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The sociopolitical discourse on health data sharing in Switzerland: lessons learned from 1992 to 2023 for present public trust building – a multi-method study

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Summary

BACKGROUND: Public trust is central for the successful implementation of health data sharing initiatives, and it is partly shaped by the public's past experiences with the system. Understanding how these experiences have framed current public trust is essential to adequately inform trust-building measures in current and future health data sharing initiatives. The aim of the present study was to trace the evolution of the sociopolitical discourse surrounding health data sharing in Switzerland from 1992 to the present by identifying (1) key policy documents; (2) opinion-shaping and (3) negative events influencing public experience and trust in health data sharing over the last 31 years; (4) implementation obstacles and (5) lessons learned throughout this period. The analysis offers the opportunity to reflect on challenges in implementing data sharing initiatives and their impact on public trust, aiming to provide insights for guiding Swiss and European policymakers in designing future health data sharing initiatives while fostering public trust.

METHODS: We designed a multi-method study comprising (A.I) a thematic analysis of online interviews with key stakeholders and (A.II) a scoping review of expert opinion papers to capture expert perspectives; (B) a policy analysis of government policies to comprehend the political trajectory of the health data sharing discourse; and (C) an analysis of news articles across eight major Swiss newspapers to trace the evolution of the media narrative around data sharing.

RESULTS: While the digitisation of private life in the early 2000s and the COVID-19 pandemic positively influenced Switzerland's sociopolitical discourse on health data sharing, triggering policy waves on the primary and secondary use of health data, recent setbacks with the Electronic Patient Dossier (EPD) initiative negatively impacted public trust. Key obstacles to EPD implementation were identified across policy, public, professional and technical levels, providing valuable lessons and actionable recommendations for improving the implementation of current and future health data sharing initiatives.

CONCLUSIONS: The sociopolitical discourse on health data sharing in Switzerland is mainly framed by past and present negative narratives on the EPD, compounded by national and international scandals. It is recommended to centralise coordination at the federal level and to foster stakeholder collaboration. To build and maintain public trust, comprehensive public engagement strategies and user-friendly solutions that offer citizens autonomy are needed. Also, careful narrative management is essential. Healthcare professionals should be actively involved in the development and policymaking process from the outset and provided with financial support to facilitate their digital transition. Considering the promising health data sharing initiatives under the DigiSanté programme, adopting these recommendations is essential to avoid delays, negative narratives and further erosion of public trust in Switzerland's health data sharing initiatives.

Background

Public trust is essential for the successful implementation of health data sharing initiatives, such as the proposal for the establishment of a Swiss Data Room (SDR) for health-related research in Switzerland and the European Health Data Space (EHDS) across the European Union, as it is closely tied to public participation and healthcare system support [1–3]. Low levels of trust can result in individuals withholding consent to share their data, and professionals opposing these initiatives [1, 4]. Without sufficient levels of public trust, political decision-makers are unable to effectively drive the policy process forward as trust is integral to governmental legitimacy, potentially leading to policy failure [5, 6]. Trust can be defined as "a bet about the future contingent actions of others" [7], and when applied to health data sharing on a system-wide level, public trust involves the expectation that institutions, organisations or individuals responsible for collecting, storing, sharing and

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working with health data will act with integrity, reliability, competence and in the public's best interest [1].

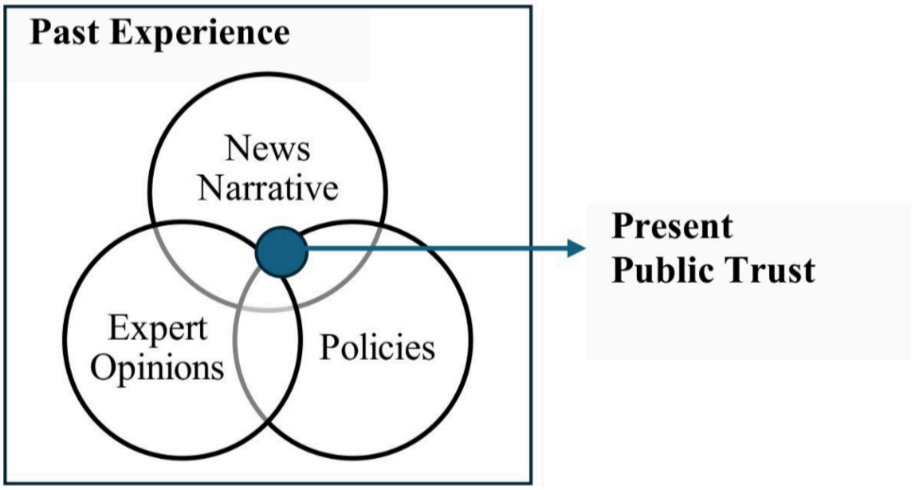
The need for public trust for digital transformation and health data sharing initiatives is highlighted by recent experiences of low public trust in Switzerland. Owing to its direct democracy system, low levels of public trust in political initiatives might lead to a call for a citizens' referendum, as seen in the rejection of the Electronic Identification Services (e-ID) Act in March 2021, which aimed at establishing a state-recognised and secure electronic proof of identification [8]. Similarly, alongside the shortcomings of political and health system actors, low public trust has contributed to the limited adoption of the Electronic Patient Dossier (EPD), introduced in 2015, with a nationwide adoption rate of 0.22% as of April 2023 [4, 9, 10]. The potentially severe effects of low public trust on the success of current and future health data sharing initiatives are acknowledged by Swiss health policymakers. In the Swiss Health 2030 strategy, the "need to build public trust" in the use of health data is identified as a priority to achieve the first objective of the initiative [11]. Similarly, in package four of the Swiss government's DigiSanté programme for 2025–2034, the development of a Swiss Data Room for health-related research is reported to be carried out with a strong emphasis on trustworthiness [12].

To ensure public acceptance of the Swiss Data Room and the achievement of its goals in the near future, it is crucial to understand the public's past experiences with health data sharing activities that frame current public trust. Public trust develops in the public sphere through open public discourse on present perceptions of system trustworthiness and future expectations of potential benefits, with familiarity and shared past experiences considered significant determinants of present public trust [1]. The close relationship between past experiences and trust is described by a trust culture arising from "the collective and shared experiences of societal members over time", defining trust culture as "a product of history" [7]. Conferring trust requires consideration of all previous experiences, as trust can only be placed in a familiar world with a reliable background [13].

We identify three dimensions equally influencing collective past public experiences and, consequently, public trust in health data sharing at present: news narratives, expert opinions and policies (figure 1). News narratives shape public trust through topic framing, reporting tone and story selection [14, 15]; expert opinions provide insights into complex issues, contributing to shaping public trust, although conflicting expert views may undermine it [16, 17]; policies promote among the public a sense of security, certainty and predictability, alleviating concerns and enhancing trust in the system [18–20]. Individual first-hand experiences with national and international data sharing initiatives also contribute to shaping public trust. However, these data sharing initiatives have not yet been fully implemented in Switzerland. For example, personal experience with the EPD is limited to fewer than 20,000 individuals nationwide [9]. Therefore, the factor "personal experiences" is not considered in the current analysis, which argues that the Swiss collective experience is primarily framed by the three dimensions outlined in figure 1. Once health data sharing initiatives are fully operational, individual experiences should be included as a fourth dimension influencing collective experience and public trust in health data sharing.

Building on the proposed interplay between policies, news narratives and expert opinions in shaping past collective experiences and thus public trust at present, we aim to analyse these three dimensions to identify (1) the policy timeline around health data sharing in Switzerland; (2) opinion-shaping and (3) negative events that have influenced public experience and trust in health data sharing over the past 31 years; (4) implementation obstacles and (5) lessons learned during this period. This study constitutes one work stream within an overarching research project entitled "Public Trust in a Swiss Health Data Space" [21] that aims to explore what a trustworthy Swiss health data space might look like from the public's perspective. The present study contributes to this goal by tracing the

Figure 1: Three dimensions shaping past public experience, hence present public trust.



evolution of the discourse surrounding health data sharing in Switzerland, while a complementary study involves interviews with members of the public to capture their understanding of trustworthiness, incorporating sociocultural dimensions of trust. The ultimate objective of the present study is to inform DigiSanté's Swiss Data Room project specifically, as well as Swiss and European policymakers in the design and implementation of future health data sharing initiatives more broadly.

Methods

We designed a multi-method study to capture the dimensions of expert opinions, policy and news narratives on health data sharing in Switzerland from 1992 to 2023. No formal study protocol was developed or registered for this research. Our approach, grounded in phenomenology (A.I) and content analysis (A.II, B, C) [22], included three data streams:

(A.I) a thematic analysis of online interviews with key stakeholders and

(A.II) a scoping review of expert opinion papers to capture expert perspectives;

(B) a policy analysis of government policies to understand the political trajectory and trace the policy timeline;

(C) a news search and analysis across Swiss newspapers to trace the evolution of media narratives.

Following an assessment of the quality of data provided by the three data streams, we used the data collected from the interviews as the primary data source for the study, with the other sources providing additional context to these findings. By integrating insights from the interview data with the policy analysis and the scoping review of expert opinion papers, we identified (1) the policy timeline within the current landscape of health data sharing in Switzerland. By combining data from the interviews, news articles and expert opinion papers, we were able to identify (2) opinion-shaping events, (3) negative events, (4) implementation obstacles and (5) key lessons for the future implementation of health data sharing initiatives in Switzerland. We conducted the data collection and analysis from October 2023 to May 2024, using German, French, Italian and English as appropriate, with all languages fluently spoken by research team members. German (61.8% of the population, 2022), French (22.8% of the population, 2022), Italian (7.8% of the population, 2022), and Romansh (0.5% of the population, 2022) are the four official languages of Switzerland [23].

Thematic analysis of stakeholders' interviews (A.I)

In February and March 2024, FZ conducted semi-structured 30-minute online interviews in English with senior experts in digital health from Switzerland. These experts were purposely sampled from academia, the pharmaceutical industry, the Federal Office of Public Health (FOPH), the Federal Statistical Office, the Swiss Personalised Health Network, the Swiss Institute of Bioinformatics, the Swiss Medical Association, politics and journalism. All potential participants were invited via an email (sent out in February 2024) providing a brief introduction to the research team and the study aim. Before the interview process started, FZ pilot-tested the interview set-up and questions.

In line with Pope and Mays' guide on designing a topic guide in qualitative research [24], FZ and FG developed five open-ended interview questions to foster discussion and exploration of the topic by interviewees. Questions were formulated based on FZ, FG and PD's prior research, and were aligned with the study's objectives (appendix 1). The online interviews were audio-recorded and then transcribed using the online software Zoom (version 5.17.11). Transcripts were then uploaded to MaxQDA24, a software for qualitative research, manually reviewed by FZ to remove identifying information (e.g. names, institutions and cities) and to check transcription accuracy. FZ coded the transcripts using a reflexive thematic approach to identify emerging themes [25]. To ensure the quality of the analysis, FG and PD reviewed the codes and reached agreement with FZ on the identified emerging themes. Additional details on the data collection and analysis processes are available in appendix 2, which aligns with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [26].

The study was conducted in compliance with the Declaration of Helsinki and obtained clarification of responsibility from the ethics committee of the Canton of Zurich on 8 January 2024 (BASEC Nr: 2023-01518). Written informed consent was obtained from all participants.

