in an inclusive and interdisciplinary way, whilst developing solutions for Switzerland and its role within the global environment.

2.1 Project: a National Participatory Process

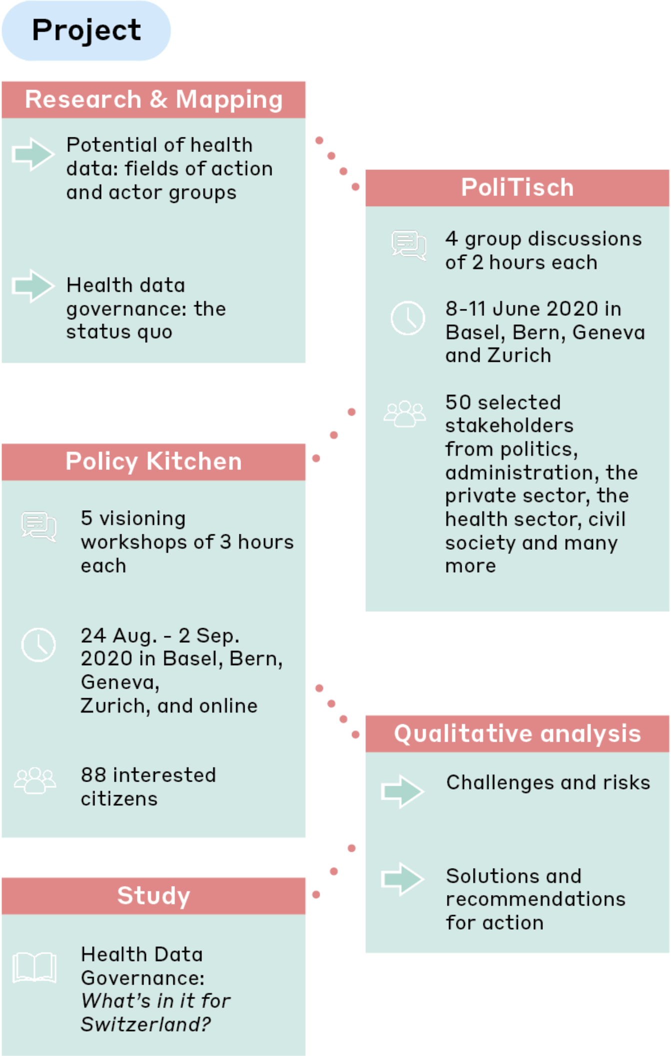
Health Data Governance: What's in it for Switzerland? is a joint project by foraus and Sensor Advice, supported by Fondation Botnar. The project aims at discussing the governance of health data and new digital technologies in an inclusive and interdisciplinary way, whilst developing solutions for Switzerland and its role within the global environment. Thus, in 2020, we led a national participatory process involving both stakeholders and interested citizens (cf. Fig. 1). For the purposes of this study, we carried out a qualitative analysis of the data resulting from this process and processed the key findings. Chapters 5 and 6 show the challenges and risks, as well as the possible solutions, with respect to health data, identified by the participants through our participatory formats PoliTisch (cf. 2.2) and Policy Kitchen (cf. 2.3). In this analysis, these have been classified according to various dimensions of governance: political, societal, ethical/legal, financial and technical. The recommendations for action are the result of the analysis of this data. They have been classified and fine-tuned with the purpose of mapping the potential of health data for the parties involved (chapter 3) and in relation to the status quo of health data *governance* (chapter 4). Primarily aimed at Swiss politics and administration, they should be playing a major role in the decision-making related to domestic and foreign policy measures aimed at improving national and cross-border health data governance. At the same time, these recommendations for action should also be understood as a call for interdisciplinary cooperation between all parties involved, in order to find inclusive and broad-based solutions.

2.2 PoliTisch: Stakeholder Perspectives

In June 2020, we held the PoliTisch in four Swiss cities with a total of around 50 participants. These are focus groups involving 12 to 13 selected stakeholders with leading roles in science, politics, administration, private companies, start-ups, insurers, health institutions, patient organizations, think tanks, international organisations, foundations, media and civil society initiatives. The guided discussions tackled the practical challenges in dealing with health data, the opportunities and risks related to global health data governance, as well as possible solutions. Sensor Advice and foraus moderated the debates, ensuring that the same topics were discussed in all groups and included in the analysis, collecting valid results thanks to the comparison of the different perspectives. The PoliTisch have been recorded and the audio recordings have been transcribed in an anonymous form to protect the identity of the participants. Sensor Advice carried out an analysis of the four group discussions according to a qualitative approach based on content[3] and discourse analysis[4]. The main findings resulting from this analysis were integrated into the identification of challenges and risks and in the formulation of solutions and recommendations for action. As data have been anonymised, the names of the PoliTisch participants do not appear in this publication.

2.3 Policy Kitchen: the Population's Visions

In August and September 2020, the Policy Kitchen Challenge "My Data - My Health: Visions for the Use and Exchange of Personal Health Data in 2030" took place, building upon the initial findings of the PoliTisch. Policy Kitchen is a digital innovation platform developed by foraus, with the support of Engagement Migros, based on a crowdsourcing method. Policy Kitchen enables any interested party to find and discuss creative political recipes for the challenges faced by society. This allows the broader population to take part in a participatory and location-independent process to shape political solutions. In four in-person workshops across Switzerland and one virtual, a total of 88 participants had the chance to develop their own visions on the use of personally generated health data. The workshops were public and the invitation was shared with interested people via various channels and networks. In addition to relevant parties from the health sector, special attention was given to interested youth organisations, student unions and university institutes interested in the topic. There were no requirements of previous knowledge on health data and governance. A total of ten experts from research, administration, civil society and the private sector introduced participants to the topic and shared their knowledge and expertise on the opportunities and risks involved in handling health data. In the subsequent visioning process[5], participants worked in small groups of two to four people, developing positive or negative visions on how health data could be handled in ten years' time. They wrote an article in an imaginary international newspaper with a headline supposedly from year 2030 (cf. UN Sustainable Development Goals), reflecting either their greatest hopes or their worst fears. This resulted in a total of 36 positive and negative visions, which are all available on the Policy Kitchen online platform.[6] They have been integrated into this publication and some excerpts are quoted to support arguments and recommendations for action. In the following pages, some selected newspaper articles can also be read in full. A list of all contributors to the Policy Kitchen Challenge is available at the end of the publication. ●



Project

Research & Mapping

Potential of health data: fields of action and actor groups

Health data governance: the status quo

PoliTisch

4 group discussions of 2 hours each

8-11 June 2020 in Basel, Bern, Geneva and Zurich

50 selected stakeholders from politics, administration, the private sector, the health sector, civil society and many more

Policy Kitchen

5 visioning workshops of 3 hours each

24 Aug. - 2 Sep. 2020 in Basel, Bern, Geneva, Zurich, and online

88 interested citizens

Qualitative analysis

Challenges and risks

Solutions and recommendations for action

Study

Health Data Governance: *What's in it for Switzerland?*

Fig. 1: Overview of the project "Health Data Governance: What's in it for Switzerland?"

3. Potential of Health Data: Fields of Action and Actor Groups

Health data and digital technologies have great potential to improve healthcare and make it more efficient.

Health data (cf. Box 1) and digital technologies have great potential to improve healthcare and make it more efficient.[7] In order to better understand this potential, both our research and our preparation for the participatory process were based on the identification of four fields of action, in which, already today, health data play an important role, and also in future could bring about a number of positive changes: health policy, healthcare services, research, and commercial use. The main actor groups in Switzerland dealing with health data, who took part in our PoliTisch and Policy Kitchen formats, can be assigned schematically to these four fields of action (cf. Fig. 2).

Box 1

Health data

Traditionally, health data is deemed to mean medical data, i.e. “laboratory test results, diagnostic images, medical records, public health registry data, and data produced in the context of biomedical or clinical research”.[84] Thanks to the increasing digitalisation of patient files, health data have become increasingly easier to view and use. On the other hand, the scope has been expanding in recent years, to include a series of new types of data: thanks to scientific and technological progress, genomic data, i.e. information about the genetic material of humans, is increasingly generated.[85] In particular, however, health data is no longer produced and analysed only by health service providers, but increasingly also in non-clinical environments by private companies or directly by private individuals with the help of portable measuring and analysis instruments such as smartphones or wearables. Today, data which do not have a direct connection with health can become health data too. When combined with other data and analysis using new, data-based technologies, it can contribute to making statements about the health status of an individual or a population group. Therefore, we will take into account the broader definition of health data by the OECD understanding it as: “any information relating to an identified or identifiable individual that concerns their health, and includes any other associated personal data”. [86]

3.1 Health Policy

The scope of health policy includes decisions, plans and measures by state governments or international organisations aimed at achieving certain goals in health care and at protecting and improving the health of society. Health policy includes health care reforms, prevention campaigns or the provision of infrastructures for general health care.

Potential: Future government health policy and healthcare could benefit from more precise data on the health conditions of individuals, as well as from new modalities of information and communication with the population.[8] This no longer refers to clinical data only, but also to new types of data from the private environment of citizens and patients. In relation to the fight against communicable diseases, the Covid 19 crisis has been the perfect example of how digital technologies and the regulated handling of health data can support governments and authorities. For example, digital contact tracing based on data can help reduce social and economic restrictions. Governmental entities are already collecting health data in national registers and databases for the prevention and early detection of diseases. In Switzerland, one example is the national cancer registry, created at the beginning of 2020, which requires doctors, hospitals and other private and public health care institutions to report diagnosed cancerous diseases to the responsible public authorities.[9]

Stakeholders in Switzerland: Confederation, cantons and administration (e.g. Federal Office of Public Health), initiatives (e.g. Swiss Personalized Health Network (SPHN)), international organisations (e.g. WHO, UNAIDS, The Global Fund), civil society organisations (including patient organisations)

3.2 Healthcare Services

The scope of healthcare services includes interactions between healthcare service providers and citizens or patients for the purposes of monitoring, maintaining and improving their personal health.

Potential: Already today, the diagnosis and treatment of patients can be massively improved through data-based technologies such as machine learning. Particularly successful, for example, is the prognosis and detection of cancer cells through the automated comparison of medical images. The analysis of the data through powerful algorithms is much more reliable than the human eye.[10] Increasingly personalised medicine will allow, in future, symptoms to be recognised even earlier and treatments to take place through individually tailored therapies. A flow of information in real time would enable healthcare providers such as doctors or hospitals to obtain immediate and comprehensive information about the health conditions of patients and their disease and treatment history. As regards the non-clinical sphere, wearables and apps are already enabling personal health monitoring. In future, health data generated in the private sphere could, if desired, be shared with healthcare service providers via an interface and linked to clinical data.