Scoping review of expert opinion papers (A.II)

We conducted a scoping review of editorials and viewpoints to trace the evolution of expert opinions on health data sharing in Switzerland from 1998 to 2023. Our approach was guided by Arksey and O'Malley's [27] 6-step methodological framework for conducting scoping studies (appendix 3). In collaboration with a specialised librarian from the University of Zurich, we developed a search strategy for PubMed, Scopus, Embase and Cochrane (appendix 4). We included Swiss Health Web, Swiss Medical Forum and Swiss Medical Weekly due to the study's geographical focus. Keyword searches were conducted with "Gesundheitsdaten" (German for "health data"), as well as "Swisstransplant", "Meineimpfungen" (German for "myvaccination") and "Patientendossier" (German for "patient dossier"), which emerged from interviews as key events affecting public perception of health data sharing in Switzerland (appendix 4). Searches were conducted in November 2023 and in January 2024, covering publications from 1998 to 2023. We included articles in English, French, German and Italian that focused on Switzerland and health data sharing initiatives. Editorials were included from PubMed, Scopus, Embase and Cochrane, while a broader range of article types – including editorials, commentaries, position papers, themed issues and updates – were included from the Swiss journals. Publications were pasted into an Excel file in their original language, along with their English translations (produced using ChatGPT version 3.5). FZ and FG used an inductive approach to code publications, to identify their topic, date and tone using colour-coded indicators. Expert opinion papers coded in red predominantly conveyed a negative message about the topic, reflecting a potential negative influence on public opinion. Publications coded in yellow were considered as neutral, reflected by their reporting of facts or pros and cons in a balanced approach. Publications coded in green reflected those with a more positive tone on the impact of data sharing initiatives on society. Colour coding was based on the original language text to capture nuances of tone in each language. FZ colour-coded Italian and French articles, while FG colour-coded the ones in German. To mitigate the risk of interpretation bias and to enhance reliability, FZ and FG subsequently independently coded the English translations of the German, Italian and French articles, respectively, then cross-checked the codes against the initially assigned codes. In cases of discrepancy in assigned codes, PD, who is fluent in all four languages, was consulted in order to reach a consensus.

Policy analysis (B)

The policy analysis focused on documents tracing the political development of the health data sharing discourse in Switzerland, up to 2023. The first search started with documents in 1998, due to the publication of the Federal Council's Information Society Strategy on 18 February, which marked the first acknowledgement of the potential of digital data for Switzerland and the need for specific safeguards. Among the identified policy documents, FZ and FG selected the relevant documents pertaining to health data sharing and digitisation of the health system. Following compilation of interview findings, we extended the research timeframe by conducting a second search for documents dating back to 1992. We searched for policy documents on the Swiss Government and Parliament websites (https://www.bag.admin.ch/bag/de/home and https://www.parlament.ch). These searches involved the following key terms: "data", "health data" in Italian ("dati", "dati sanitari") and German ("Daten", "Gesundheitsdaten"); as well as identifying relevant cross-references within the identified policies. We identified broad search terms, and we included different types of documents (acts, strategies, motions, referenda, mandates, press releases, interpellations and postulates) to gain a comprehensive overview of the relevant political developments on health data sharing. Once the list of policy documents deemed influential in the Swiss health data sharing discourse by FZ and FG was compiled in chronological order, the Policy Streams Approach [28] was applied to identify windows of opportunities for health data sharing policies.

News analysis (C)

We first conducted news searches on the digital news archives "e-newspaperarchives.ch" and "swissdox.ch" using key term searches with the terms "health data" and "electronic health record" in German ("Gesundheitsdaten", "Patientendossier"). Due to limited results, we opted to search the digital archives of seven leading newspapers in Switzerland across the three language regions: Italian ("Corriere del Ticino", "La Regione"), French ("Le Temps", "Tribune de Genève") and German ("Der Bund", "Tages-Anzeiger", "Neue Zürcher Zeitung"). The editorial teams of each newspaper were contacted for advice on the best search methods using their digital search engines. In the case of Neue Zürcher Zeitung, despite subscribing to different plans and contacting the support team, we were unable to access the news articles in a researchable format from their digital archives, resulting in exclusion of this publication from the study. Additionally, we conducted news searches on Medinside and Inside IT, two Swiss digital news platforms that cover healthcare and technology topics, respectively. Broad key search terms in German, Italian and French included "health data" and "electronic health record" from January 1998 to December 2023, as well as "Swisstransplant" and "Meineimpfungen" from January 2020 to December 2023 to capture news related to the two main scandals during that period that emerged from the interviews (appendix 4). The news search was conducted by FZ. Articles were pasted into an Excel file in their original language, alongside their English translations (produced using ChatGPT version 3.5). The accuracy of the translations was verified by the research team. Articles were then coded based on topic, date and tone using colour-coded indicators (see section "Scoping Review of Expert Opinion Papers [A.II]")

Results

We identified 86 policy documents (appendix 5), 27 expert opinion publications, 528 news articles (appendix 4), and interviewed 11 key stakeholders (appendix 2). From these sources and guided by interview data, we selected:

1. 44 key policy documents and events that delineated the policy timeline around health data sharing;
2. 4 opinion-shaping events that supported public trust;
3. 3 negative events that impacted public trust;
4. 15 obstacles that hindered the implementation of health data sharing initiatives; and
5. 19 key lessons learned that can inform the implementation of future health data sharing initiatives in Switzerland.

1. Policy timeline

We identified 44 relevant policy documents and events (table 1) from a total of 86 (appendix 5). These documents represent significant political and legal milestones that have framed the discourse on health data sharing in Switzerland, thereby setting the timeline for the present study. We identified a first policy wave beginning in the late 1990s, coinciding with the initial phase of digital transformation, which primarily focused on establishing the legal foundation for the use of health data for primary purposes. A second policy wave, catalysed by the COVID-19 pandemic, centred on creating the legal framework for the secondary use of health data.

First policy wave – Legal foundation for the primary use of health data

From the interviews, it emerged that two of the earliest policies instrumental in shaping the political discourse on health data sharing in Switzerland, both published in 1992, were the Federal Act on Data Protection (SR 431.01), which categorised health data as "sensitive personal data" under Article 5 and introduced the concept of explicit consent for the processing of personal data, and the Federal Statistics Act (SR 431.01), which regulated for the first time the linkage of personal data between different databases. In 1994, the Federal Health Insurance Act referred for the first time to the secondary use of data with the involvement of multiple actors. In 1998, the Information Society Strategy became the first policy document to emphasise the potential of digital data for Switzerland and the necessity of establishing specific safeguards. In 2001, five Swiss university hospitals (Basel, Bern, Geneva, Lausanne, Zurich) launched the "Patient Dossier 2003" initiative aimed at enhancing computer utilisation in data management and standardising the dissemination of patient records. This represents the first attempt to systematically disseminate the use of digital patient files [29]. The need for a legal framework for primary health data use emerged in 2004 with the Noser motion 04.3243, which called for a draft law on eHealth to provide Swiss citizens with access to electronic health records. Following the European eHealth Action Plan, in 2004 the Swiss government commissioned a Swiss eHealth situation analysis to assess the implementation status of eHealth in Switzerland, which was described as "heterogeneous". Based on this analysis, the eHealth Swiss strategy was published in 2007 with the aim of improving the efficiency, quality and security of electronic services in the health sector. Moreover, this strategy set a nationwide objective to gradually implement electronic medical records. In 2010, the Humbel Postulate 10.3327 urged the Federal Council to present the necessary

Table 1:
List of key Swiss policy documents/events shaping the health data sharing political discourse.

Date	Documents/Events
First policy wave – Legal foundation for the primary use of health data	
1992	SR 235.1 – Federal Act on Data Protection (FADP)
	SR 431.01 – Federal Statistics Act (FStatA)
1994	SR 832.10 – Federal Health Insurance Act (KVG)
1998	Federal Council's Information Society Strategy in Switzerland
2001	Patient Dossier Initiative
2004	Swiss eHealth Situation Analysis
	04.3243 Noser Motion – E-Health. Use of electronic means in healthcare
2006	Strategy of the Federal Council for an Information Society in Switzerland (Updated from 1998)
2007	AS 2007 479 – Ordinance on the Insurance Card for Compulsory Health Insurance (VVK)
	eHealth Swiss Strategy (2007–2015)
	Founding of "eHealth Swiss"
2010	SR 818.101 Epidemics Act – entered into force in 2016
	10.3327 Humbel Postulate – Implementation of the e-Health Strategy
	Electronic health record: mandate for the development of legal bases
2011	SR 810.30 – Human Research Act (HRA) – entered into force in 2014
2012	Federal Strategy for Switzerland's Digital Future
2015	SR 816.1 – Federal Act on the Electronic Patient Record (EPRA) – entered into force in 2017
	15.4225 Humbel postulate – Better use of health data for high-quality and efficient healthcare
2016	SR 818.33 – Cancer Registration Act (CRA) – entered into force in 2018
2017	Establishment of the Swiss Personalised Health Network (SPHN)
2018	eHealth Swiss 2.0 (2018–2024)
	Establishment of the CARA Association
	18.4328 Wehrli Postulate – Electronic patient record. What else can be done to ensure that it is fully used?
2019	Health Policy Strategy 2020–2030 (Health 2030)
Second policy wave – Legal foundation for the secondary use of health data	
2020	Digital Switzerland Strategy (updated from 2018)
	20.3243 FDP_SR Motion: COVID-19. Accelerating the Digitalisation in Healthcare
2021	Electronic Identity Act (e-ID Act) – Referendum
	21.3957 Ettlin Motion – Digital transformation in healthcare. Finally catching up!
	21.4373 Silberschmidt Motion – Introduction of a unique patient identifier
2022	Report from the FOPH on improving data management in the healthcare sector
	Report from the Federal Council following up on 15.4225 Humbel Postulate
	Transplantation Act – Referendum
	22.3890 WBK_SR Motion: Framework law for the secondary use of health data
	22.4022 FDP_NR Postulate: Exploiting the potential of digitalisation and data management in the healthcare sector. Switzerland needs an overarching digitalisation strategy
	Creation of trustworthy data rooms based on digital self-determination
	Swiss Digital Strategy 2023
2023	DigiSanté 2024–2034 – Programme to promote digital transformation in the health system – Commitment credit
	Code of Conduct for managing trustworthy data spaces based on digital self-determination
	SR 235.1 – (New) Federal Act on Data Protection (nFADP)
2024	DigiSanté 2024–2034 – Federal Decree on the commitment credit for a programme to promote digital transformation in the healthcare sector for the years 2025–2034
Ongoing	Revision of the EPRA
	Revision of the Epidemics Act to better manage future public health crises
	Revision of the HRA
	Implementation of 22.3890 WBK_SR Motion: Framework law for the secondary use of data

legal basis to support the implementation of the eHealth strategy, leading the Federal Council to instruct the Federal Department of Home Affairs (EDI) to establish the legal framework for the implementation of electronic patient records by September 2011. These policy developments culminated in the publication of the SR 816.1 – Federal Act on Electronic Patient Records (EPRA) in 2015, which provided a legal framework for data sharing for primary use in Switzerland.

Second policy wave – Legal foundation for the secondary use of health data

While the Human Research Act of 2011 (SR 810.30) introduced general informed consents and established a foundation for health data sharing for research purposes in Switzerland, the COVID-19 pandemic catalysed policymakers' recognition of the need for a comprehensive strategy in healthcare digitalisation, particularly regarding the use of data for research purposes. This was highlighted in motion 20.3243 FDP_SR, which directed the Federal Council to take necessary measures, in collaboration with relevant stakeholders, to accelerate the digitalisation of the Swiss healthcare system. In January 2022, the FOPH released a report on improving data management in the healthcare sector, drawing on lessons from the pandemic and outlining seven guiding principles for future data management. Subsequently, in May 2022, the Federal Council responded to the 2015 Humbel postulate 15.4225 which emphasised the need for better reuse of health data, by issuing a report that directed the EDI to define the processes and structures of the data system and make the necessary legal adjustments. These developments led to several political initiatives in 2022, including the adoption of motion 22.3890 WBK_SR, which called for a framework law on the secondary use of health data, as well as postulate 22.4022 FDP_NR, which advocated for a comprehensive digitalisation strategy in healthcare. In May 2022, the Federal Council tasked the EDI with developing a programme to enhance the use of digitalisation and data management, integrating existing mandates including the 21.3957 Ettlin motion, the 21.4373 Silberschmidt motion as well as the 15.4225 Humbel postulate. In November 2023, the Federal Council submitted a request for commitment credit to the Federal Assembly to finance the DigiSanté programme, aimed at promoting digital transformation in the healthcare system. This culminated in the Federal Decree on the commitment credit for DigiSanté, covering the years 2025–2034, published on 13 June 2024, thereby formally initiating the programme, which includes in package 4 ("Secondary use for planning, strategic management, and research") the establishment of the necessary conditions for secondary data use within the Swiss health data space.