Stakeholders in Switzerland: public and private health institutions (e.g. hospitals, home care (Spitex) and care homes), health professionals (e.g. doctors, psychologists, physiotherapists, nutrition specialists, fitness trainers), tech companies, civil society organisations (including patient organisations)

3.3 Research

The field of research includes all activities which, with the help of health data, generate new knowledge, thus improving existing prevention and treatment methods, or allowing new ones to be discovered.

Potential: Health data offer enormous potential for research to develop new treatment methods and improve existing ones. Different research projects require different types of data. Therefore, potentially, all types of health data can represent an important drive to medical advancement through research and development. New methods and technologies for data analysis are constantly being

International Future Times **2 September 2030**

Citizen-led data sharing platform helps to find vaccine for COVID-30

A Swiss based citizen-led data sharing platform was instrumental in finding a vaccine for COVID-30. Patient participants were motivated to provide data to medical researchers for the public good.

A large number of datasets collected from patients have played an instrumental role in the development of a COVID-30 vaccine. These datasets include data on genomics, proteomic structures, antibodies, drugs used in treatment, and patient hospitalisation records. These data were contributed by patients voluntarily as part of a research project established by the Federal Office of Public Health (FOPH) and the University of Zürich. The purpose of this project was to create a health informatics platform for data contribution and exchange by citizen participants. This data was then made available to medical researchers at the University Hospitals of Bern, Basel and Zürich, who used it to develop candidate vaccines. Crucially, this platform helped researchers overcome shortfalls in the data that would have otherwise only been available from clinical trials. The researchers worked with the FOPH to ensure that the platform and data collection methods were compliant with the Swiss data protection and human research legislation. In addition, regulatory authorities relied on exceptions in therapeutic products legislation to hasten the process of candidate vaccine development. Finally, the datasets were anonymised and aggregated before being made publicly and openly available to comply with the FAIR (Findable, Accessible, Interoperable and Reusable) scientific data principles. The process of data collection would not have been possible though without general practitioners and hospital physicians. These doctors played a key role in notifying COVID-30 patients of the study and encouraging them to participate and contribute their data. The data collected using hospital information systems was also used to identify patients and motivate them to participate. One of the benefits from this study has been a significantly reduced cost of running clinical trials to identify a target vaccine.

James Scheibner and Vijaya Shinde
Policy Kitchen participants

developed, enabling new insights and giving rise to scientific findings. Thus, for example, machine learning is used in various research projects for a vaccine against Covid-19.[11] In future, for example, traditional clinical studies involving patients could be replaced, or supplemented, by new analyses of standardised patient data. This could speed up the development and approval of new drugs and treatments, in addition to making them more efficient.[12]

Stakeholders in Switzerland: universities and research institutes, hospitals, life science industry, initiatives (e.g. SPHN), foundations, civil society organisations (including patient organisations)

3.4 Commercial use

The scope of commercial use refers to the use of health data by private actors for commercial purposes. This means the use of data for the creation or improvement of commercial products and services. From an individual perspective, it is possible to conceive health data by citizens to be used also for commercial purposes, indeed when they monetise their data in exchange for products, services or money.

Potential: Commercial products and services can be developed and constantly improved by the use of more and better quality health data. In particular, data from the non-clinical sphere are expected to play an important role in future. Such products and solutions have the potential to improve healthcare services and make them more cost-effective.

Stakeholders in Switzerland: health insurers, life science industry, private data infrastructure providers, tech companies ●

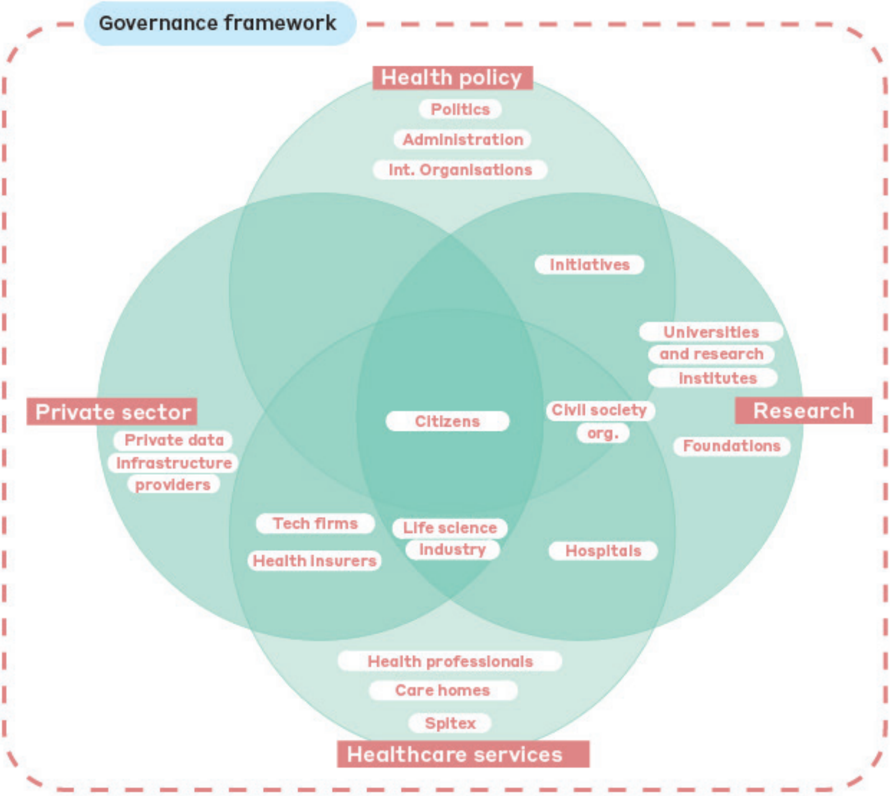


Fig. 2: Mapping of stakeholders in Switzerland with reference to health data by fields of action

4. Health Data Governance: The Status Quo

Numerous laws, strategies and guidelines which regulate various aspects of the handling of health data already exist.

The enormous potential of health data faces challenges and risks, such as misuse. At the national, regional and international level, numerous laws, strategies and guidelines already exist which regulate various aspects of the handling of health data. This chapter provides an overview of the ethical, legal and political status quo in terms of health data governance (cf. Box 2). It should help classify the challenges and approaches identified by the study participants in chapters 5 and 6, and the resulting recommendations for action.

Box 2

Health data governance

In this study, we refer to health data governance as the modalities, regulation and monitoring of the handling of health data by and between various parties who deal with such health data. Therefore, health data governance (as also shown by the analysis of the participatory formats) not only has implications on an ethical-legal and political level, but it also involves actors and actions from other dimensions, i.e. societal, financial and technical. The term should be understood in a normative sense, corresponding to that of a "good governance", the aim of which is to guarantee data security, data protection, access rights, data availability and data quality for citizens and patients.[87] According to the goals of the UN Agenda for Sustainable Development up to 2030, the focus is on access to healthcare for all and the improvement of public health.

4.1 National Legislation

The handling of health data in Switzerland is regulated at various legal levels (Federal government, Cantons, municipalities and international law) and is subject to various laws: general laws such as the **Federal Act on Data Protection (FADP)**, Cantonal data protection rules and health laws, as well as special laws on certain types and uses of data, such as the **Human Research Act** (**HRA**) and the **Federal Act on the Electronic Patient Record (EPRA).**[13] Although some laws have recently been revised, they do not all follow the same concept. According to law professor Franziska Sprecher, many laws in Switzerland are outdated, incomplete[14] and "meet the challenges of Big Data and other data-based technologies only in a limited way"[15]. In September 2020, after more than eight years of elaboration, the Swiss Parliament agreed on a revised FADP.[16] This way, Switzerland was able to adapt its legislation to technological developments. Furthermore, the revision of the FADP was intended to ensure compatibility with the EU General Data Protection Regulation (GDPR) (also known as adequacy decision). This is important to ensure the smoothness of data transfers between Switzerland and the EU (cf. 4.3).[17] From a data protection perspective, Switzerland could expect a positive signal from the EU.[18] At the same time, the EU Commission may use Switzerland's adequacy decision as an instrument of political leverage to enter into the institutional agreement, as it has already done, for example, with the stock market equivalence.

4.2 National Strategies and Guidelines

The Federal Government, with the means of various domestic and foreign policy strategies and guidelines, takes into account the growing importance of digitalisation and of health data governance. Last year, the Federal Council adopted the **Swiss Health Foreign Policy 2019–24**, with the aim of committing to more sustainable and efficient global healthcare, including through digitalisation. Switzerland intends to promote the use of information and communication technologies, enable the use of high-quality data, and work with other countries, both bilaterally and multilaterally, for responsible use and to exchange experiences. Among other things, it intends to commit to "cross-border, individual access to patient data" and "if needed, will establish the necessary legal framework".[19] Furthermore, "Switzerland supports the development of a global health data governance framework, as well as meaningful international cooperation in this area".[20]

Digital governance is also one of four central fields of action of the Federal government's **Digital Foreign Policy Strategy 2021–24** adopted in November 2020.[21] It should "allow for the creation of common rules in the digital space and strengthen both institutions and cooperation mechanisms".[22] The Federal Council is focusing on promoting International Geneva as a hub for digital governance.[23] Other focal points are the creation of cross-border data rooms to preserve prosperity and innovation, cybersecurity and digital self-determination. The Digital Foreign Policy Strategy is a follow-up to the **Foreign Policy Strategy 2020–2023**, in which the Federal Council, for the first time, defined digitalisation as one of four priorities of its foreign policy.[24] Digital foreign policy is also part of the **Digital Switzerland Strategy**, which was updated in September 2020. This umbrella strategy should allow the Federal government, through its digital policy, to react to "relevant economic, legal, technical and societal developments".[25]

In terms of domestic politics, the Federal Council's health policy strategy **Health2030**, adopted at the end of 2019, describes technological and digital change as one of the four most pressing challenges.[26] In order to address this, two goals should be pursued until 2030: the use of health data and new medical technologies as well as strengthening the population's health literacy. The **eHealth**

Schweiz 2.0 strategy specifically focuses on the electronic patient record (EPR). This strategy, adopted by the Federal Council in 2018, involves both Federal and Cantonal goals and measures aimed at the general adoption of the EPR and at coordinating the digitalisation around the EPR.[27]

4.3 Regional and International Legislation

Beyond national legislation, the **General Data Protection Regulation (GDPR)** introduced in 2018 by the European Union (EU) has the most far-reaching effects for health data cross-border transfer. The GDPR is applicable to the member states of the European Union, therefore Switzerland is not subject to the GDPR. However, the GDPR has an "extraterritorial" effect: as soon as any operator in Switzerland processes personal data of natural persons located within the EU, European legislation applies to such processing.[28] Like the FADP, the GDPR treats health data as particularly sensitive data. Such type of personal data is subject to stricter legal requirements in terms of collection, storage and processing compared to other personal data (e.g. address data or data related to the purchase of goods). They may be used exclusively in specific situations and with the explicit consent of the data subject, e.g. for medical diagnoses or for research purposes.[29] Data protectionists see the GDPR as a great achievement, highlighting its pioneering role in the protection of personal data. However, a few research groups have also criticised this legislation due to the fact that cross-border data transfer in research projects becomes more difficult.[30] In addition to the GDPR, the EU is working on overarching governance on the topics of artificial intelligence (AI) and digitalisation, so as to reconcile the protection of civil rights with economic interests.[31] At European level, Switzerland has also signed, in 2019, the modernised version of the **Council of Europe's Data Protection Convention 108**.[32] Other data protection laws relevant to stakeholders in Switzerland and applying to larger, regional health data rooms are, for example, the Health Insurance Portability and Accountability Act (HIPAA) in the USA or the California Consumer Privacy Act (CCPA). However, these data protection guidelines are not as strict as the GDPR.[33]

Furthermore, there are various international agreements for cross-border data flows and transfers. Thanks to so-called *Adequacy*

Decisions (formerly known as *Privacy Shields*), states can mutually recognise their data protection legislation as equivalent and thus simplify the cross-border exchange of data. However, this recognition between the USA and the EU, and respectively Switzerland, was declared invalid by the European Court of Justice[34] and by the Federal Data Protection and Information Commissioner[35] in June and September 2020, respectively. This decision was justified by both instances with the fact that legal monitoring and access to personal data in the US were too extensive. The standard contractual clauses recognized by the EU Commission, aimed at enabling cross-border data transfer between two parties, must now be integrated with supplementary clauses or additional technical measures, depending on the case.[36] This results in significant legal uncertainty.

4.4 Multilateral and Global Regulations, Strategies and Guidelines

For health data governance, there are a number of soft regulations, strategies and guidelines in place at the international level. The **Secretary-General's High-level Panel on Digital Cooperation**, of which former Federal Councillor Doris Leuthard was also a member, identified in its **report** more than a thousand multilateral governance mechanisms in the field of digital cooperation.[37] This includes regulations with specific reference to health data such as the 2017 **OECD Recommendation on Health Data Governance**. It recommends the creation of framework conditions for the handling of health data. It is based on 12 principles such as promoting the interoperability of different health data sets, transparent communication with the population or ensuring adequate data protection and data security. Another recommendation on health data protection and use comes from the UN Special Rapporteur on the right to privacy.[38] The World Health Organization (WHO) is currently working on the operationalisation of its **Draft Global Strategy on Digital Health 2020–2025.**[39] It contains considerations for an international health data regulation. Such an international treaty, negotiated within the framework of the WHO, could regulate health data cross-border handling, ensuring a fair, responsible and inclusive health data exchange on a global level.[40] Furthermore, the WHO and the International Telecommunication Union (ITU) in 2018 jointly set up the Artificial Intelligence for Health (AI4H) working group, in order to develop international standards for the assessment of health-related, artificial intelligence-based technologies.[41] In addition to other multilateral regulations, non-governmental regulations are increasingly being drawn up by private bodies, such as standards for biobanks, for example.[42] ●

5. Challenges and Risks in Dealing with Health Data

> "Switzerland is actually too small to do Big Data." - PoliTisch participant

As part of our national participatory process, the stakeholders and interested citizens who took part were faced with the question of what, in their opinion, are the greatest challenges and risks associated with health data and digital technologies. The empirical analysis based on the data from the PoliTisch and Policy Kitchen events shows the range of current challenges and risks that are perceived in Switzerland today in relation to health data. We have summarised the results and classified them according to different health data governance dimensions. The following chapters describe the central challenges and risks identified by the PoliTisch and Policy Kitchen participants on a political, societal, ethical/legal, financial and technical level.[43]

5.1 Political

A complex and fragmented collaboration

The study participants identified the complexity and fragmentation of the stakeholder landscape as a somewhat nebulous but crucial challenge: “There are so many parties involved: pharmacies, doctors, health insurance companies, hospitals and tech companies, [it is] incredibly complex”. Furthemore, the different parties often pursue different interests. A participant from the insurance industry criticised today’s silo mentality: “[...] the biggest challenge is that we think in a far too compartmentalised way. [...] Switzerland is already much too small, but in addition, within Switzerland, every single party thinks [again] for themselves.” This was attributed by some to a lack of political will to cooperate, while others focused on the structural characteristics of the Swiss political system, such as federalism.

> “Switzerland does not have one, really *one* vision in terms of global health” - PoliTisch participant

This fragmentation in domestic politics also impacts on foreign policy, as one participant described: “How difficult it was to set up a national cancer registry. Because there is this cantonal, federal structure. Which has so many advantages. But at the same time, it restricts Switzerland’s ability to strengthen its position at the international level”. There is a lack of coherent strategies, for example in terms of participation in foreign data markets, research programs, but also in terms of expressing clear health policy positions: “Switzerland does not have one, really *one* vision in terms of global health, based on which to take a stance and move forward, saying, for example, we stand for the right to health worldwide, we want the international organisations to work on this and look for appropriate coalitions”, one participant said.

Different value systems

At the international level, cultural differences in the handling of health data make political cooperation difficult. While already within Switzerland different ideas about the use of data exist, these views diverge even more at the global level. A participant from a non-governmental organisation said: “[...] health is a personal topic very linked to one’s culture, [which impacts] also on our attitude towards data”. Someone else described governance as human views which have something to do with values and are very different around the world, from the “surveillance capitalism of American companies” to “state surveillance in China”. Such differences in values between geopolitical blocks are considered one of the greatest challenges for global health data governance: “Data is knowledge and knowledge is power. [...] Thus, I reckon it’s not going to be easy to find a common denominator”, said one participant. Some identified a specific risk in the design of digital technologies: “We actually implement digitalisation following patterns at work in colonial systems. Large tech companies from the Northern hemisphere define how these technologies should look like and how they are to be implemented”.

5.2 Societal

Lack of data literacy and awareness

Many study participants identified the lack of data literacy in the population as the main societal challenge. They see a great lack of knowledge among citizens and patients in terms of their handling of health data. “When we talk of patients being responsible and of the self-management of their health data, then we also need competence, we need health data literacy, and there are still a few hurdles to overcome”, said one participant. Many blamed the state for this lack of knowledge. Its current work in terms of education and raising awareness does not reflect at all the importance of data literacy in society: “An extremely large amount of energy is invested [in organ donation campaigns]. However, there is nothing similar for data. The same is true for the patient record. There is no explanation. Also in schools, empowerment through data is not a topic”. In relation to this, many study participants criticised the lack of awareness of the added value of health data and its use. Too often, citizens and patients are not aware of the specific benefits of sharing data with stakeholders in the healthcare system. This results in them being less willing to provide the data. Also, data usage in the public debate is often represented in a negative way. The focus is on pharmaceutical companies as beneficiaries. Indeed, the population and individual patients could actually benefit from a better use of health data: “People read about life science companies, pharmaceutical companies wanting the data. That is of course misfortunate. [...] And I reckon that now we will need two or three times more funds, more awareness, until the people of this country understand that [their data] has added value for their own benefit and not just for Roche and Novartis”, said one participant.

> “Even from a professional point of view, it is often no longer understandable what happens [with the data]” - PoliTisch participant

Complexity, lack of transparency and loss of trust

Today, citizens and patients are overwhelmed when dealing with their personal health data, as noted by many study participants. The topic is complex and there is a lack of transparency about how and where data can be accessed: “We keep hearing from patients who feel very lost. They feel completely left alone and at the same time, they have no real access to their data”, said a patient representative. Many people do not know what their personal health data is used for or how they can access it. This lack of transparency results in distrust among the population. A massive loss of trust has been observed in Switzerland in recent years, particularly among the 40–65-year-olds. According to a study, over 90 percent of the interview participants in this age group agreed to the electronic storage of their health data in 2018, compared to just under 50 percent in 2020.[44] One researcher summarised the issue of trust as follows: “Even from a professional point of view, it is often no longer understandable[...] what happens [with the data]. That is why trust is so important, as it can be a mechanism that helps reduce complexity”. This could also lead to increased social awareness of the benefits of digital technologies in the health sector. Such awareness at the moment is not very widespread, but it would be extremely important in crises such as the current Covid 19 pandemic.

International Future Times **25 August 2030**

Students get infected on purpose with rare diseases to increase value of their health data

Recent research has brought into light how students with limited economic resources are inoculating rare diseases on purpose in order to acquire economic advantage from pharmaceutical companies.

Students from different universities are trying to get advantage of the current system monetizing health data. The introduction of medical data in the stock exchange has led to dramatic price increase of medical data related to rare diseases.

The low barrier access for tracking technologies has encouraged students to measure all different types of valuable data and get infected with a diversity of diseases. In particular there has been a worrying increase of reported infections with the rare disease of the East Nile Virus in multiple university campuses. Indeed at Wall Street, the East Nile Virus related data went from 5$ to 100$ within one week.

Government wants to curb the increase of self-inoculations by introducing new regulations. The debate is open for discussion should the students that get inoculated on purpose be punished or should the government regulate the companies buying the data.

Eduardo Belinchon de la Banda,
Guillaume Stern
Policy Kitchen participants

5.3 Ethical/legal

Legal protection of individuals against data misuse

Data protection is a crucial issue when dealing with sensitive personal health data. In the opinion of many participants, today, it is insufficient: “Our data protection laws come from the past. Unfortunately, the law is very much behind. New inputs are urgently needed”, said a lawyer. The legislator has a duty to adequately protect individuals from misuse of data and from the resulting discrimination. Another participant said: “It is not just a question of protecting the privacy of these data, but, occasionally, to protect the very life of people. Indeed, such health data may also impact on the way in which, subsequently, people may be victims of targeted attacks”. Misuse of data could also lead to discrimination, for example in the labour market.[45] In particular, the ability to use genomic data to better predict disease predisposition made some participants uneasy. Accordingly, they demanded adequate data protection. Some also feared that without the necessary legal protection, people may end up having to sell their personal data in exchange for health.[46]

But from whom must sensitive personal health data be protected? The Policy Kitchen visions focussed, in particular, on commercial use of data by tech companies, insurers and pharmaceutical companies.[47] Various participants decried that some parties outside the traditional, clinical field of action benefit from a legal gray area. “Google [or] Apple are not subject to regulations at all”, while some private parties in the Swiss healthcare system are subject to much stricter laws, someone said. At the same time, the collection and use of health data by the state was not viewed uncritically either. For example, some warned of the risk of a discriminatory police state, which, thanks to improved access to health data, and in particular genomic data, could end up imposing restrictions on freedom in future.[48]

> “Our data protection laws come from the past” - PoliTisch participant

Lack of control over the use of health data

Controlling personal health data was also perceived as a challenge. It is not clear yet what the rights relating to data are. In future, clearer legal frameworks will be needed in this regard.[49] One participant criticized the concept of data ownership: “It’s about data rights. I have a right to all data that somehow relates to me, [...] as an individual as well as as a citizen. And I realize that this way of thinking is not there yet. [...] We don’t think in terms of data rights. We only think in terms of data protection.” A particularly controversial issue in the discussion was the general consent. It is widely used in research in Switzerland today and allows people treated in hospital to consent to the further use of their data and samples for research purposes. Some viewed this practice as a positive development for modern data science. It provides researchers with access to important clinical data. Others criticized the fact that a subsequent withdrawal of consent to the use of data is practically impossible for patients. One participant described the general consent as a “blank check”, another called it “a joke and insult to self-determination and control”.