The complete list of described policy documents and their references can be found in appendix 5.

2. Opinion-shaping events

From the interviews, four events emerged that contributed to framing the sociopolitical discourse surrounding health data sharing in Switzerland (table 2). Supportive quotes from interviewees can be found in appendix 6.

1. Digitisation of private life

Interviewees emphasised that the digitisation of private life in the early 2000s, including increased access to internet and mobile devices, has contributed to the data sharing discourse by raising public awareness about the ubiquitous data flows.

2. COVID-19 pandemic

Interviewees noted that the pandemic raised public awareness of the critical role of health data and served as a catalyst for policymakers, highlighting the need for a comprehensive health data governance strategy. Additionally, the SwissCovid digital contact tracing app was reported by interviewees as a digital health success in Switzerland, as it was developed quickly and with high standards.

3. "MyVaccination" solution

Interviewees reported that, prior to the 2021 data leak [30], "meineimpfungen/myvaccination" was an accepted digital solution that positively contributed to the discourse on health data sharing. The data leak shifted the narrative in a negative direction.

4. DigiSanté programme

The establishment and initialisation of the DigiSanté programme by the FOPH and the Federal Statistical Office in 2023 was cited by interviewees as a positive development for the digital transformation of the Swiss healthcare sector, demonstrating that governmental bodies are fulfilling their commitments to a solid national digital health strategy.

3. Negative events

We identified three main negative events (table 3). Quotes from interviewees can be found in appendix 7.

1. Scandals

When investigating events that negatively impacted the sociopolitical discourse on health data sharing in Switzerland, interviewees mentioned (table 3) the 2013 Edward Snowden scandal, which was the biggest intelligence leak in the history of the USA's National Security Agency (NSA) [31]; the revelation in 2018 of the unauthorised processing of personal data belonging to millions of Facebook users for political advertising by the British consulting firm Cambridge Analytica [32]; the investigation of Swiss platforms "My Vaccination/meineimpfungen" in 2021 [30] and "Organ Donation/Swisstransplant" in 2022 for data protection violations [33]; and the online leakage of med-

Table 2:
Events contributing to the framing of the sociopolitical discourse on health data sharing – chronological order.

Opinion-shaping events positively influencing the sociopolitical discourse on health data sharing – Interview data
1. Early 2000s – Digitisation of private life
2. 2020 – COVID-19 pandemic
3. Before 2021 – "Myvaccination" solution
4. 2023 – DigiSanté programme

ical files belonging to thousands of residents in Neuchâtel, Switzerland, in 2022 [34]. In particular, the 2013 Edward Snowden scandal, "My Vaccination" and "Organ Donation" were the most frequently reported negative events by interviewees. While it was acknowledged that other data leaks occurred over the years that negatively impacted public opinion on health data sharing, interviewees noted that these incidents did not significantly influence the broader public. Additionally, the e-ID referendum in 2021 was noted for sparking debates around government involvement in the governance of sensitive data. Stakeholders reported the outcome of this referendum with negative connotations since it revealed a lack of public trust in the state.

From the analysis of 55 news articles and expert opinion papers on "My Vaccination" and "Organ Donation" scandals covering the timeframe 2020–2023, it emerged that the tone of the articles was predominantly negative (67% and 57%, respectively, coded in red – appendix 8).

2. Slow implementation of the Swiss EPD initiative (2015–2024)

Interviewees reported that the negative narrative around the implementation of the EPD over the years has had a more significant impact on the overall public perception of health data sharing in the country compared to national and international scandals.

From the analysis of 476 news articles and expert opinion papers on health data sharing and the EPD (keywords: "health data", "Patientendossier") covering the timeframe 1998–2023, it emerged that the tone of expert opinion papers was mainly positive (66% coded in green), contrasting with news articles, which tended to adopt a negative to neutral tone (39% red, 38% yellow – appendix 8). Moreover, the tone of news articles gradually turned more negative after the publication (2015) and enforcement (2017) of the Federal Act on the Electronic Patient Dossier (EPRA) (figure 2). From this point onwards, articles began regularly reporting delays in implementation of the EPD, highlighting inefficiencies, raising security concerns, up to accusing the federal government and the cantons of lacking a "holistic vision" [35] and referring to the EPD initiative as "the small failure of a modern state" [36]. A similar trend is visible from the analysis of the tone of expert opinion papers, which underwent a negative shift in tone in the years between 2016 and 2021 (figure 2). In the early 2000s, expert opinion papers typically highlighted the positive impact of the computerised patient record on the improvement of "the quality of care and patient management" [37], with the Swiss Medical Association (FMH) describing the EPRA as "an opportunity" in 2015 [38]. From 2016, the tone of expert opinion papers shifted negatively. In 2016, an editorial from the FMH criticised the too-high regulatory density and requirements of the newly published EPRA [39]. This negative tone persisted in most expert opinion papers in the following years, becoming more neutral in 2018 and 2019. In 2022, the tone turned negative again, culminating in an article referring to the EPD as a "monster that will never work" [40], highlighting the need to not give any further power to the FOPH. The tone then became more neutral towards the end of 2022, as expert opinion papers mentioned the revision of the Federal Act on the Electronic Patient Dossier [41] and positive in 2023 with the launch of a national awareness campaign to accompany the introduction of the EPD [42].

Table 3:
Events negatively influencing the sociopolitical discourse on health data sharing – ordered from most to least frequently mentioned.

Events negatively influencing the sociopolitical discourse on health data sharing – Interview data	
1. Scandals	2013: Edward Snowden leaked intelligence data from the US National Security Agency.
	2018: Cambridge Analytica's unauthorised processing of personal data from Facebook.
	2021: Data breach of "Myvaccination" platform exposed Swiss citizens' vaccination records. Rejection of the Electronic Identification Services (e-ID) referendum.
	2022: Data breach of the Swiss Organ Donation register.
	2022: Online leak of medical files in Neuchâtel, Switzerland.
2. Slow implementation of the Swiss Electronic Patient Dossier initiative (2015–2024).	
3. Switzerland's reliance on paper-based systems revealed by COVID-19.	

3. Switzerland's reliance on paper-based systems revealed by the COVID-19 pandemic

The COVID-19 pandemic was reported as exposing the Swiss healthcare system's heavy reliance on paper-based practices, underscoring the significant work needed to advance its digitalisation efforts.

4. Implementation obstacles

The interview data revealed 15 obstacles to implementing health data sharing initiatives, particularly concerning the EPD. These challenges span the policy process, the public, healthcare professionals and technical issues (table 4). Quotes from interviewees can be found in appendix 9.

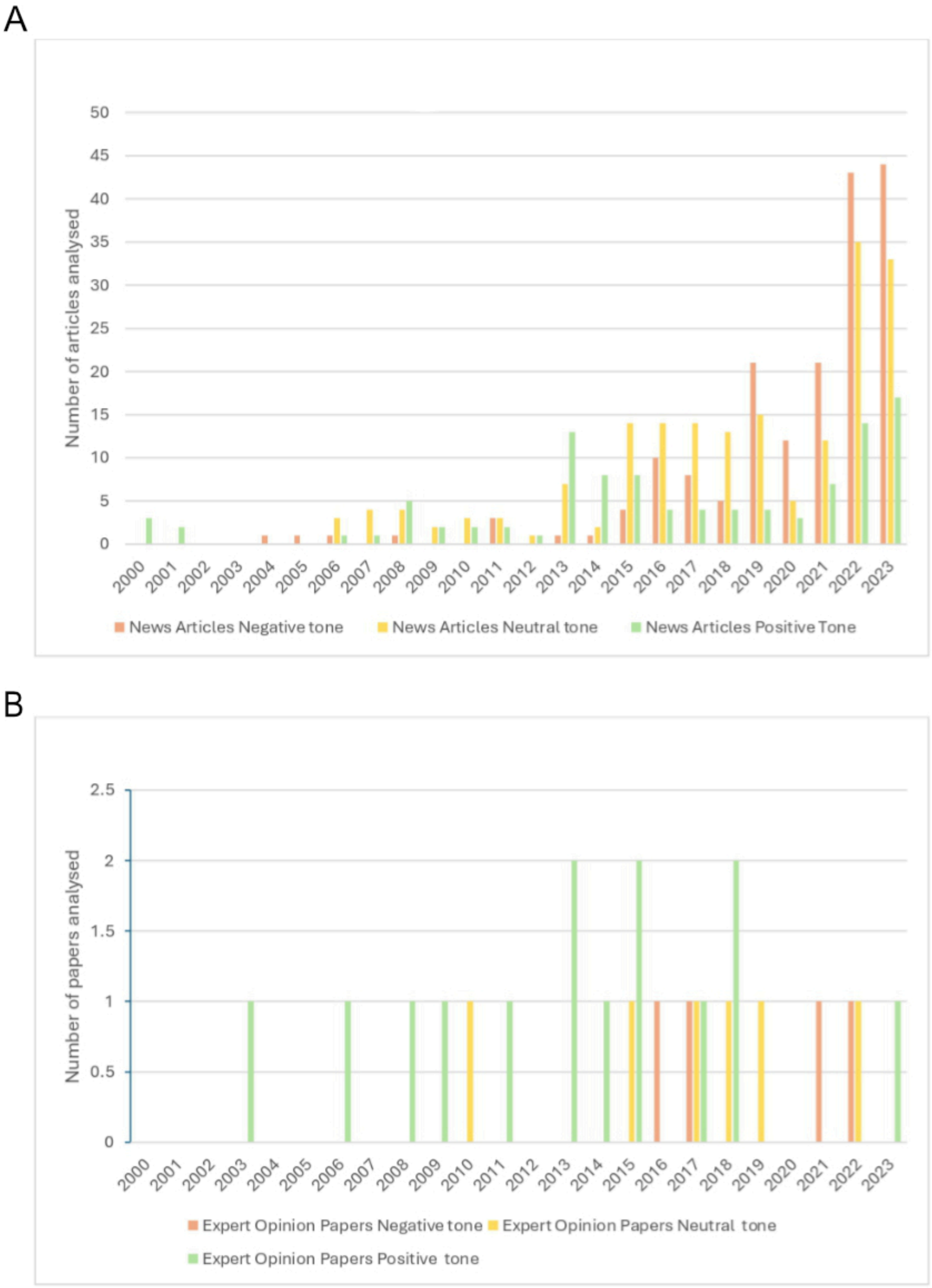
Policy

One of the main obstacles to the implementation of health data sharing initiatives in Switzerland is the lack of alignment of interests among different stakeholders on health data use, including researchers, healthcare professionals and politicians, resulting in power dynamics among various actors. Cultural attitudes towards data sharing emerged as a prominent obstacle, along with reluctance to share data for secondary use due to individualistic reasons such as wanting to keep the benefits for oneself and not recognising the broader benefits of data sharing. Interviewees reported a disparity in pace between technological advancement and policymaking processes, often resulting in delays in the regulation of crucial measures. Federalism emerged as an obstacle to implementing nationwide coordinated health data sharing initiatives in Switzerland, due to a lack of central coordination, resulting in the absence of common standards and a unified strategy. Voluntary participation in the EPD was identified as an obstacle to its implementation, along with limited public involvement in policymaking. Regulatory hurdles and lack of legal clarity on secondary data use slowed down the implementation process, compounded by limited funding resources.

Public

A key obstacle for the implementation of health data sharing solutions is the lack of awareness among the public, healthcare professionals and politicians regarding the initiative and its benefits, with some of the interviewees questioning the current existence of a proper public discourse on health data sharing for secondary purposes. Moreover, interviewees pointed to an underlying cultural resistance to change, given the highly effective Swiss healthcare system. Privacy and security concerns were reported by stakeholders as obstacles, though deemed marginal, for the public to participate in data sharing initiatives as the public

Figure 2: The graphs illustrate the tone of news articles (A) and expert opinion papers (B) – negative (red), neutral (yellow) and positive (green) – alongside the total number of articles analysed each year. Publications coded red predominantly conveyed negative messages, yellow reflected a neutral and balanced approach and green emphasised the positive societal impact of data-sharing initiatives.



fears that their sensitive health data could be accessed by insurance companies, potentially prompting changes in their business practices. Additionally, the non-user-friendly interface of the EPD and the complex registration process were reported as implementation barriers.

Healthcare professionals

The reluctance of healthcare stakeholders to support the EPD had a detrimental impact on public trust. When patients see that healthcare professionals are unwilling to use the EPD, they become suspicious and lose trust, believing that if medical professionals do not trust the system, neither should they. Three main reasons for healthcare professionals' reluctance towards the EPD emerged from the interviews and expert opinion papers:

(a) Their role as trust anchors for patients, feeling responsible for the handling of health data and the maintenance of patient privacy. This concern has been central also in expert opinion papers since 2010, where trust and confidentiality were identified as "fundamental principles in medicine [...] not negotiable" [43] and as "the foundations of safe and effective patient treatment" [44]. References to Hippocrates and his principle of confidentiality have been cited since 2015, highlighting it as a cornerstone of trust between doctors and patients and, consequently, of the therapeutic relationship and treatment quality [45].

(b) Healthcare professionals perceived limited benefits from the EPD solution due to their poor involvement in its development and the policymaking process, likening it to a storage system for PDF documents. Expert opinion papers since 2017 have criticised the insufficient involvement of medical professionals in the health policy process, pointing out that the FOPH tries "to prevent specialist medical personnel from participating in the development of laws and their implementation", with the direct consequence being that healthcare professionals have to work with solutions poorly suited to practical implementation [46]. This criticism persisted until 2021, with the FMH affirming that for the EPD to provide added value, "the improvements proposed by doctors – who are the first users of the EPD – must be heard and taken seriously" [47], and that eventually the involvement of health professionals in the policymaking process doesn't have to be just an "alibi exercise" [47].

(c) The lack of financial support to facilitate healthcare professionals' digital transition, with the FMH stating in an opinion paper that their tariff requests were disregarded, "missing the opportunity to create financial incentives for the EPD" [47].

Technical obstacles

Interoperability remains a significant obstacle to overcome for the implementation of health data sharing initiatives in Switzerland, primarily due to non-harmonised, unstructured or siloed data.

5. Key lessons for the future implementation of health data sharing initiatives in Switzerland

From the interviews, 19 key lessons for the future were identified for overcoming implementation barriers for data sharing initiatives, spanning policy, public, healthcare professionals and broader health data sharing solutions (table 5). Relevant quotes are in appendix 10.

Policy

At the policy level, it is necessary to align stakeholders' interests by increasing their involvement in the policy process and convening discussions to identify common solutions and advance the system. Interviewees also mentioned the need to establish a legal framework governing the secondary use of health data and the opportunity to consider the centralisation of the coordination of the initiative at the federal level, given the small size of Switzerland, to increase efficiency. Interviewees mentioned the need to increase funding for the initiative's effective implementation, and the need to have separate bodies for data

Table 4:
Obstacles that emerged from interviews – ordered from most to least frequently mentioned.

Obstacles to the implementation of health data sharing initiatives – Interview data		
Policy	Misalignment of stakeholder interests with power dynamics among actors.	
	Cultural attitudes and individualistic approaches towards data sharing.	
	Pace disparity: policy processes lagging behind digitisation.	
	Challenges posed by federalism.	
	Voluntary participation in data sharing initiatives.	
	Limited public involvement in policymaking.	
	Absence of legal framework for secondary use of health data.	
	Insufficient funding for the implementation of the initiative.	
Public	Lack of public awareness of the potential of their data and the benefits of the solution being implemented.	
	Lack of public discourse on health data sharing for secondary purposes.	
	Resistance to change in a functioning healthcare system.	
	Data security and privacy concerns.	
	Non-user-friendly interface and complex registration process.	
Healthcare professionals	Lack of support from physicians, negatively impacting patient adoption of the solution being implemented.	Physicians serving as trust anchors for patients, creating a sense of accountability in data handling.
		Limited perceived benefits from the health data sharing solution being implemented.
		Lack of direct financial incentives to support their digital transition.
Technical obstacles	Challenges with interoperability (unstructured/siloed data).	

storage and use to avoid conflicts of interest. It was pointed out that politicians should set priorities and take the lead for the implementation of the initiative once technical officers have demonstrated the system's functionality. Lastly, there emerged the need to streamline the policy process to adapt more swiftly to digital technological advancements.

Public

Interviewees emphasised the importance of demonstrating the benefits of data sharing initiatives to the public with concrete examples and of investing in educational and communication campaigns to inform citizens about the initiative. Using ambassadors from cancer registries, given their high level of public trust, was suggested as a viable strategy to promote health data sharing initiatives. Lastly, involving the public more in the policymaking process was highlighted as a valuable approach to trust-building.

Healthcare professionals

Interviewees highlighted the importance of involving healthcare professionals in the design of health data sharing solutions, given their role as both users and intermediaries between patients and the system. It also emerged that it is important to explain the benefits of such solutions to them and to provide financial incentives or sanctions for their use or non-use of the implemented system. To alleviate the burden of responsibility on healthcare professionals, some suggested adopting a more patient-centric approach to data sharing, which potentially minimises the involvement of healthcare professionals in the data sharing chain.

Data sharing solutions

Data security and privacy emerged as prominent themes. Interviewees emphasised the need to acknowledge data security risks while demonstrating to the public that every possible measure has been taken to protect the data and enhance privacy. Moreover, identifying an external third party for data oversight while ensuring transparency in data access were suggested as viable strategies to build public trust. Lastly, one interviewee pointed out data should be nationally stored.

Concerning the technical aspects of data sharing solutions, interviewees highlighted that standardising taxonomy is necessary to facilitate interoperability and optimise the secondary use of health data, as well as using patient identifiers to link different datasets. Moreover, it was suggested to establish a competence centre to ensure high-quality data at the source.

Overall, interviewees emphasised that the primary prerequisite for establishing trust in a health data sharing solution is its functionality: it must work effectively, benefit all stakeholders and be easy to use. Regarding implementation, one interviewee highlighted the importance of allowing the public to familiarise themselves and build trust with one initiative at a time, such as starting with the eID and then, as a natural second step, adding health data without any imposition from institutions. It was also suggested that a one-size-fits-all solution for health data sharing may not be appropriate, given the diversity of the public. Instead, citizens should be able to choose from multiple user profiles with varying levels of openness to health data sharing.

Discussion

In line with the Policy Streams Approach [28], we identified two health data sharing policy waves in Switzerland. The first, starting in the late 1990s, focused on establishing legal frameworks for primary health data use, leading to the Federal Act on the Electronic Patient Dossier in 2015. The second, catalysed by the COVID-19 pandemic, centred on developing the legal framework for the secondary

Table 5:
Lessons for the future – ordered from most to least frequently mentioned.

Key lessons for the future – Interview data		
Policy	Align stakeholders' interests.	
	Establish a legal framework for secondary health data use.	
	Centralise the coordination of the initiative at federal level.	
	Increase funding available to promote the implementation of health data sharing solutions.	
	Separate bodies for data storage and use to avoid conflicts of interest.	
	Set political priorities after the system's functionality has been successfully demonstrated.	
	Accelerate policymaking to match pace of technology development.	
Public	Illustrate to the public the benefits of the health data sharing initiative being implemented.	
	Improve public communication (use of ambassadors).	
	Involve the public in policymaking.	
Healthcare professionals	Involve healthcare professionals from the start in developing the health data sharing solution.	
	Explain benefits of the health data sharing solution to healthcare professionals.	
	Provide financial support to healthcare professionals.	
	Consider a patient-centric approach to data sharing.	
Data sharing solutions	Data security and privacy	Acknowledge risks and enhance data protection measures.
		Use an external third party for data oversight and ensure transparency on data access.
		Store data in Switzerland.
	Technical features	Align taxonomy of health data.
		Use patient identifiers to optimise the secondary use of health data.
		Demand high-quality data from the source
	Ensure the solution works, benefits all actors and is easy to use.	
	Establish trust with eID before adding health data – without imposition.	
	No one-size-fits-all solution due to diverse public composition.	

use of health data, leading to the initialisation of the DigiSanté national programme in 2023. In contrast, the negative narrative surrounding the implementation of the EPD has become a significant factor eroding public trust. The sustained negative portrayal of this national initiative, primarily driven by the media, has undermined confidence in the administration's ability to implement it effectively. Consequently, national and international scandals have exacerbated the downward trend in public trust regarding health data sharing initiatives.

The present study revealed that discussions on the secondary use of health data have not yet permeated public discourse. This presents an opportunity for Switzerland to take a proactive approach by applying the learnings from the implementation of the EPD to avoid encountering similar obstacles that could further erode public trust in health data sharing initiatives. Reflecting on the EPD experience, implementation obstacles resulted in delays that contributed to its negative narrative over the years, which affected public trust in the initiative. These obstacles encompass four main categories: (a) Policy process, (b) Public, (c) Healthcare professionals and (d) Technical aspects.

Although the technical challenges of data sharing initiatives – such as ensuring data security, protecting privacy, and addressing patient identifiers and taxonomy alignment – are acknowledged in this study, these technical challenges have already been discussed in other scientific publications [48–51]. Therefore, our discussion will focus on challenges related to (a) Policy process, (b) Public and (c) Healthcare professionals. Building on these insights, we then propose recommendations to inform DigiSanté's Swiss Data Room project specifically, as well as Swiss and European policymakers in the design and implementation of future health data sharing initiatives more broadly (table 6).

Policy process

Interviews with key stakeholders in digital health in Switzerland revealed a perceived disparity between the pace of digitisation and the Swiss policy process. Digitisation has brought the need to streamline the policy process to adapt more swiftly to technological advancements. Politically, Switzerland's complex governance structure, characterised by federalism, liberalism and direct democracy, impedes rapid and sweeping reforms, favouring incremental changes over fundamental reforms in health policy [52]. Federalism decentralises and fragments the health system, with responsibility divided among the 26 cantons. Liberalism introduces multiple interest groups, including healthcare professionals, insurers and service providers, all of which must be coordinated in the health policymaking process. The direct democracy system, which requires federal, cantonal and sometimes municipal health policy initiatives to be approved by popular vote (referendum), makes voters and interest groups significant veto players. Federalism and the misalignment of stakeholders' interests were identified by interviewees as key obstacles to the smooth implementation of health data sharing initiatives in Switzerland, such as the EPD. With multiple stakeholders come diverging interests, unless efforts are made to establish a jointly coordinated approach. Without such coordination, key stakeholders in the Swiss system, as exemplified by the EPD experience, may resist adoption, resulting in delays that perpetuate a negative narrative around the initiative, undermining public trust in both current and future health data sharing initiatives.

To overcome these challenges, interviewees suggested centralising the coordination of health data sharing initiatives at the federal level, by involving stakeholders with varying interests to convene and agree on a shared vision and strategy. This approach is essential to ensure that all parties work constructively towards common goals. Given the peculiarities of Swiss federalism and decentralisation, Switzerland requires a bottom-up approach that actively engages cantonal authorities and local stakeholders in the decision-making process, unlike centralised countries such as France, where directives can be uniformly implemented [53]. In centralised governance structures, uniform policy directives and streamlined decision-making are facilitated at the national level by a central authority – such as the Ministry of Health or specialised agencies like the French Health Data Hub – that oversee the development, imple-

Table 6:
Recommendations to address past implementation obstacles and enhance public trust for facilitating the implementation of data rooms in Switzerland and Europe.