5.4 Financial

Insufficient financing of technical systems and infrastructures

From an economic point of view, several study participants identified the financing of technical systems for the use and exchange of health data as an unsolved challenge. The electronic patient record (EPR) was mentioned several times as a prime example. It is not working properly currently because of insufficient and unsustainable funding: "With technology, this could be solved if there was the will to do it. It wouldn't be such an issue. The question is simple: who wants it and who pays for it?". In the opinion of many participants, the same problem applies to other infrastructures that are needed, in order to facilitate the handling of data, in future, for the various parties involved in Switzerland. Data preparation alone is a costly process, as one scientist remarked: "It needs work in terms of preparation and cleaning [...] of the data. [...] This is very expensive." A lot of money needs to be invested even only to make sure that data can be used for research purposes. One participant also reminded that not only the costs of building new infrastructures need to be considered, but also those for their maintenance: "The question of financing [...] is crucial. When you change an entire system, you need to think not only about the costs of the technology but also about the costs for support for the 20 years afterwards."

Securing prosperity and innovation

The question of the financing of technical systems and infrastructures allowing health data cross-border use and exchange also has significant economic implications. If it wants to maintain its prosperity and its ability to innovate, Switzerland depends on the participation in large data rooms. "Switzerland is actually too small to do big data", one scientist summarised the challenge. Another added: "For certain topics, we need global data sets. We are too small when it comes to patient data in this country. [This] applies to cancer research, for example, but also other topics". Research in Switzerland needs access to large amounts of high-quality data. But with a self-contained, fragmented data ecosystem, there is the risk for it to lose ground. Adequate infrastructures and standards are essential for Switzerland to act as a research and innovation hub, and they must be sustainably financed.

5.5 Technical

Data formats and standards

The study participants identified the development and use of consistent data formats and standards as the main technical challenge. According to the participants, despite existing initiatives, there are still no standardised structures at national or international level allowing barrier-free health data exchange between different parties and different areas. Too often data is locked in silos. In Switzerland, differences between hospitals alone cause problems: “If we try to integrate the data of hospital A with those of hospital B, immediately we face the problem [that] the information does not represent the same thing”, one scientist explained. Even between individual departments, data management systems are often not compatible. In relation to this, reference was also made to the sluggish effect resulting from having a highly developed health system such as the Swiss one. As so many structures are already in place, innovation is more difficult and more expensive compared to “countries and systems that do not have 20 years of history”.

Data quality and quantity

The steadily growing volume of data is a major challenge for many parties. This is particularly true for smaller organisations, suffering from a lack of knowledge and resources to be able to process large amounts of health data. “There are avalanches of data being recorded and nobody really knows what is happening to them”, said a representative of a patient organisation. Also in the clinical environment, data processing sometimes reaches its limits. This impacts on data quality, as one scientist observed: “If we look at routine data in hospitals today, there is not much that can be done with it. You cannot use the data as it arises. We need to invest in annotations [...] and in the richness of this data”.

Security in handling data

According to some study participants, the security in handling health data and new digital technologies represents a technical risk. This was illustrated by several dystopian Policy Kitchen visions, for example: “A Basel hospital’s internal database was hacked recently, causing data manipulation on an AI platform used to treat patients. Consequently, hundreds of patients received the wrong treatment, leading to severe conditions and even deaths».[50] There is the fear that in future more sensitive health data could be leaked or algorithms hacked, exposing individuals or entire population groups to the risk of data misuse and discrimination. Other study participants saw this danger as less real, referring to the common practice in research of anonymising personal data. In addition, the technical possibilities to render data secure thanks to so-called privacy preserving technologies are already advanced. ●

International Future Times **26 August 2030**

Centralized health data hack reported to be behind Covid-25 bio-engineered virus outbreak

Suspected large scale data breach including omics health information from centralized PGHD lake with inadequate cybersecurity. Data possibly used to bioengineer a virus for commercial or hate crime.

Scientists suspect the Covid-25 outbreak to be a result of bioengineering. The genetic make-up of the virus indicates that it might not have been naturally produced. The Gotham-based company Badman Health Corporation has been criticized by scientists on the basis that their vaccine against this new virus could not possibly have been created in such a short timeframe. «Someone must be behind the hacking of 23andMe and other national genomic databases», says chief-scientist Dr. Robin. He further argues that Badman Corp. used this massive lake of personally-generated health data (PGHD) to identify personal vulnerabilities of people in society who can be targeted for financial gains or hate crime reasons. He claims that the company created this virus along with an associated vaccine to further its Machiavellian objectives.

The individuals involved will never know whether they were actually targeted because they had no control over their data in the first place. The death toll yesterday topped 20 million and the economic consequences are as yet unforeseeable. The private sales of Badman's antidote have surpassed all other medical advances in the past two decades. The company has just beaten Huawei as the fastest growing company on any stock-market and is featured on Forbes.

The question we should all be asking ourselves is, how did we get to this? Why did we not learn from Covid-19? Clearly digital democracy should have been the savior of our world leading to great medical advances and longevity for everybody. But the failure to leave the control of personal data with people themselves opened the door to the abuse of this technology with terrifying consequences. Citizens' trust in their governments has been eroded and is in an all time low. The economic consequences of increased inequality in society as a result of the high price of the antidote are causing unrest in many countries. Neither national governments nor international institutions were able to mandate broad access to the antidote. In the past 2 weeks, citizen movements started to campaign in all major cities worldwide to demand immediate control of all their personal information as a human right.

Interestingly, Estonia as a digital nation suffered less in the current outbreak whilst backward Switzerland suffered terrible consequences. The Estonian health minister expressed sympathy with his Swiss counterpart and is providing a task force of experienced people to help guide the Swiss digital transformation which can protect against such things in the future. The minister added that a cohesive strategy in Switzerland was needed that looked beyond health data and included all government services leading to the adoption of a single digital ID with blockchain controlled transaction of information which puts people in the control of their own data. This system would also lead to the ability to leverage the positive benefits of info-tech and biotech without the risk of the alleged activities of Badman Corporation. Hopefully it is not too late.

Niculin Detreköy and Andy Bushell
Policy Kitchen participants

Challenges and Risks

Political:

- Lack of a health policy vision in Swiss foreign policy due to lack of cooperation within a complex, fragmented landscape of actors involved
- Lack of a common understanding on the handling of health data on a global level due to different value systems

Societal:

- Lack of data literacy among the population and lack of awareness of the added value of health data for public health
- Declining trust in the use of data and new technologies due to increasing complexity and lack of transparency

Ethical/legal:

- Outdated data protection laws and associated risk of discrimination through health data misuse
- Lack of legally binding individual rights with data and insufficient individual control over personal health data

Financial:

- Insufficient funding of technical systems and data infrastructures for cross-border health data use and exchange
- Swiss research and innovation hub at risk due to uncertain framework conditions for cross-border data exchange

Technical:

- Lack of consistent data infrastructures and standards for a barrier-free national and international health data exchange
- Inconsistent data quality and increasing data quantity
- Risk of data misuse and discrimination due to insufficient data security

6. Recommendations for Action for Better Health Data Governance

"I think what we need is a new social contract." PoliTisch participant

In this chapter, 12 recommendations for action are presented, aimed at improving national and cross-border health data governance. These are the results of the participatory process analysis. The solutions and visions suggested by the participating stakeholders and interested citizens in relation to the previously identified challenges and risks are summarised below. Again, they are sorted by the different governance dimensions (political, social, ethical/legal, financial, technical) and backed up with quotations.

From this synthesis, two to three recommendations for action result for each governance dimension, which we then place in the context of current Swiss health and foreign policies. The recommendations are primarily addressed to the Confederation and the Cantons. Swiss politics should play a leading role in improving the framework conditions for the handling of health data. The mapping and analysis of our formats also shows that the successful implementation of health data governance depends on the interaction of all parties involved. In this sense, the main responsible parties in the Swiss stakeholder landscape (see mapping in chapter 3) are identified for each recommended action. It is also specified whether the recommendations for action relate to the national or cross-border (regional or global) handling of health data.

6.1 Political

The participants demand more exchange between the federal government and other parties involved in health policy in Switzerland, in order to counteract fragmentation at the political level. Domestic political interactions are crucial in order to be able to create a national consensus on how to deal with health data: “It takes a conglomerate of all stakeholders and a very strong Federal Office of Public Health”, as one participant said. As regards the Swiss Health Foreign Policy and other health policy strategies, several study participants called for more transparency in the consultation process and stated that “there should be a certain consensus in foreign policy”. In their opinion, this is often not the case. Better domestic political coordination is required in order for Switzerland to be able to position itself more clearly and engage in international cooperation.

> “It takes a conglomerate of all stakeholders and a very strong Federal Office of Public Health” - PoliTisch participant

However, when dealing with health data at a multilateral level, different cultures and values are a reality which cannot be easily changed. Therefore, many participants suggested working more closely with like-minded partners in order to gradually contribute to international governance: “I think that the ideal is having one global governance […] However, sometimes you also need to be pragmatic and begin by working with like-minded countries or parties.” At the regional level, the EU is Switzerland’s most important partner and cooperation seems judicious, especially on a legal level (cf. 6.4). A stronger connection to the European data markets is also crucial for business and research: “The EU [wants] to create an internal market for data in order to enable its member states to generate an added value [...] We should really be very interested in how we could be part of it”, one participant said. Therefore, the question that needs to be answered is: “How do we get to Europe? And how do we bring Europe to Switzerland?”, as one participant put it.

At the same time, Switzerland as the host state of numerous international organisations in the health sector should advocate a “strengthened multilateralism”. A special role is to be played by International Geneva. It could actually become a global hub for health data governance, since it already hosts numerous relevant stakeholders and platforms: “There is really a concentration of parties involved who are interested in these matters, how to improve the well-being of people all over the world”. A Policy Kitchen vision, for example, suggests that Switzerland becomes the host country of an international eHealth Data Alliance that creates a “global data sharing and access framework for personally-generated health data”[51] and organises regular summits, following the example of the World Economic Forum.