Recommendations		**Potential implementation challenges**
Policy process	Centralise the coordination of the initiative at Federal level.	Switzerland's decentralised system may resist centralisation unless it prioritises coordination while preserving cantonal autonomy.
	Facilitate stakeholder discussions to align interests and promote cooperative efforts towards shared goals.	Diverse and conflicting stakeholder priorities, combined with time pressures, may complicate consensus-building.
Public	Conduct targeted communication campaigns to inform the public about both the risks and benefits of the health data sharing initiative.	Reaching diverse demographic groups and ensuring balanced messaging may be challenging, particularly for linguistic minorities and less digitally literate individuals.
	Implement an effective, user-friendly data sharing solution that benefits both the public and healthcare providers without adding unnecessary burdens.	Balancing simplicity for users with technical and security requirements could complicate design and implementation, especially given resource constraints.
	Consider the narrative surrounding the health data sharing initiative, ensure a contingency plan is in place, and adopt a proactive approach to trust-building.	Managing public perception and maintaining trust during crises or negative events requires significant, ongoing effort and adaptability.
	Provide citizens with the autonomy to choose between different data sharing models by selecting various types of consent, avoiding one-size-fits-all solutions.	Designing a flexible consent framework that is both user-friendly and compliant with data protection laws might pose technical and administrative challenges.
Healthcare professionals	Engage healthcare professionals in the development phase to ensure the solution meets their requirements. Provide clear explanations of its benefits so they can effectively communicate these to patients.	Ensuring meaningful engagement with healthcare professionals may be challenging due to time constraints, diverse needs and varying levels of digital literacy among practitioners.
	Consider offering financial support to facilitate their transition to digital practices.	Providing financial support could face budgetary limitations and require careful allocation to ensure equitable distribution across healthcare providers.

mentation and regulation of national health initiatives uniformly applied across regions [54]. In contrast, Switzerland's decentralisation necessitates coordination mechanisms that respect cantonal autonomy while fostering collaboration at the federal level. The establishment of eHealth Suisse in 2007, a national coordination body for eHealth, was an initial attempt to address the challenges posed by federalism, tasked with promoting interoperability at technical, legal and political levels by integrating federal and cantonal levels of governments [4]. The launch of the DigiSanté programme in 2025 offers a promising step forward, as DigiSanté is envisioned as having a coordinating role, by setting objectives and guiding stakeholders in pursuing a common vision and the goals derived from it. One of the programme's four strategic objectives is to orchestrate activities for the digital transformation of the healthcare system, ensuring alignment towards common goals and maximising impact by engaging relevant stakeholders in the healthcare sector [3]. Stakeholder involvement and networking within the programme will be facilitated through various channels, including "DigiSanté Roundtables", a digital exchange format designed to foster informal discussions on the specific challenges of healthcare digitalisation. Additionally, ad hoc events and a newsletter subscription will be available to provide updates on the programme's progress and milestones [55]. If the FOPH fulfils DigiSanté's objectives, it could offer a viable solution to overcoming some key obstacles that hindered the EPD initiative in the past.

Public

Low public awareness was cited as a reason for slow EPD implementation. Although the 2007 Swiss e-Health Strategy aimed for full implementation and accessibility of the EPD by 2015, structured public information campaigns only began in June 2023, targeting healthcare professionals, with campaigns for the general population starting in 2024 [42]. Communication is a key principle in trust theory [1]: timely, clear and audience-tailored communication, highlighting the risks and benefits of the data sharing solution, is essential for empowering the public to make informed decisions and ultimately trust the implemented solution. Moreover, ongoing public engagement from the early stages of the policy process is crucial for establishing trust, as it promotes both the co-design of the solution and the awareness-building process.

The study also highlights the importance of monitoring the narratives presented by news outlets and experts regarding the initiative being implemented, as these narratives can directly influence public trust. As interviewees highlighted, scandals erode public trust, but prolonged negative narratives, such as those surrounding the implementation of the EPD, have a more significant long-term impact. Given that the EPD experience serves as a reference point for the Swiss public's collective experience with national health data sharing initiatives, it is crucial for health policymakers and implementers to establish contingency plans to rebuild public trust in such initiatives. Moreover, proactive trust-building measures should be undertaken when developing and implementing future health data sharing initiatives, such as the Swiss Data Room. Looking at neighbouring countries, France experienced a similar situation to Switzerland's EPD with the implementation of their "Dossier Médical Personnalisé" (DMP) in 2007. The adoption of the DMP initially faced limitations, delays and criticisms. In 2022, the French Ministry of Health launched "*Mon espace santé*", a more user-friendly and comprehensive rebranding of the DMP [56]. This successful relaunch enabled France to reach a participation rate of over 95% of socially insured people as of 2024, accounting for almost 17% of the population [57], compared to the 0.22% of the Swiss population as of April 2023 [9].

Several aspects may have contributed to the success of the French programme *Mon espace santé* . The programme was implemented using a top-down, user-centric approach. This included iterative developments, regular user testing and citizen workshops from the pilot phase onward. The programme adopted an opt-out model and provided financial incentives to healthcare professionals, facilitating adoption. A major driver of adoption was a three-wave national communication campaign launched in February 2022, aligned with the programme's rollout. This contrasts with Switzerland, where communication about the EPD began only in June 2023, six years after the EPD regulation's enforcement. The French campaign emphasised patient-centred benefits through diverse channels including TV, online videos, radio, magazines, social media and in-person promotions at pharmacies, laboratories and healthcare establishments. In addition, the initiative also employed influencer ambassadors to promote *Mon espace santé* and established a network of nearly 4000 digital advisors and mediators, including professional caregivers, tasked with raising awareness and supporting citizens – especially underrepresented groups or those less familiar with digital technology – through outreach and education [56]. Given Switzerland's diverse migrant communities, which are recognised as minority groups requiring additional outreach efforts, strategies to engage underrepresented groups should be considered in Switzerland's upcoming initiatives.

Insights from unpublished studies and the current research underscore that the non-user-friendly interface and complex registration process of the EPD were prominent obstacles to its implementation [41]. Therefore, in order to establish public trust in future health data sharing initiatives, it is crucial, as supported by the Technology Acceptance Model [58], that the implemented data sharing solution is effective, user-friendly and provides clear benefits to both the public and healthcare providers, offering added value for all stakeholders without imposing unnecessary burdens. Interviewees emphasised that a one-size-fits-all solution for the secondary use of health data is not viable, as it is important to give citizens autonomy to choose between different profiles based on their willingness to share certain types of data with specific parties. These profiles could be associated with different consent models, ranging from the broad consent model [59], where data owners consent to multiple future studies from both private and public researchers, the nature and specificities of which are not known at the time of consenting; to a more conservative profile where data owners select which data can be shared and with whom. This latter approach can align with the dynamic consent model, which provides a transparent, flexible and user-friendly means for data owners to consent over time and receive information about the uses of their data [60].

Healthcare professionals

Healthcare professionals, particularly physicians, play a pivotal role in the discourse on health data sharing as they directly influence both the health policy processes and public opinion. Politically, physicians are influential actors in Switzerland, with the FMH serving as a powerful interest group in health policy [61]. From the patient's perspective, physicians historically serve as the primary point of contact within the healthcare system and are seen as trusted anchors. Patients rely on their expertise and guidance, highly valuing their opinions [62], with healthcare providers playing a role in reducing patient privacy concerns and enhancing their intention to share personal health data [10]. Therefore, physicians act as essential intermediaries between policy and public opinion, serving as gatekeepers in the discourse on health data sharing.

The analysis of news articles, expert opinion papers and interviews revealed that healthcare professionals supported the Electronic Patient Dossier in principle but were not favourable towards its implementation strategy. Three main obstacles emerged: limited perceived benefits of the solution due to their poor involvement in its development and in the policymaking process, resulting in an EPD not reflecting healthcare professionals' needs; concerns about the trust relationship with patients being endangered by data sharing initiatives; and an anticipated increase in administrative burden, especially in the initial phase of EPD implementation, prompting calls for financial incentives and compensation systems [63]. These obstacles in the EPD experience resulted in limited support from the FMH, with physicians not consistently advocating for the EPD to their patients, who typically follow their doctors' advice, leading to low adoption rates.

While a patient-centred solution was mentioned as a way to mitigate physicians' perceived burden of protecting patient data, given the crucial role physicians play in both policy development and shaping public perception, it is advisable to invest in their involvement instead. This can be achieved by actively engaging them from the early stages of policymaking and solution development to ensure the solution meets their requirements, and by clearly explaining its benefits so they can effectively communicate these to patients. Additionally, offering financial incentives will support their digital transition.

Implications

The recommendations provided in this study are relevant for health data sharing initiatives in Switzerland and beyond. Policymakers involved in the Swiss DigiSanté programme, as well as those working on the conceptualisation and development of European and national health data spaces, should consider the following:

1. Current levels of public trust in health data sharing initiatives are largely shaped by the public's past experiences with similar initiatives;
2. The public must be well-informed about the initiative being implemented;
3. Healthcare professionals, being at the forefront of the healthcare system, serve as trusted points of contact for the public.

It is therefore crucial to reflect on each state's past experiences with health data sharing and to plan strategies to rebuild or maintain public trust. Additionally, the narrative surrounding such initiatives in the media should be closely monitored. Both the public and healthcare professionals should be actively engaged from the outset of these initiatives to ensure that the data sharing solution meets their needs as users. For healthcare professionals specifically, early involvement will enable them to be informed about it and eventually recommend the solution with confidence to the public.

Strengths and limitations

This study represents a novel contribution to the field as it integrates data from four distinct data sources to investigate dimensions of policy, media narrative and expert opinion spanning 31 years. To our knowledge, it is the first study to comprehensively analyse the past experience of the Swiss public in health data sharing, thus informing future data sharing initiatives. Previous research is limited to studies primarily focused on specific policy analysis, such as investigating the process of adopting the Federal Law on Electronic Health Records [4], as well as on legal, ethical and logistical obstacles to health data sharing through literature reviews or stakeholder interviews alone [49, 63, 64].

The accuracy of news searches from newspaper archives might be compromised due to inconsistent search engine performance. The newspaper "Neue Zürcher Zeitung" (NZZ) had to be excluded from the analysis due to the impossibility of accessing and downloading their articles in digital form. This may pose a limitation in the analysis and generalisability of findings from news articles in the German-speaking region of Switzerland, as the inclusion of the centre-right leaning NZZ would have balanced the other two newspapers, "Der Bund" and "Tages Anzeiger", which are more left-wing.

For the scoping review of expert opinion papers, the limited inclusion of Swiss journals representing all three linguistic regions equally constitutes a limitation of our study. Future research should consider broader inclusion of regionally representative sources to ensure a more comprehensive representation of Switzerland's multilingual and multicultural context.

Conclusion

The digitisation trend of the early 2000s and the COVID-19 pandemic influenced the sociopolitical discourse on health data sharing in Switzerland, by raising public awareness on the potential of health data and driving two waves of intense policy activity. However, the negative narrative on the EPD, compounded by national and international scandals, largely frames public trust in health data sharing at present, serving as the Swiss public's reference point for national health data sharing initiatives. It is opportune to learn from the obstacles faced during the EPD implementation, to extract valuable lessons applicable to upcoming health data sharing initiatives. At the policy level, it is recommended to centralise the coordination of initiatives at the federal level, while fostering active collaboration among stakeholders to align interests and promote cooperative efforts towards common goals. At the public level, a comprehensive public engagement strategy is advised, with a focus on implementing effective, user-friendly solutions that offer citizens autonomy of choice, while monitoring the narrative surrounding the initiative and adopting a proactive approach to trust-building. Healthcare professionals should be involved in the development of the solution and the policymaking process from the outset and should receive financial support to facilitate their digital transition. Given the promising health data sharing initiatives in the Swiss pipeline as part of the DigiSanté programme, it is crucial to consider these recommendations. Failing to do so risks implementation delays and the perpetuation of negative narratives, ultimately undermining public trust in both current and future efforts to advance health data sharing in Switzerland, as has occurred in the past.

Data availability statement

The anonymised interview data supporting this study are available on Zenodo (10.5281/zenodo.14384120).

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Appendix 1

Five interview questions to key stakeholders:

1. *How would you describe the evolution of the socio-political discourse around health data sharing in Switzerland from 1998 to the present?*
2. *What were the main obstacles for the implementation of health data sharing initiatives in Switzerland in the past, and what are the ones we are facing today?*
3. *Can you recall any specific events that played a positive role in shaping the socio-political discourse around health data sharing in Switzerland?*
4. *Are there any specific scandals or events that had a negative impact on the socio-political discourse surrounding health data sharing in Switzerland?*
5. *What lessons, if any, can we learn from these events in terms of shaping policies and public perception that we can apply to the future?*

Appendix 2

In February and March 2024, FZ conducted 11 semi-structured 30-minute online interviews in English. The participants were senior experts in digital health from Switzerland, purposively sampled to ensure representation from diverse sectors.

A stakeholder analysis was undertaken to identify the most relevant stakeholders in digital health in Switzerland, focusing on the three dimensions investigated: policy, news, and expert perspectives. Following this mapping process, potential interviewees were purposively selected based on the advisory board network of the study and online searches targeting senior experts in digital health. All targeted interviewees replied to the email and accepted the invitation, no dropouts were registered.

The final group of interviewees included representatives from academia (two interviewees), the pharmaceutical industry (one interviewee), the Federal Office of Public Health (one interviewee), the Federal Statistical Office (one interviewee), the Swiss Personalized Health Network (one interviewee), the Swiss Institute of Bioinformatics (one interviewee), the Swiss Medical Association (one interviewee), politics (two interviewees), and journalism (one interviewee).

Thematic saturation was achieved after seven interviews and was subsequently discussed among the research team. However, additional interviews were conducted to ensure representation across all targeted stakeholder groups. The interviews were conducted by FZ, who has two years of experience in qualitative research methods and has previously interviewed over 90 participants in related studies. FZ did not have any prior relationships with the interviewees before the study began, and participants were unaware of the researcher or the specific details of the research project. To establish rapport and provide context, FZ began each interview with a brief introduction, including her background, her primary PhD topic, the reasons for focusing on trust in health data sharing, and the research objectives.

All interviews were conducted with only the participant and the researcher present to maintain confidentiality and create an open, comfortable environment for discussion. At the conclusion of each interview, participants were asked whether they would like their interview transcripts returned for review or comment; none of the participants opted for this.

As outlined in the consent form signed by each participant prior to the interview, the online sessions were audio-recorded and transcribed using Zoom (version 5.17.11). No field notes were taken.

A reflexive inductive thematic analysis was performed using MaxQDA24, qualitative research software. The final version of the coding tree, representing the emerging themes and subthemes from the interview analysis, is presented in Tables 2, 3, 4, and 5.

Appendix 3

Arksey and O’Malley’s [27] six-step methodological framework for conducting scoping studies:

- Stage 1, Identify the Research Question: Guided by the study’s aim, we formulated the research question as follows: “What is the evolution of expert opinions on health data sharing in Switzerland from 1998 to 2023?”
- Stage 2, Identify Relevant Studies: In collaboration with a specialized librarian of the University of Zurich, we developed a comprehensive search strategy for PubMed, Scopus, Embase, and Cochrane (*Appendix 4*). Given the geographical focus of the study, the following online medical journals were included in the scoping review: Swiss Health Web, Swiss Medical Forum, and Swiss Medical Weekly. We conducted keyword searches for the term ‘health data’ in German (‘Gesundheitsdaten’) since structured search strings were not supported, and the website languages were set to either German or French. Additionally, we included the keywords ‘Swisstransplant’, ‘Meineimpfungen’ (‘myvaccination’ in German), and ‘Patientendossier’ (‘patient dossier’ in German), which emerged from the interviews as events that influenced public perception of health data

sharing in Switzerland (*Appendix 4*). Searches were conducted on November 13, 2023, and updated on January 5, 2024, to cover publications until the end of December 2023.

- Stage 3, Study Selection: We included publications written in English, French, German or Italian, published from 1998 to 2023, focusing on Switzerland and with findings pertaining to Swiss health data sharing initiatives. From the search results in PubMed, Scopus, Embase, and Cochrane, we included articles labeled as 'editorials', as they are not peer-reviewed and are written more freely by authors expressing their opinions and perspectives on the topic. From Swiss Health Web, Swiss Medical Forum, and Swiss Medical Weekly, we broadened the scope of article types including editorials, commentaries, position papers, theme issues, and updates. This was done to cover a wide spectrum of opinion articles, while acknowledging that the peer review-process of some articles may have influenced the opinions expressed by the authors in these publications.
- Stage 4, Charting the Data: Selected publications were pasted into an Excel file, translated into English using ChatGPT (version 3.5), and coded by FZ based on topic, date, and tone using color-coded indicators. Expert opinion papers coded in red predominantly conveyed a negative message about the topic, reflecting a potential negative influence on public opinion. Publications coded in yellow were considered as neutral, reflected by their reporting of facts or pros and cons in a balanced approach. Publications coded in green reflected those with a more positive tone on the impact of data sharing initiatives on society. Colour coding was based on the original language text to capture nuances of tone in each language. FZ color-coded Italian and French articles, while FG color-coded the ones in German.
- Stage 5, Collating, Summarizing and Reporting the Results: Results from the analysis were then summarized in the form of a table.

Appendix 4: Scoping review of expert opinion papers and news search

Search String/Key words	Database	Results	Excluded	Included
Expert Opinion Papers				
(("Information Dissemination"[Mesh] OR "Health Information Exchange"[Mesh] OR "Routinely Collected Health Data"[Mesh] OR "Patient Generated Health Data"[Mesh] OR "Medical Records"[Mesh] OR "Electronic Health Records"[Mesh] OR "Information Dissemination"[Title/Abstract] OR "Health Information Exchange"[Title/Abstract] OR "Routinely Collected Health Data"[Title/Abstract] OR "Patient Generated Health Data"[Title/Abstract] OR "Medical Records"[Title/Abstract] OR "Electronic Health Records"[Title/Abstract] OR "Health Data"[Title/Abstract]) AND "Switzerland"[Mesh]) Filters: Editorial, from 1998–2023	Pubmed	6	6	0
(health AND information AND exchange) OR (information AND dissemination) OR (routinely AND collected AND health AND data) OR (patient AND generated AND health AND data) OR (medical AND record) OR (health AND data) AND Switzerland AND (LIMIT-TO (AFFILCOUNTRY, "Switzerland"))	Scopus	36	36	0
('health data'/exp OR 'electronic health record'/exp OR 'ehr (electronic health record)' OR 'electronic health record' OR 'electronic health records') AND 'switzerland'/exp AND [publication type]: 'editorial' AND [1999-2023]	Embase	8	8	0

('health data'/exp OR 'electronic health record'/exp OR 'ehr (electronic health record)' OR 'electronic health record' OR 'electronic health records') AND 'switzerland'/exp AND 'editorial' from 1999	Cochraine	25	25	0
Swisstransplant; Meineimpfungen; Patientendossier; health data	Swiss Health Web	755	731	24
Swisstransplant; Meineimpfungen; Patientendossier; health data	Swiss Medical Forum	167	166	1
Swisstransplant; Meineimpfungen; Patientendossier; health data	Swiss Medical Weekly	84	82	2
TOTAL		**1081**	**1054**	**27**
News articles				
Swisstransplant; Meineimpfungen; Patientendossier; Gesundheitsdaten	Medinside	Not possible to count the total number of articles per search		106
Swisstransplant; Meineimpfungen; Patientendossier; Gesundheitsdaten	InsideIT			104
Swisstransplant; mievaccinazioni; cartella informatizzata del paziente; dati sanitari	La Regione			7
Swisstransplant; mievaccinazioni; cartella informatizzata del paziente; dati sanitari	Corriere del Ticino			27
Swisstransplant; mesvaccins; dossier électronique du patient; données de santé	Tribune de Genève	2731	2694	37
Swisstransplant; mesvaccins; dossier électronique du patient; données de santé	Le Temps	Not possible to count the total number of articles per search		122
Swisstransplant; Meineimpfungen; Patientendossier; Gesundheitsdaten	Der Bund	316	250	66
Swisstransplant; Meineimpfungen; Patientendossier; Gesundheitsdaten	Tages Anzeiger	229	157	72
TOTAL				**528**

Appendix 5

** Documents or events included in the table 1 selected as the key legal milestones that have influenced the discourse on health data sharing in Switzerland as reported in the manuscript*

Date	Documents/Events	Comments
1992	***SR 235.1 - Federal Act on Data Protection (FADP)**	Introduction of the concept of explicit consent for personal data processing, except under specific circumstances. Health data are classified as 'sensitive personal data' (Art. 5). Link: https://www.fedlex.admin.ch/eli/cc/1993/1945_1945_1945/en
	***SR 431.01 - Federal Statistics Act (FStatA)**	First reference to the possibility for the Federal Statistics Office to aggregate and link personal data, provided that it is anonymised (Art. 14). Link: https://www.fedlex.admin.ch/eli/cc/1993/2080_2080_2080/en
1994	***SR 832.10 – Federal Health Insurance Act (KVG)**	First mention of secondary data use involving multiple parties (Art. 23 - Processing insurance data for statistical purposes in collaboration with insurance companies, federal and cantonal authorities). Link: https://www.fedlex.admin.ch/eli/cc/1995/1328_1328_1328/it
1998	***Federal Council's Information Society Strategy in Switzerland**	Coordinated introduction of new information and communication technologies. Reference to the need for intensifying statistical research. Link: http://www.infosociety.ch/site/default.asp
2001	***Patient Dossier Initiative**	First effort to digitise patient records in Switzerland: A working group comprising five Swiss university hospitals (Basel, Bern, Geneva, Lausanne and Zurich) aimed to enhance computer utilisation in data management and standardise the dissemination of patient records. Link: https://saez.swisshealthweb.ch/fileadmin/assets/SAEZ/2001/saez.2001.07965/saez-2001-07965.pdf
2002	**On the Way to an Information Society: A Critical Assessment of the Activities of the Swiss Federal Government on Information Society in Switzerland**	The results of an evaluation commissioned by the Information Society Coordination Group and the Working Group on Scientific Assistance prompted the Federal Council to commission the Department of Home Affairs to assess the need for action in health regarding new technologies. This initiative led to the eHealth situation analysis in 2004, based on the evaluation of federal activities in the information society sector.