Recommendations for action

1. Promotion of an inclusive consultation process in Switzerland for a broad-based health policy vision in foreign policy

An inclusive consultation process involving all relevant parties of the healthcare system, especially citizens and patients, should be promoted, focusing on the handling of health data and the future of the Swiss health data ecosystem. An institutionalised dialogue among all parties involved is required, in order to allow for the implementation of the goals in terms of health data governance as defined in the Swiss Health Foreign Policy and other health and foreign policy strategies (cf. chapter 4).

Governance level: National
Lead: The Confederation

2. Increased international cooperation with like-minded partners and connection to the EU health data ecosystem

Switzerland should strengthen its cooperation with like-minded partners. As already recommended in a foraus study in September 2020[52], Switzerland's primary focus should be its connection to the EU's health data ecosystem which is currently being set up. It aims at making health data exchangeable and usable at EU level for research and medical purposes. This project is coordinated by the eHealth Network, to which Switzerland was also a member until 2018. In future, an EU code on the processing of personal data in the health sector will regulate and simplify the exchange and use of health data between EU member states.[53] Furthermore, Brussels is currently working on new EU legislation for digital services and online

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International Future Times **26 August 2030**

Fair data alliance summit convenes key stakeholder at Davos

Switzerland convenes International E-Health Data Alliance at Davos, leveraging its full potential in digital transformation. Global stakeholders agree on global data sharing and access framework for personally generated e-health data.

The E-Health Data Alliance's fifth annual assembly will take place next week at Davos. Commentators expect considerable progress to be made with regard to further strengthening international cooperation.

The leaders will discuss the set-up of a global data pool of personally generated health data to foster international public health research by committing to share local data. They will also discuss the set-up of a global governance framework defining fair access and use of the data as well as the definition of common data standards.

Particularly promising signals were reported from the Chair of the Cybersecurity working group, finding consensus on applicable technical standards for a robust IT infrastructure. «After a deadlock for several months, we finally were able to agree on general terms», Jiao Bista said in relief. «I am thankful for the flexibility of all stakeholders in leading to this consensus.» This was the last remaining issue as the framework could not be passed during last years' summit.

Former Swiss Federal Prime Minister Reto Köpfli is handled as the new chair of the alliance due to his demonstrated success in leading the implementation of the Swiss Digital Health Data Network as well as driving global coordination efforts with neighboring countries.

An international research consortium supported by the WHO will be granted controlled access to the data to perform global research with the aim to develop tools that can focus on the prevention of future pandemics.

Nathalie Stieger and Claus Gawel,
Policy Kitchen participants

platforms.[54] Both projects will shape the future handling of health data at EU level, directly impacting on Switzerland as well. It would be of interest for Switzerland to ensure its compliance with these new standards and to participate in EU bodies such as the eHealth Network. However, due to the unresolved institutional questions between Switzerland and the EU, this matter is currently politically stalling.[55] Therefore, the benefits of a shared health data ecosystem should increasingly be included in the political debate on Switzerland-EU relations.

Governance level: Cross-border (regional)
Lead: The Confederation

3. Promotion of International Geneva as a hub for health data governance and support for corresponding initiatives

Switzerland should further strengthen its role as host country for major international organisations of the health sector and position International Geneva as a leading location for debates on digitalisation and technology.[56] In order to become a global hub for health data governance, it will need further political and financial support from dedicated initiatives and platforms. The federal government is already promoting the exchange between scientific and diplomatic expertise on the challenges of digitalisation through the Geneva Science and Diplomacy Anticipator foundation (GESDA). Furthermore, the Geneva-based International Digital Health & AI Research Collaborative (I-DAIR) initiative is committed to the inclusive, fair and responsible use of health data and AI-powered technologies, and aims at serving as a platform for international research collaborations in the field of digital health.[57]

Governance level: Cross-border (global)
Lead: The Confederation and Canton of Geneva; universities and research institutes; international organisations; foundations; civil society organisations; tech firms; life science industry.

6.2 Societal

Citizens and patients must be well-equipped to deal with their personal health data. This was one of the most frequent demands from study participants. Health data literacy among the population should be promoted through awareness campaigns organised by the state, in cooperation with other parties from the health sector.[58] Moreover, there is the need for an in-depth exchange between all stakeholders and civil society, in order for citizens to be able to have a better knowledge of what is happening with their data: “As regards governance, it [seems to me] very important this knowledge be strengthened at all levels of society, in politics, in societal exchange, among patients. It’s still a long journey ahead of us”, said one participant.

Such an in-depth interaction with the population not only serves to educate and promote data literacy, but also represents an important means of building trust. This trust toward digital technologies and the sharing of personal health data has declined over the past few years and should now be restored. In order to do this, a new social contract is required, as suggested by a scientist: “Countries that perform well are countries where people have trust in policies and data. Therefore, I think what we need is a new social contract. This, in my opinion, comes down to governance, which is a political act”. Also a more positive public and media representation of the use of health data could contribute to build trust. A few participants called for the topic to be re-framed in public discourse, steering away from the risks and focusing on the potential of health data and new technologies. Indeed, the latter is currently being pretty much “annihilated” in the public sphere “due to the data privacy argument”, one participant said.

Furthermore, study participants considered innovative ways in which citizens could play a more active role in the use of health data. Thus, various ideas for participatory platforms for the exchange of health data were introduced. Some Policy Kitchen visions presented decentralised databases, in which private individuals could share personally-generated health data, for example for research into new vaccines.[59] One vision also envisaged the possibility of only providing certified researchers access to data pools, so as to minimise the risk of data misuse.[60] Such platforms could be particularly important for cross-border research into, and treatment of, rare diseases, as one researcher emphasised: “If I had a rare disease, then I would want to connect with all the patients who have the same disease”. Thanks to its well-rooted democratic culture, Switzerland could play a leading role in the creation of such platforms at the international level: “Civil society and democratic structures are the opportunity. […] This is where citizen science comes in: It’s no longer just traditional research, but citizens as scientists who are able to make a contribution with their data”. As positive examples, numerous participants referred to existing cooperative platforms on which citizens have the possibility to manage their health data themselves.[61] With such models, Switzerland could “promote the democratisation of the personal data economy […] based on trust [and] the cooperative democratic ideal”.

International Future Times **26 August 2020**

Innovative health knowledge exchange at your fingertips

A mobile application allowing you to control your personally generated health data (PGHD), meet the right doctor and connect with people with similar conditions.

A mobile application has been developed for every citizen to be able to give consent to their personally generated health data (PGHD) when they visit healthcare professionals. With this app being interoperable across medical institutions, specialities, cantons (within Switzerland) and countries, they don‘t have to explain their medical history every time they consult with a new health professional. This is particularly helpful as patients often do not have the scientific knowledge to describe their medical condition.

The app is able to «matchmake» the right doctor to treat the specific condition the patient has and this will help to reduce healthcare costs and prevent doctor hopping. This «matchmaking» function can be extended to linking users with patients suffering from similar conditions, therefore creating a community that has a pool of immense knowledge to share with each other and to support each other in the course of diagnosis to treatment and care. This could be particularly useful for patients suffering from rare diseases.

When their doctors are informed of newly approved treatments targeting their medical conditions (in the event of rare diseases and cancer), the patients will get a tele-consult on the app with their doctor to see if they will like to move forward with such a treatment.

The uploaded data and flows are secured and controlled. There will be buy-in from the government, medical institutions and insurance companies. Every user will be empowered by having a chance to control and limit the access to their PGHD. We have a video which explains how to use this app and do look out for our champions who will be going around cities and towns to assist you with this app. Click here to download it today!

Peiling Yap, Selina Marti, Patrick Meier,
Policy Kitchen participants

Recommendations for action

1. Promotion of health data literacy in society through educational programs, information campaigns and institutionalised exchanges with the population

Health data literacy is the ability to understand, collect, manage and use health data.[62] It should be improved through educational programs and information campaigns by both the Confederation and the Cantons. Accordingly, a parliamentary request for a data literacy campaign was made to the Federal Council in September 2020.[63] The use of digital technologies must be explained in a transparent and understandable manner, whilst clearly stating the added value of health data for improving both personal and public health. To this end, inspiration could be found in successful blood donation campaigns. At the same time, a regular, institutionalised exchange with the population is needed, in order to create trust in relation to the handling of health data and to ensure that, in particular, older groups, or groups who are less familiar with the digital world, are not excluded.[64] For a start, a participatory discussion platform could be created, enabling citizens to exchange ideas with experts. Our dialogues and workshops with stakeholders and interested citizens have shown that such an exchange can be of great interest on both sides.

Governance level: National
Lead: Confederation and the Cantons; civil society organisations; initiatives; foundations

2. Creation of a democratic health data ecosystem by promoting participatory platforms for a citizen-centered use of health data

A democratic data ecosystem is needed, in order for individuals to acquire more rights and control over their personal health data. Participatory platforms are a crucial element for the promotion of a more active role for citizens in the treatment of their health data. The development of such platforms follows the current trend in healthcare, which is that of gradually steering away from a reactive model of treating diseases towards a model based on proactive prevention, where the “boundaries between health, lifestyle and disease, prevention and therapy [...] are becoming increasingly blurred”.[65] While pilot projects should be developed and funded at the Swiss level, it would be worthwhile having citizen-centered platforms also operating across borders and able to connect with similar initiatives. At the same time, analogue alternatives to digital platforms are important, so as to prevent discrimination against population groups, which are less familiar with digital systems and tools.

Governance level: National, in the longer term also cross-border
Lead: The Confederation and the Cantons

6.3 Ethical/legal

Numerous study participants were of the opinion that an improved, more consistent and clearer legal basis is required, in order to ensure the adequate protection of citizens against data misuse and the resulting discrimination. Many laws are no longer up to date and lag behind technological advances. As several participants claimed, the rights to personal data and thus, the control over health data, should be regulated by law: “[...] I have a fundamental right as a person on all data that, somehow, are related to my person. Period. My Data”, someone said. As regards data protection, the EU’s GDPR is considered as a guideline. Regulatory cooperation with the EU is important for Switzerland: “When we talk about data and artificial intelligence, Europe may not be the driver of innovation in the world, however, it is certainly the driver of regulation at the global level [...] and the path to Europe would certainly be a helpful one.”

A strong ethical/legal alignment with the EU is important not only from a data protection perspective, but it is also of vital interest to the economy and research in Switzerland. One researcher explained the importance of legal security: “It is essential to have an embedding, a legal framework allowing us to exchange high-quality data with trustworthy partners in a legally reliable manner. Because if you are a small country, you have to rely on a network”.

Furthermore, the vast majority of study participants sees a need for legally binding health data governance at the global level. “The functioning of the global data economy calls for a consequent global governance on certain matters", said a representative from the private sector. Switzerland's goal of contributing to the creation of an international legal framework for the handling of health data within the framework of its Health Foreign Policy was welcomed. At the same time, some considered this goal to be a "noble" one. Taking into account the different cultures and value systems of the members of the international community (cf. 5.1), doubts exist about the feasibility of a legally binding global health data governance. New international treaties and mechanisms are not always and immediately necessary: "There are more than one thousand global mechanisms on digital cooperation [...]. Therefore, it is also a naive view that we think that everything starts from scratch", said a participant from International Geneva. Instead, Switzerland should strengthen multilateralism in a targeted manner (cf. 6.1), participating in the development of international ethical and legal regulations and standards.

Recommendations for action

1. Standardisation of national and cantonal legislation on the handling of health data and guarantee of individual data rights

In order to ensure data protection, the data protection legislation and guidelines relating to the storage, provision, transmission and use of health data should always be adapted to technological progress. This has been the case in recent years, for example, with the revision of the federal law on genetic testing in humans.[66] As described in chapter 4 and mentioned by various study participants, the legislation on the handling of health data at the national level is currently complex and fragmented. Therefore, a reflection is needed in order to standardise the current legislation. Despite the fact that existing data protection laws regulate the use of personal data by third parties, the question of the control over health data and corresponding rights has not been fully clarified, either in Switzerland or internationally. It should be checked whether informational self-determination, i.e. individual data rights, can be anchored in legislation as a fundamental right. A new debate on this topic could begin by discussing general consent, which has been subject to various criticisms. The concept for a harmonised practice published by the Swiss Academy of Medical Sciences in 2019 was criticized since it "only partially" considers the rights of patients.[67] Opt-out options should also be discussed, which would allow individuals to constantly being able to revoke their consent to the use of their electronically stored data or withdraw access to their data for certain parties.

Governance level: National
Lead: The Confederation and the Cantons

2. Guarantee and further development of data protection in Switzerland by ensuring compliance with leading regional and international legislations, as well as ongoing adjustments to technological progress

With the GDPR, the EU has created a world-leading legal framework in the field of data protection. Switzerland has ensured compliance with data protection law by revising the FADP. However, EU law is not static, and further reforms in data protection are to be expected. Therefore, Switzerland, also from an economic point of view, should ensure that the legislation will continue to comply with leading EU standards and guidelines, such as the GDPR.

Governance level: Cross-border (regional)
Lead: The Confederation

3. Participation in the development of a legal framework for handling health data on a multilateral level

At the multilateral level discussions are currently in place for an International Health Data Regulation[68], in the form of an international treaty negotiated within the framework of the WHO (cf. 4.4). Similar binding regulations are already in place in the field of tobacco control (WHO Framework Convention on Tobacco Control) and in the fight against cross-border infectious diseases (International Health Regulations).[69] With such agreement, the WHO intends to regulate the cross-border handling of health data and ensure a fair, responsible and inclusive exchange of health data within the international community.[70] In its Digital Foreign Policy Strategy 2021–24, the Federal Council is “sceptical of any single all-encompassing and legally binding instrument to regulate the digital space”[71]. However, “for Switzerland, it is important that there are processes and structures in place that enable as many countries as possible to make a substantial contribution in this area“[72] It is in this sense that Switzerland should support a binding framework agreement envisaged by the WHO.

Governance level: Cross-border (global)
Lead: The Confederation

6.4 Financial

When considering the financing for the construction and maintenance of national data infrastructures, many study participants see the state as being responsible. The Confederation and the Cantons should play a key role in the implementation of national platforms and initiatives on the use and exchange of health data, as already is the case with the EPR. In future, many more funds will have to be invested in this. However, overall, study participants remain vague on the question of financial responsibility and no concrete solution is provided. The question of who should pay for the necessary infrastructure, and how much, remains largely unanswered. Indeed, it is precisely this question which needs to be clarified, not only from a health policy point of view, but also especially from an economic point of view. The study participants frequently emphasise the qualities of Switzerland as a hub for research and development: “We have [...] top universities for AI, data and health, we have the Center for Digital Trust at the EPFL, we have global pharmaceutical big players, we have a health system that is second to none”. If this is to last, appropriate financial framework conditions will be needed, everyone agrees without exceptions. In future, Switzerland should invest more in the development of internationally scalable solutions and best practices. The development of the SwissCovid app has been mentioned several times as a prime example.

Recommendations for action

1. **Sustainable financing of technical data infrastructures to enable the exchange and use of health data**

The Confederation and the Cantons are currently investing relatively little in data infrastructures in Switzerland. According to current legislation, the Federal government is providing a maximum of 30 million francs for the creation of the EPDG infrastructure, of which 26.6 million francs have already been invested.[73] Once this amount has run out, the operators should bear the costs themselves, e.g. by requesting fees from participating healthcare facilities.[74] The question remains whether the financial resources provided are sufficient for a functioning, sustainable and effective EPR. The Confederation and the Cantons should increase their financial support towards national platforms and initiatives which facilitate the use and exchange of health data. What kinds of additional data infrastructures are needed should be clarified with the parties involved. At the same time, depending on the type of initiative, it should be determined how these parties can be involved in the financing by the Confederation and the Cantons.

Governance level: National
Lead: The Confederation and the Cantons

2. Promotion of Switzerland as a hub for research and innovation in the field of digital health

In order to strengthen Switzerland as a global hub, innovative research and development in the field of digital health should receive more financial support. National research programs, such as NRP 75 “Big Data” or NRP 77 “Digital Transformation” strengthen the know-how in Switzerland.[75] When supporting new technologies, approaches, initiatives and platforms, focussing on scaling is particularly important, and this, according to some study participants, is still not reflected enough by the funding. The scaling and export of best practices developed in Switzerland is crucial in order to ensure a sustainable promotion of the location. Also important are the connections to regional and international research programs. For example, Switzerland should work towards the full association at EU level with Horizon Europe, the “largest and most comprehensive global research funding program”[76].

Governance level: National, cross-border (regional)
Lead: The Confederation and the Cantons

6.5 Technical

The study participants agree that common standards for health data use and exchange are essential from a technical perspective. They welcome the existing data infrastructure that is being set up in the research area, for example, by the national, government-funded initiative Swiss Personalized Health Network (SPHN), aimed at making health-related data usable for research.[77] However, when developing technical infrastructures and standards, not only national, but also international data exchange must be taken into account, as one expert explained: “How are medication data, vaccination data, laboratory data, etc. standardised and exchanged? We are not going to be able to establish Swiss solutions in Switzerland, this is a global matter. [...] In order to be efficiently and usefully integrated and evaluated, information must be coded in a common way. This means that we have to join some kind of international standardisation. Switzerland is not very good in this regard, we are good at innovation, but we are not good at implementing international standards”. According to the study participants, the standardisation of terminology would also be helpful: “The Global Alliance for Genomics and Health is now beginning to formalise certain aspects in the genomics area, however, I think it should be approached on a much broader level and I would consider that any standard body (be it the WHO or another organisation) should at least establish a standardised terminology”, a scientist said. As regards the data security challenge described in chapter 5, there were no direct proposals for a solution. Some participants mentioned, in general, the possibility of new technologies for the anonymisation of data. One scientist expressed the hope that “we will find technical possibilities so that the question of data sharing will become obsolete in certain or many respects, by simply saying that it does not matter, since a lot is done through privacy preserving methodologies and computer-aided changes to data points which provide actual anonymisation”.

Recommendations for action

1. Development, consolidation and application of consistent technical standards for both the national and cross-border use of health data

In Switzerland, technical standards and principles are already used, e.g. the FAIR principles, according to which data should be findable, accessible, interoperable and reusable.[78] The application of these principles is compulsory for projects under the Swiss National Science Foundation.[79] Furthermore, certain standardisation organisations such as Health Level 7, Integrating the Healthcare Enterprise, the International Electrotechnical Commission (IEC), the International Organisation for Standardisation (ISO) or the AI4H WHO/ITU task force are promoting the development of standards for the handling of health data. In Switzerland, the Swiss Personalised Health Network (SPHN) has also developed a semantic interoperability framework designed to ensure that clinical data are interpreted consistently by both machines and humans, across projects, systems, countries and over time.[80] In addition to the research sector, eHealth Suisse, the competence and coordination centre of the Confederation and the Cantons for eHealth projects, is also working on the standardisation of the practices for handling clinical health data. At the international level, information and practices are exchanged between eHealth Suisse and partners from other countries, as part of the Global Digital Health Partnership.[81] Such an exchange is important for the harmonisation of technical standards. In general, Switzerland should continue to commit to the further development and adoption of consistent international standards.

Governance level: National and cross-border
Lead: The Confederation; public and private health institutions; health professionals; life sciences industry; private data infrastructure providers

2. Improving data security by promoting research into new technologies for privacy protection

In the area of data security, Swiss stakeholders such as the EPFL's Laboratory for Data Security play a leading role in the development of innovative privacy preserving technologies. One example is homomorphic encryption.[82] There are also initiatives such as the Trust Valley Initiative, aimed at building a local ecosystem in French-speaking Switzerland, involving companies, organisations and initiatives to promote data security.[83] Similar initiatives should be increasingly promoted, for Switzerland to maintain a leading role in the field of data security.

Governance level: National and cross-border
Lead: The Confederation and the Cantons; universities and research institutes; tech firms ●

Recommendations for action

Political:

- Promotion of an inclusive consultation process in Switzerland for a broad-based health policy vision in foreign policy
- Increased international cooperation with like-minded partners and connection to the EU health data ecosystem
- Promotion of International Geneva as a hub for health data governance and support for corresponding initiatives

Societal:

- Promotion of health data literacy in society through educational programs, information campaigns and institutionalised exchanges with the population
- Creation of a democratic health data ecosystem by promoting participatory platforms for a citizen-centred use of health data

Ethical/legal:

- Standardisation of national and cantonal legislation on the handling of health data and guarantee of individual data rights
- Guarantee and further development of data protection in Switzerland by ensuring compliance with leading regional and international legislations, as well as ongoing adjustments to technological progress
- Participation in the development of a legal framework for handling health data on a multilateral level

Financial:

- Sustainable financing of technical data infrastructures to enable the exchange and use of health data
- Promotion of Switzerland as a hub for research and innovation in the field of digital health

Technical:

- Development, consolidation and application of consistent technical standards for both the national and cross-border use of health data
- Improving data security by promoting research into new technologies for privacy protection

7. Conclusion

In times of geopolitical polarisation, Switzerland can play an important role through its commitment to digital cooperation within multilateral organisations and contribute to a regulated handling of health data.