		Link: https://wissenschaftsrat.ch/images/stories/archiv/CEST_2002_Informationsgesellschaft_e.pdf
2004	***Swiss eHealth Situation Analysis**	Following the 2004 adoption of the European eHealth Action Plan, aimed at improving national eHealth infrastructure, electronic health records, and interoperability, the Federal Office for Social Security/Federal Office of Public Health commissioned Swift Management AG to assess Switzerland's eHealth landscape. The analysis found a highly heterogeneous implementation status and recommended integrating eHealth into the Federal Council's strategy. Link: https://www.newsd.admin.ch/newsd/message/attachments/2886.pdf
	***04.3243 Noser Motion - E-Health. Use of electronic means in healthcare**	The Federal Council is instructed to submit a draft law and a clear timetable to Parliament to achieve a series of objectives in eHealth, including providing Swiss residents with access to electronic health records. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20043243
2005	**Revision of the 1998 Information Society Strategy by the Interdepartmental Information Society Committee**	The 7th Report of the Information Society Coordination Committee to the Federal Council provides a summary of the progress made in implementing the Federal Council's strategy and offers an overview of the work conducted since the strategy's adoption in 1998. Gaps identified in the report include the absence of effective measures for protection from misuse, insufficient information security and inadequate data protection. Of particular concern is the significant gap in the health sector, where better cooperation between the Confederation and various stakeholders was recommended. Link: https://www.newsd.admin.ch/newsd/message/attachments/1731.pdf
2006	*** Strategy of the Federal Council for an Information Society in Switzerland** (Updated from 1998)	Revision of the 1998 Information Society Strategy, adding a new chapter titled 'Health and Public Health' (Measure No. 7). Strategic goals include the improvement of quality and safety through consistent (national) electronic processes for health data. Link: https://www.newsd.admin.ch/newsd/message/attachments/1727.pdf

2007	*** AS 2007 479 - Ordinance on the Insurance Card for Compulsory Health Insurance (VVK)**	Introduction of a microchip on the health insurance card for electronically storing emergency data and consent for organ donation. This marks the first attempt at the digital storage of health data (and prior data following the subject's consent). Link: https://www.fedlex.admin.ch/eli/oc/2007/101/it
	***eHealth Swiss Strategy 2007–2015**	First eHealth strategy aiming to improve the efficiency, quality and security of electronic services in the health sector. Key to this strategy is the gradual introduction of an electronic medical record, granting authorised healthcare providers access to patient-relevant information with prior consent. Additionally, an 'eHealth' coordination body, including a secretariat (eHealth Swiss), was established to implement the strategy. Link: https://www.e-health-suisse.ch/upload/documents/Strategie_eHealth_Schweiz_1.0.pdf
	***Foundation of 'eHealth Swiss'**	The Confederation and Cantons jointly decided to establish a coordination body known as 'eHealth Suisse', funded by both the Confederation and the Swiss Conference of Cantonal Health Boards (GDK/CDS). Its primary objective is to promote the technical, organisational, political and legal interoperability of electronic health record solutions, as well as to address the federal structure of Switzerland and to coordinate and regional initiatives. Link: https://www.e-health-suisse.ch/en/about-us/ehealth-suisse
	eGovernment Strategy Switzerland	eHealth is highlighted as a crucial factor for maintaining competitiveness on the international stage. Additionally, within the framework of eGovernment, plans are underway to collaborate with stakeholders in the eHealth sector to implement electronic identity management, with the goal of achieving a unified and comprehensive approach. Link: https://joinup.ec.europa.eu/sites/default/files/inline-files/eGovernment_in_Switzerland_2018_0.pdf
2008	**Report on eHealth development by the Centre for Technology Assessment**	The brochure was produced to explain the goals of eHealth, its implications for citizens and to raise public awareness concerning eHealth. In the document, it is stated that 'for a more efficient healthcare system, eHealth in the public focus and electronic patient summary are needed'. Link: https://www.ehealth-strategies.eu/database/documents/Switzerland_CountryBrief_eHStrategies.pdf (p. 14)

	08.3493 Heim Postulate - Protection of Patient Data and Insured Persons	The Federal Council was assigned to present a report on measures to combat discrimination experienced by certain groups of patients due to newly established forms of insurance (cf. Art. 93 et seq. KVG) and to ensure the protection of patient data by health insurers. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20083493
2009	**Federal Council Approves the Implementation of the Swiss eHealth Strategy**	The potential of new information and communication technologies within the Swiss health system has yet to be fully realised. Electronic system networking (eHealth) remains underdeveloped, online health information lacks coordination and quality control is lacking. The systematic use of electronic processes can enhance medical care by ensuring immediate access to patient data and improving efficiency. Additionally, eHealth can empower citizens to improve their health literacy. To address these issues, the Federal Council has approved the continued implementation of the Swiss eHealth strategy. The EDI has been tasked with submitting a report by the end of 2010 on the necessary legal framework for eHealth. These regulations aim to establish uniform conditions for data protection, decentralised data access rights, liability and financing. Other implementation measures include the development of a health portal that offers quality-controlled health information and access to electronic medical records. Further initiatives are planned to enhance the training and professional development of healthcare staff. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-29610.html
	Introduction of the eHealth Barometer	The eHealth Barometer, part of the Swiss eHealth Forum, assesses the current status and progression of eHealth in Switzerland. It provides a comprehensive overview by surveying doctors, pharmacists, retirement and nursing homes, nonprofit home care organisations, IT experts, authorities and voters. Link: https://e-healthforum.ch/barometer/
2010	***SR 818.101 – Epidemics Act** (entered into force in 2016)	The Federal Act on the Control of Communicable Human Diseases introduces the sharing of health data for public health purposes. The Act permits data sharing with cantonal authorities for tasks related to communicable disease control. Link: https://www.fedlex.admin.ch/eli/cc/2015/297/en

	***10.3327 Humbel Postulate - Implementation of the e-Health Strategy**	The Federal Council is tasked with submitting a report to Parliament by the end of the year on the implementation of the e-health strategy. The report will outline the areas of action, responsibilities, authorities, and tasks of the respective stakeholders, along with a binding timeline for the implementation of the various sub-projects. Additionally, the Federal Council is expected to present the necessary legal basis required to support the implementation of the e-health strategy. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20103327
	***Electronic health record: mandate for the development of legal bases**	The Federal Council has directed the Federal Department of Home Affairs to establish the legal framework for implementing an electronic patient file by September 2011 to enhance the quality of medical care and bolster patient safety. The Federal Council also approved the report on the implementation status of the "National eHealth Strategy", drawn up in compliance with 10.3327 Humbel Postulate. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-36567.html
2011	**Draft of the Federal Law on Electronic Patient Records: Start of the consultation procedure**	The Federal Council has launched a consultation on the draft Federal Act for the electronic patient file until 20 December 2011. This file aims to improve patient safety and coordinate information among healthcare professionals. The new legal framework outlines requirements for secure data processing, including technical standards and organisational aspects. Data transmission to health insurers is not within the scope of this law. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-41209.html
	***SR 810.30 - Human Research Act (HRA)** (entered into force in 2014)	Introduction of the ‘consent for further use in research’ (Article 17), later referred to as ‘general consent’, marking a milestone in the Swiss data sharing discourse. Link: https://www.fedlex.admin.ch/eli/cc/2013/617/en
2012	***Federal Strategy for Switzerland’s Digital Future**	Aims to accelerate the reform of the health system through eHealth by integrating information and communication technologies into the healthcare system and introducing electronic patient records, in collaboration with cantons, private partners and international organisations. Link: https://www.admin.ch/gov/en/start/dokumentation/medienmitteilungen.msg-id-43694.html

	Electronic patient records: The Federal Council orders the drafting of the dispatch to the new law	The Federal Council has tasked the EDI with preparing the dispatch and draft legislation for the electronic patient record by the end of 2012. The introduction of this record aims to enhance treatment quality, boost patient safety and optimise healthcare system efficiency through improved coordination. The electronic patient record aligns with the goals of the ‘National eHealth Strategy’, and a legal basis is crucial for its implementation. The draft legislation received extensive support during the consultation process. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-44170.html
2013	**Health2020 Report**	Swiss health policy prioritises four areas and 36 objectives for the next 8 years. One priority is to increase eHealth utilisation. Insurers are excluded from EHR development and data access to prevent potential exploitation. The Health2020 report was approved by the Federal Council on 23 January 2013. Final goals: innovation, transparency and administrative efficiency. Link: https://www.bag.admin.ch/dam/bag/en/dokumente/nat-gesundheitsstrategien/gesundheit2020/g2020/bericht-gesundheit2020.pdf.download.pdf/report-health2020.pdf
	Computerised patient records should increase the quality and safety of medical treatments	The Federal Council approved the draft federal law on computerised patient records and sent it to Parliament. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-49029.html
2014	**Strategy on Open Access to Public Data in Switzerland 2014–2018**	The Federal Council aims to enhance public data access, focusing on leveraging the potential of open government data (OGD) in Switzerland. This strategy promotes a shared understanding of the value of open access to public data, sets objectives for utilisation and outlines the Federal Administration's activities in this domain until 2018. Link: https://www.bfs.admin.ch/asset/en/11147097
2015	***SR 816.1 - Federal Act on the Electronic Patient Record (EPRA)** (entered into force in 2017)	First legal framework for health data sharing for primary use that regulates the handling of health data in the electronic patient dossier). The law permits storing and accessing relevant health data from patients or healthcare providers with patient consent. Entered into force in 2017 to promptly introduce the EPD (hospitals to implement the EPD by 2020, patients to open it from 2018). Link: https://www.fedlex.admin.ch/eli/cc/2017/203/it

	Confederation and cantons accelerate the implementation of the EPD	The introduction of the EPD must occur as swiftly as possible. Both the Confederation and the cantons intend to enact the necessary legal framework at the beginning of 2017. Link: https://www.admin.ch/gov/it/start/dokumentation/medienmitteilungen.msg-id-59578.html
	***15.4225 Humbel postulate - Better use of health data for high-quality and efficient healthcare**	This postulate, stemming from parliamentary discussions on the Federal Act on Cancer Disease Registration (enacted in 2018), is pivotal in the data sharing discourse since it underscores the need for targeted, population-representative health data for enhanced healthcare management. The Federal Council was commissioned to demonstrate how data from different disease-specific registries or medical studies can be linked together to improve evaluation whilst upholding data protection. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20154225
2016	*** SR 818.33 - Cancer Registration Act (CRA)** (entered into force in 2018)	The parliamentary discussions beginning in 2014 directly impacted Humbel's postulate 15.4225, significantly shaping the discourse on health data sharing. This initiative, drafted and approved to enhance cancer understanding, highlights the importance of having access to better data to enhance prevention, early detection and treatment efforts. Link: https://www.fedlex.admin.ch/eli/cc/2018/289/de
	Introduction of the computerised patient record is closer	The implementation of the computerised patient record is nearing completion. The Federal Department of the Interior initiated a fact-finding investigation into the ordinances pertaining to the federal law on EPD. These regulations govern the technical and organisational provisions for the setup and operation of the computerised patient record. The fact-finding investigation is scheduled to conclude on 23 June 2016. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-61068.html
	Federal Council strategy for a digital Switzerland	Switzerland adopts the 'Digital Switzerland' strategy to maximise digitisation's benefits across all sectors, with immediate effect. Success depends on close collaboration and a stable national framework. Key benchmarks must be agreed upon, and a coherent data policy is essential to harness increased data collection whilst protecting personal data. The eHealth Strategy supports the 'Health2020' agenda reforms and collaborations with European health authorities.

		Link: https://www.bakom.admin.ch/dam/bakom/en/dokumente/bakom/digitale_schweiz_und_internet/Strategie%20Digitale%20Schweiz/Strategie/Strategie%20Digitale%20Schweiz.pdf.download.pdf/digital_switzerland_strategy_Brochure.pdf
2017	**Introduction of the computerised patient record is underway**	The Federal Council has adopted ordinances concerning the Federal Act on Electronic Patient Records. The law and the implementing provisions will enter into force on 15 April 2017. From that date, hospitals will have 3 years to introduce the electronic patient file. The first patients should be able to open one in the second half of 2018. Link: https://www.edi.admin.ch/edi/it/home/dokumentation/comunicati-stampa.msg-id-66071.html
	***Establishment of the Swiss Personalised Health Network (SPHN)**	First federal government initiative aimed at creating interconnected data infrastructure to make relevant health information interoperable in Switzerland. Link: https://sphn.ch/organization/about-sphn/#:~:text=The%20Swiss%20Personalized%20Health%20Network,and%20omics%20data%20for%20research.
2018	**Electronic patient file: adaptation of the accreditation procedure**	Changes in the accreditation of certification bodies and a technical provision on how to register the data of health professionals in the data search service. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-69642.html
	***eHealth Swiss 2.0 (2018–2024)**	Aim: to promote the adoption of electronic patient dossiers and coordinate digitalisation efforts around the EPD. Link: https://www.bag.admin.ch/bag/it/home/strategie-und-politik/nationale-gesundheitsstrategien/strategie-ehealth-schweiz.html
	Swiss Digital Strategy	The 2018 ‘Digital Switzerland’ strategy outlines the desired goals and guidelines for digitisation across key areas of life. It supersedes the 2016 strategy of the same name and introduces several new key themes for the subsequent 2 years. Objectives include promoting equal opportunities and solidarity, ensuring security, trust and transparency, enhancing digital skills, and fostering value creation, growth and welfare. Additionally, Section 4.8.2 highlights the centrality of the interconnectedness of stakeholders in the health sector to facilitate personalised healthcare.