The assessment by our national participatory process shows that there is a significant need for action in the area of health data *governance*. There is a reason why the Federal Council has increased its commitment in the area of digitalisation and data, and defined governance as one of the main aspects in Swiss health and foreign policy. Improvements in health data governance are now needed on a political, societal, ethical/legal, financial and technical level.

This includes strengthening internationally-oriented Geneva as the hub for global health policy and a leading location for governance. In times of geopolitical polarisation, Switzerland can play an important role through its commitment to digital cooperation within multilateral organisations such as the WHO, contributing to the regulation of health data handling. At a regional level, the EU remains a central focus point and an important partner for Switzerland, since it is a driver for regulation in the area of data protection, artificial intelligence and new technologies. Switzerland could also benefit economically from a connection to the EU health data ecosystem, securing its place at the forefront of innovative research and development.

At the national level, along with the measures taken by the Confederation and the Cantons, all other actors which are active in health policy, research, health services and in the private sector use of health data must also be involved. Multi-stakeholder collaborations can sustainably improve the handling of health data.

Crucial is the exchange with those most concerned: citizens and patients. In our opinion, the current discussion about the opportunities and risks of digitalisation in the healthcare system in the context of the Covid 19 crisis represents a great opportunity. Social understanding and trust in the handling of health data are essential prerequisites for inclusive, broad-based solutions. Intensifying the exchanges with stakeholders and population allows a better use of the potential of health data and new technologies for public health. ●

8. Glossary

Acronym	Name
FADP	Federal Act on Data Protection
EPRA	Federal Act on the Electronic Patient Record
EU	European Union
ITU	International Telecommunication Union
SPHN	Swiss Personalized Health Network
UNAID	Joint United Nations Program on HIV/AIDS
WHO	World Health Organization
I-DAIR	International Digital Health & AI Research Collaborative
GESDA	Geneva Science and Diplomacy Anticipator

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The independent think tank foraus publishes evidence-based policy recommendations in the form of discussion papers, policy briefs and blog posts, and organizes high-level debates with the aim of creating innovative solutions for the foreign policy of tomorrow. foraus was founded in 2009 and is based on a unique grassroots model with several hundred volunteers in Switzerland and abroad.

Sensor Advice

Sensor Advice stands for goal-oriented, personal consulting and support in communication, political and organisational management. An interdisciplinary team of experienced practitioners and scientists working independently and connected, with the aim of achieving effective communication between the economy, politics and society. The qualitative dialogue and discourse analysis is a basis for the development of sustainable strategies.

Project funding partner

Fondation Botnar

Fondation Botnar is a Swiss-based foundation which champions the use of AI and digital technology to improve the health and wellbeing of children and young people in growing urban environments. To achieve this, the foundation supports research, catalyses diverse partners, and invests in scalable solutions around the world.

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*This list is not intended to be exhaustive.

Endnotes

1 WHO, «Digital Health», URL: https://www.who.int/health-topics/digital-health#tab=tab_1 (last accessed on 21.11.2020).

2 Federal Office of Public Health (2019): “Swiss Health Foreign Policy 2019–2024”, Bern, p. 16.

3 See e.g.Flick, Uwe (1995): “Qualitative Forschung. Theorie, Methoden, Anwendungen in Psychologie und Sozialwissenschaften”, Reinbek bei Hamburg.

4 See e.g. Warnke, Ingo H. & Spitzmüller, Jürgen (Hrsg.) (2008): “Methoden der Diskurslinguistik. Sprachwissenschaftliche Zugänge zur transtextuellen Ebene”, Berlin, New York.

5 The central idea of visioning is to allow participants to break out of traditional thought patterns in small groups whilst developing a common vision for the future. Afterwards, they reflect about the steps which are necessary to achieve their vision. For more information on methodology, see UK Government Office for Science (2017): «Tools for Futures Thinking and Foresight Across UK Government», p. 57.

6 Policy Kitchen: “My Data - My Health: Ideas”, URL: https://www.policykitchen.com/group/39/ideas.

7 Thiel, R. et al. (2018): #SmartHealthSystems: Digitalisierungsstrategien im internationalen Vergleich. Bertelsmann Stiftung, S. 6.

8 Working Group on Digital and AI in Health of the Broadband Commission for Sustainable Development (2020): Reimagining Global Health through Artificial Intelligence: The Roadmap to AI Maturity», S. 18.

9 Federal Office of Public Health: «Meldepflicht einer Krebserkrankung», URL: https://www.bag.admin.ch/bag/de/home/gesetze-und-bewilligungen/gesetzgebung/gesetzgebung-mensch-gesundheit/gesetzgebung-krebsregistrierung/meldepflicht_krebserkrankung.html (letzte Konsultation am 22.10.2020).

10 Tanzila, Saba (2020): «Recent advancement in cancer detection using machine learning: Systematic survey of decades, comparisons and challenges», Journal of Infection and Public Health Volume 13, Issue 9, S. 1274–1289, URL: https://www.sciencedirect.com/science/article/pii/S1876034120305633.

11 Working Group on Digital and AI in Health of the Broadband Commission for Sustainable Development (2020): «Reimagining Global Health through Artificial Intelligence: The Roadmap to AI Maturity», S. 35.

12 Handelszeitung (2018): «Es gibt nur wenige gute Daten da draussen», URL: https://www.handelszeitung.ch/unternehmen/es-gibt-nur-wenige-gute-daten-da-draussen (last accessed on 21.11.2020).

13 These laws reflect the fundamental rights defined in the Federal Constitution (Art. 13) and in the European Convention on Human Rights (Art. 8), which ensure the protection of personal privacy. For detailed information on the legal base: Sprecher, Franziska (2019): «Datenschutz im Gesundheitsbereich, Aktuelle Entwicklungen» in «Datenschutztagung 2018 – ein Blick auf aktuelle Rechtsentwicklung», p. 144.

14 Ibid., S. 173.

15 Sprecher, Franziska (2018): «Datenschutz und Big Data im Allgemeinen und im Gesundheitsrecht im Besonderen», in Zeitschrift des Bernischen Juristenvereins, Band 154, p. 525 (translated by authors).

16 The revision of the FADP was divided into two parts. The parliament had already ratified the Council of Europe’s data protection convention ETS 108 in 2018.

17 Ritcher, Leonie & Herzog, Erich (2020): «Datenschutz: Totalrevision erfolgreich abgeschlossen», economiesuisse, URL: https://www.economiesuisse.ch/de/artikel/datenschutz-totalrevision-erfolgreich-abgeschlossen (last accessed on 10.11.2020).

18 For the assessment of the data protection equivalence FADP-GDPR: Verein Unternehmensdatenchutz: «Rohstoff zum revidierten Datenschutzgesetz», URL: http://www.vud.ch/view/data/2124/vud_rohstoff_revidiertes_dsg.pdf (letzte Konsultation am 23.10.2020).

19 Federal Office of Public Health (2019): «Swiss Health Foreign Policy 2019–2024», Bern, p. 17.

20 Ibid., S. 16.

21 Federal Department of Foreign Affairs (2020): “Digital Foreign Policy Strategy. 2021–24”, Bern.

22 Ibid., S. 4.

23 Switzerlands’ 2028 Foreign Policy Vision

(AVIS28) even provides for Switzerland to be “a leading global hub for governance and research inartificial intelligence and other new technologies” by 2028. Report by the working group “Switzerland’s 2028 Foreign Policy Vision”, p. 36.

24 Federal Department of Foreign Affairs (2020): “Foreign Policy Strategy 2020–2023”, Bern.

25 BAKOM (2020): «Digital Switzerland Strategy», URL: https://www.digitaldialog.swiss/de/ (last accessed on 17.11.2020).

26 Federal Office of Public Health (2019): “Health2030. The Federal Council’s health policy strategy”, Bern.

27 eHealth Suisse (2018): «Strategie eHealth Schweiz 2.0 – 2018–2022», Bern.

28 Regarding the scope of application of the GDPR, see Article 3, Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

29 See Article 9, GDPR.

30 In particular, the “Guidelines 03/2020 on the processing of data concerning health for the purpose of scientific research in the context of the COVID-19 outbreak “ published in April 2020 by the European Data Protection Board have, according to critics, unnecessarily complicated international data transfer and thus, raised concerns among certain researchers. In Bovenberg, Jasper et al. (2020): “How to fix the GDPR’s frustration of global biomedical research: Sharing of data for research beyond the EU must improve”, Science 370 (6512), S. 40–42; NZZaS vom 03.10.2020, Hirstein, Andreas: «Datenschutz bremst den Fortschritt», URL: https://nzzas.nzz.ch/wissen/datenschutz-bremst-den-fortschritt-ld.1579776 (last accessed on 24.10.2020).

31 European Commission (2020): “WHITE PAPER On Artificial Intelligence: A European approach to excellence and trust”, COM(2020) 65 final, URL: https://ec.europa.eu/info/sites/info/files/commission-white-paper-artificial-intelligence-feb2020_en.pdf, S. 1.

32 Federal Department of Justice and Police (2019): «Datenschutzkonvention des Europarates: Bundesrat beschliesst Unterzeichnung», URL: https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-76861.html (last accessed on 22.10.2020).

33 Marini, Alice et al. (2018): “Comparing privacy laws: GDPR v. CCPA, Data Guidance & Future of Privacy Forum”, URL: https://fpf.org/wp-content/uploads/2018/11/GDPR_CCPA_Comparison-Guide.pdf (last accessed on: 17.10.2020); Fair Warning (2020): “GDPR and HIPAA: What are the Differences and How Can I Work Towards Compliance?”, URL: https://www.fairwarning.com/insights/blog/gdpr-and-hipaa-compliance-what-are-the-differences-and-how-can-i-work-towards-compliance (last accessed on 17.10.2020).

34 Court of Justice of the European Union (2020): “The Court of Justice invalidates Decision 2016/1250 on the adequacy of the protection provided by the EU-US Data Protection Shield”, URL: https://curia.europa.eu/jcms/upload/docs/application/pdf/2020-07/cp200091en.pdf (last accessed on 17.11.2020).

35 Federal Data Protection and Information Commissioner (2020): «Privacy Shield CH-USA bietet nach Auffassung des EDÖB kein adäquates Datenschutzniveau», URL: https://www.edoeb.admin.ch/edoeb/de/home/aktuell/medien/medienmitteilungen.msg-id-80318.html (last accessed on 17.11.2020).

36 Wymann, Lovey (2020), «Was bedeutet die Aufhebung des EU-US Privacy Shield für die Schweiz?», SWICO, URL: https://www.swico.ch/de/news/detail/was-bedeutet-die-aufhebung-des-eu-us-privacy-shield-fur-die-schweiz (last accessed on 20.11.2020); Global Alliance for Genomics and Health, «GA4GH GDPR Brief: Standard Contractual Clauses for Transferring Genomic and Health Data», 17.03.2020, URL: https://www.ga4gh.org/news/ga4gh-gdpr-brief-standard-contractual-clauses-for-transferring-genomic-and-health-data-march-2020-bonus-brief/ (last accessed on19.20.2020).

37 UN Secretary-General’s High-Level Panel on Digital Cooperation (2019): «The Age of Digital Interdependence, URL: https://www.un.org/en/pdfs/DigitalCooperation-report-for%20web.pdf (last accessed on 17.11.2020).

38 United Nations Special Rapporteur on the Right to Privacy – Task Force on Privacy and the Protection of Health-Related Data (2019): «Recommendation on the protection and use of health-related data», URL: https://www.ohchr.org/Documents/Issues/Privacy/SR_Privacy/FINALHRDDOCUMENT.pdf (last accessed on 17.11.2020).

39 Mariano, Bernardo, «Towards a global strategy on digital health», Bulletin of the

World Health Organization 2020;98:231-231A.

40 WHO (2020): «Draft Global Strategy on digital health 2020-2025»,URL: https://www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf?sfvrsn=f112ede5_54 (last accessed on 18.10.2020).

41 International Telecommunication Union (ITU): «Focus Group on Artificial Intelligence for Health», URL: https://www.itu.int/en/ITU-T/focusgroups/ai4h/Pages/default.aspx (last accessed on 08.11.2020).

42 International Organization for Standardization (2018): «ISO 20387:2018 Biotechnology — Biobanking — General requirements for biobanking», URL: https://www.iso.org/standard/67888.html (last accessed on 17.11.2020); World Medical Association (2016): «WMA Declaration of Taipei on Ethical Considerations regarding Health Databases and Biobanks», URL: https://www.wma.net/policies-post/wma-declaration-of-taipei-on-ethical-considerations-regarding-health-databases-and-biobanks/ last accessed on 17.11.2020).

43 Quotations by PoliTisch participants are anonymous (see chapter 2). References to affiliation of participants to a specific group of actors is possible in certain cases. Yet, no source references are being made.

44 Golder, Lukas et al. (2020): «Swiss eHealth Barometer 2020 Bericht zur Bevölkerungsbefragung», gfs.bern, p. 15.

45 Bushell, Andy & Detreköy, Niculin, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/centralized-health-data-hack-reported-be-behind-covid-25-bio-engineered-virus; Angst, Laura; Roten, Noemi & Calamida, Amos, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/google-makes-genomic-testing-mandatory; https://www.policykitchen.com/mydatamyhealth/idea/google-makes-genomic-testing-mandatory.

46 One Policy Kitchen vision describes such an ethical dilemma: «Recent research has brought into light how students with limited economic resources are inoculating rare diseases on purpose in order to acquire economic advantage from pharmaceutical companies [buying their data for research on new therapies].» in Belinchon de la Banda, Eduardo & Stern, Guillaume, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/students-get-infected-purpose-rare-diseases-increase-value-their-health-data.

47 Hitz, Anna & Nakonz, Jonas, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/google-launches-insurance-service; Scharf, Tamara, Darcan, Emirhan & Fegert, Moritz, Policy Kitchen participants: URL: https://www.policykitchen.com/mydatamyhealth/idea/smart-watch-company-now-working-insurance-company-develop-penalty-not-sticking; Bushell, Andy & Detreköy, Niculin, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/centralized-health-data-hack-reported-be-behind-covid-25-bio-engineered-virus.

48 Balakrishnan, Aniruddhan & Widmer, Philip, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/eintritt-die-bar-am-eigenen-geburtstag-verweigert.

49 See f. ex. Bischofberger, Cindy & Jörg, Andreas, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/pghd-finally-belong-you; Page, Philippe & Balavoine, Michael, Policy Kitchen participants, URL: https://www.policykitchen.com/node/535/collaboration.

50 Lensmith, Elisabeth & Bachmann, Nino, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/ukbb-datacenter-hack-ai-hurting-patients-hundreds-dead.

51 Stieger, Nathalie & Gawel, Claus, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/fair-data-alliance-summit-convenes-key-stakeholder-davos.

52 Fegert, Moritz (2020), in Farman, Darius et al. (2020): «Der Bilaterale Weg: Wie weiter mit einem überholten Betriebssystem?», Zürich, p. 34.

53 Europäische Kommission: «eHealth Network», URL: https://ec.europa.eu/health/ehealth/policy/network_de (last accessed on 23.10.2020).

54 European Commission (2020): «The Digital Services Act package», URL: https://ec.europa.eu/digital-single-market/en/digital-services-act-package (last accessed on 11.11.2020).

55 Fegert, Moritz (2020), in Farman, Darius et al. (2020): «Der Bilaterale Weg: Wie weiter mit einem überholten Betriebssystem?», Zürich, p. 34.

56 See also EDA (2020): «Digitalaussenpolitik 2020–2024», Bern, p. 8.

57 Amandeep, S. Gill (2020): “Realising the promise of digitally-enabled health”, URL: https://i-dair.org/wp-content/uploads/2020/09/Resource-1-Why-I-DAIR.pdf.
58 Bischofberger, Cindy & Jörg, Andrea, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/pghd-finally-belong-you.
59 Voélin, Fanny; Moi, Gianfranco & Clivaz, Claire, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/global-health-database-helps-find-cure-against-eg-malaria; Scheibner, James & Shinde, Vijaya, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/citizen-led-data-sharing-platform-helps-find-vaccine-covid-30.
60 Stieger, Nathalie & Gawel, Claus, Policy Kitchen participants, URL: https://www.policykitchen.com/mydatamyhealth/idea/fair-data-alliance-summit-convenes-key-stakeholder-davos.
61 On this, see the MIDATA platform, which was co-initiated by researchers from ETH Zurich: https://www.midata.coop/en/home/.
62 Member of the Council of States Rieder, Beat (2020), «Nationale Datenkompetenz-kampagne. Datenkompetenz (Data literacy) ist gefragt», Interpellation an den Bundesrat n°20.4173, URL: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20204173.
63 Ibid.
64 Find more on the challenges related to the “generational gap” in Golder, Lukas et al. (2020): «Swiss eHealth Barometer 2020 Bericht zur Bevölkerungsbefragung», gfs.bern, p. 31.
65 Sprecher, Franziska (2019): «Datenschutz im Gesundheitsbereich, Aktuelle Entwicklungen in Datenschutztagung 2018 – ein Blick auf aktuelle Rechtsentwicklung», p. 141; Frick, Karin et al. (2020): «NEXT HEALTH: Einfacher durch das Ökosystem der Gesundheit», Rüschlikon, p. 19–23.
66 Federal Office of Public Health, «Revision Gesetz über genetische Untersuchungen beim Menschen», URL: https://www.bag.admin.ch/bag/de/home/medizin-und-forschung/genetische-untersuchungen/aktuelle-rechtsetzungsprojekte1.html (last accessed on 22.10.2020).
67 Talanova, Vladislava und Sprecher, Franziska (2020): «Forschung und COVID-19: Verbesserungspotenzial des Generalkonsents», Schweizerische Ärztezeitung, n°101(38), p. 1197–1200.
68 WHO (2020): «Draft Global Strategy on digital health 2020-2025», URL: https://www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf?sfvrsn=f112ede5_54, pp. 13–14 (last accessed on 18.10.2020).
69 WHO: «Framework Convention on Tobacco Control (FCTC)», URL: https://www.who.int/fctc/en/ (last accessed on 17.11.2020); WHO: «International Health Regulations», URL: https://www.who.int/health-topics/international-health-regulations#tab=tab_1 (last accessed on 17.11.2020).
70 Mariano, Bernardo (2020): «Towards a global strategy on digital health», Bulletin of the World Health Organization, 98:231-231A.
71 Federal Department of Foreign Affairs (2020): “Digital Foreign Policy Strategy 2021–24”, Bern, p. 8.
72 Ibid.
73 Figures from January 2020, in Meister, Franziska, «Elektronisches Patientendossier: Wer haftet? Wer zahlt?», Die Wochenzeitung, 02/2020, 09.01.2020, URL: https://www.woz.ch/-a3f2 (last accessed on 19.10.2020).
74 Ibid.
75 Schweizerischer Nationalfonds zur Förderung der wissenschaftlichen Forschung (SNF), «Nationale Forschungsprogramme (NFP)», URL: http://www.snf.ch/de/fokusForschung/nationale-forschungsprogramme/Seiten/default.aspx#Laufende%20NFP (last accessed on 20.11.2020).
76 Balthasar, F. , Cantalou, J. und F. Egli (2020), in Farman, Darius et al. (2020): «Der Bilaterale Weg: Wie weiter mit einem überholten Betriebssystem?», Zürich, p. 50.
77 Swiss Personalized Health Network (SPHN): URL: https://sphn.ch/de/home/ (last accessed on 17.11.2020).
78 GOFAIR: «FAIR Principles», URL: https://www.go-fair.org/fair-principles/ (last accessed on 01.11.2020).
79 SNSF: «Open Research Data», URL: http://www.snf.ch/en/theSNSF/research-policies/open_research_data/Pages/data-management-plan-dmp-guidelines-for-researchers.aspx (last accessed on 10.11.2020).
80 Swiss Personalized Health Network, URL: https://sphn.ch/network/projects/data-coordination-center/the-sphn-semantic-interoperability-framework/ (last accessed on 17.11.2020).
81 eHealth suisse: «Internationale Koordina-

tion», URL: https://www.e-health-suisse.ch/de/politik-recht/strategische-grundlagen/internationale-koordination.html (last accessed on 17.11. 2020).

82 Laboratory of Data Security: «Protecting data for personalized health», URL: https://lds.epfl.ch/pdph/ (last accessed on 11.11.2020).

83 Seydtaghia, Anouch (2020): «La «Trust Valley» suisse voit grand, entre Vaud et Genève», URL: https://www.letemps.ch/economie/trust-valley-suisse-voit-grand-entre-vaud-geneve (last accessed on 09.11.2020).

84 Vayena, Effy & Blasimme, Alessandro (2017): «Biomedical Big Data: New Models of Control Over Access, Use and Governance», Bioethical Inquiry 14, S. 501–513.

85 Stephens, Z.D., Lee, S.Y. & Faghri, F. et al. (2015): «Big data: Astronomical or genomical?», PLOS Biology 13(7): e1002195.

86 OECD (2019): «Recommendation of the Council on Health Data Governance», OECD/LEGAL/0433.

87 iRights.lab: «Data Governance», URL: https://irights-lab.de/projects/mfund/ (last accessed on 19.10.2020).

Quotations
Knobel, Isabel, Fegert, Moritz and Detreköy, Niculin (2020): “Health Data Governance: What’s in it for Switzerland?”, Zurich: Sensor Advice and foraus - Forum on Foreign Policy.

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