		Link: https://www.walderwyss.com/assets/content/publications/2391.pdf
	***Establishment of the CARA Association**	Within the framework of the CARA association, the Cantons of Fribourg, Geneva, Jura, Vaud and Valais joined forces to promote Digital Health by providing access to a unique eHealth platform (provided by Swiss Post) for access to EPD and business to business services. Link: https://www.cara.ch/fr/Qui-sommes-nous/Les-objectifs-de-l-association/Les-objectifs-de-l-association.html
	18.3432/18.3433 Motions - Have uncontested statistics established by an independent body. An essential prerequisite for managing the health system	To manage the health system and adapt it to changing needs and costs, the Federal Council is instructed to entrust the task of compiling undisputed and up-to-date statistics to an independent body, such as the Federal Statistics Office (FSO). Link: https://www.parlament.ch/fr/ratsbetrieb/amtliches-bulletin/amtliches-bulletin-die-verhandlungen?SubjectId=44485
	18.4102 SGK_SR Postulate - A coherent strategy for healthcare data discovery	The Federal Council has accepted a postulate tasking them with developing a data strategy to improve transparency and cost containment in compulsory health insurance. They will produce a report addressing the following: - Current data collection practices and stakeholders. - Data requirements and purposes. - Reliable and efficient data collection methods. - Personal data protection for insured individuals. - Legal changes needed for a coherent data collection strategy. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20184102
	***18.4328 Wehrli Postulate - Electronic patient record. What else can be done to ensure that it is fully used?**	The Federal Council is tasked with assessing existing measures and those required to accelerate the adoption of the EPD and maximize its utilisation. There are concerns that its voluntary nature, particularly among outpatient service providers, may result in lower-than-expected usage and effectiveness. Urgent action is required to incentivize voluntary adoption, supported by concrete evidence of its benefits for outpatient service providers, healthcare system stakeholders, insured individuals, and financing authorities. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20184328
2019	**Open Government Data Strategy 2019–2023**	The strategy aims to ensure that government data, produced in fulfilling statutory duties, are freely published in real-time, machine-readable, and open formats. The EDI is responsible for its

		implementation, including enshrining OGD principles in law and promoting data's free use. The 2019–2023 OGD strategy has five objectives: 1. Coordinate data publication. 2. Ensure data quality and description. 3. Maintain the opendata.swiss portal. 4. Establish and manage a central register of government data. 5. Encourage data utilisation. Link: https://www.bfs.admin.ch/bfs/en/home/services/ogd/documentation.assetdetail.16164831.html
	Computerised patient record: Federal Council opens to larger providers	The Federal Council has adjusted the ordinance on financial aid for EPRs to facilitate the creation of supra-cantonal reference communities, aiming to streamline the widespread implementation of computerised patient records. Nine reference communities are being established in Switzerland to enable patients to access EPDs, with financial assistance from the Confederation being proportional to community size. Larger communities can now receive up to 8 million CHF in financial aid, in addition to a base amount of 500,000 CHF, whilst the maximum funding remains capped at 30 million CHF per community. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-74239.html
	***Health Policy Strategy 2020–2030 (Health 2030)**	Technological and digital transformation is reported as being among the four most pressing challenges for the health policy scenario in Switzerland. Goal 1: ‘Use of health data and technologies’. To promote digital transformation in healthcare, the DigiSanté program is envisioned, as well as the establishment of data rooms for health-related research. Link: https://www.bag.admin.ch/bag/de/home/strategie-und-politik/gesundheit-2030/umsetzung-gesundheit-2030.html
	Half of GPs plan to join the computerised patient record	The survey also indicates that 46% of GPs—especially younger ones and those working in associated practices—plan to join the computerised patient record in the coming years. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-77545.html
2020	**Computerised patient record: Certification takes longer**	The initial launch of the EPD is postponed from spring to summer due to delays in certifying the reference communities. By the expected introduction date of 15 April 2020, at least one of the eight reference communities should have completed certification, with others following by autumn. The Program Committee

		acknowledges project delays due to its decentralised structure and anticipates nationwide EPD availability by autumn 2020 to ensure the optimal utilisation of the remaining time for testing. Delays in hospital participation will not adversely affect healthcare in Switzerland. Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-78147.htmlc
	***Digital Switzerland Strategy** (updated from 2018)	First reference to establishing a trustworthy data space, with a mandate to produce a report for the Federal Council by the end of 2021 on the technical, legal, economic and societal parameters required for creating trustworthy data spaces in line with digital self-determination principles. Link: https://www.bk.admin.ch/dam/bk/en/dokumente/dti/StrategieDCH/strategiedch2020.pdf.download.pdf/Digital%20Switzerland%20Strategy%202020.pdf
	Federal Act on the Statutory Principles for Federal Council Ordinances on Combating the COVID-19 Epidemic (COVID-19 Act)	The Act's primary function is to grant the Federal Council special authority to implement ordinances. These ordinances address various aspects of pandemic control, potentially including health data collection and usage. However, the Act itself does not dictate innovative approaches to health data use. Link: https://www.fedlex.admin.ch/eli/cc/2020/711/en
	***20.3243 FDP_SR Motion: COVID-19. Accelerating the Digitalisation in Healthcare**	The motion was accepted by both the National Council (25 September 2020) and the Council of States (8 March 2021). The crisis related to Covid-19 has highlighted Switzerland's lag in the digitalisation of its healthcare system. Thhe motion calls for various measures to accelerate the digitalisation process in the healthcare system. Among other things, it calls for encouraging the use of health apps. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20203243
	20.3770 Motion Regina - Introduction of an e-prescription	The Federal Council is instructed to create a legal basis so that prescriptions for medicinal products must generally be issued electronically and transmitted digitally. Given the different digital skills of patients, an appropriate alternative to the digital prescription in paper form must be provided. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20203770

	20.3923 SGK_SR Motion: Improving data management in healthcare	The motion was accepted by both the Council of States (15 December 2020) and the National Council (16 June 2021). It calls for changes to data management policy in the healthcare sector; for example, with the rapid implementation of the Open Government Data Strategy 2019–2023. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20203923
2021	***Electronic Identity Act (e-ID Act) – Referendum**	The referendum initiated a structured public discourse on sensitive data sharing in Switzerland, resulting in the rejection of the e-ID Act in March 2021. Link: https://www.admin.ch/gov/en/start/documentation/votes/20210307/federal-act-on-electronic-identification-services.html
	21.3021 WBK_NR Motion: Added value for research and society through data-based ecosystems in healthcare	Following postulates 15.4225 and 18.4102, this motion requests the Federal Council to take concrete actions on health data sharing. It commissions the Council to establish a multidisciplinary working group tasked with drafting a report on the responsible collection and use of health data, as well as the requirements for an open health data ecosystem. This report will address questions pertaining to data access, protection, interoperability, and ethical principles, among others. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20213021
	***21.3957 Ettlin Motion - Digital transformation in healthcare. Finally catch up!**	The Federal Council is mandated to advance the digital transformation of the healthcare system, drawing lessons from successful Organization for Economic Cooperation and Development (OECD) digital healthcare models. To achieve this: - A task force will be established to oversee national healthcare digitisation efforts. - A comprehensive digital strategy involving stakeholders will be developed, setting quality standards for health data and guiding digital healthcare. - The framework for paperless health data processing will be established. - Expertise from academia, industry and other stakeholders will inform decision-making. - Training programs for IT, natural sciences and public health specialists will be promoted. - A central information portal will educate the public on legal and technical aspects of health data use.

		Link: https://www.parlament.ch/en/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20213957
	***21.4373 Silberschmidt Motion - Introduction of a unique patient identifier**	The Federal Council is tasked with amending relevant laws to enable the creation and utilisation of a unique digital patient identifier ('master patient number') for communication among all healthcare system stakeholders (service providers, insurance companies, etc.). Adopted on 22 February 2022. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20214373
	21.4374 Silberschmidt Motion - Introduction of digital patient administration	The Federal Council is instructed to adapt all relevant laws so that the processes surrounding patient administration can be handled digitally for all parties involved in outpatient and inpatient care in the sense of a virtual Swiss healthcare network (hospitals, long-term care, home care, practices, pharmacies, etc.). Link: https://www.parlament.ch/en/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20214374
2022	***Report from the FOPH on improving data management in the healthcare sector**	The report highlights improvement measures in healthcare data management during the initial phase of the COVID-19 pandemic, identifying existing gaps and outlining principles for future data management. It proposes five concrete measures to enhance data handling in the healthcare sector, addressing the complexity of medical data management. Given the multitude of actors and stringent regulations shaping healthcare services, a comprehensive approach involving all levels of government and stakeholders is necessary to improve data management. Relevant measures include developing a national register of healthcare facilities, creating identifiers for health registers, streamlining data reporting processes, enhancing data evaluations and establishing a specialist group for holistic data management in the health sector. These initiatives aim to foster long-term, sustainable improvements in the healthcare sector's digital transformation. Links: https://www.bag.admin.ch/dam/bag/de/dokumente/nat-gesundheitsstrategien/digsante/bericht_zur_verbesserung_des_datenmanagements_im_gesundheitsbereich.pdf.download.pdf/Bericht%20zur%20Verbesserung%20des%20Datenmanagements%20im%20Gesundheitsbereich%20vom%2012.01.2022.pdf https://www.bag.admin.ch/bag/de/home/das-bag/aktuell/medienmitteilungen.msg-id-86762.html
	Protection of patient data and protection of	From the report, it emerged that compliance with data protection regulations has become widespread, and they are now largely

	policyholders - Additional report following up on 08.3493 Heim postulate	respected. The results of the 2019 survey show that necessary measures have been taken to ensure data protection in the area of specific insurance forms. Link: https://www.newsd.admin.ch/newsd/message/attachments/70400.pdf
	22.3015 SGK_NR Motion - Electronic patient records. Make them practical and secure them financially	The Federal Council is responsible for financing the introduction, maintenance and development of the EPD whilst coordinating tasks and responsibilities with the cantons. It aims to ensure user-friendly access, reduce administrative burdens and enhance value for stakeholders. Additionally, it seeks to streamline the technical and organisational complexity of the EPD, thereby providing a central infrastructure for data storage and exchange among healthcare professionals. Integration into digital business processes is also a priority. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223015
	The Federal Council intends to further develop the computerised patient record	As the Federal Council emphasised in a report drawn up in August 2021 (Postulate Wehrli 18.4328), the successful introduction and dissemination of the EPD requires a clear division of tasks and competencies, as well as long-term financing. Simultaneously, the Federal Council instructed the EDI to subject the Federal Act on the Electronic Patient Record to a thorough examination. Based on the results, the Federal Council has now decided to initiate a complete revision of the EPRA. Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-88245.html
	***Report from the Federal Council following up on 15.4225 Humbel postulate**	In response to 15.4225 Humbel postulate from 2015, this report set the ground for further development of the political and legal discourse on the secondary use of data for research purposes, specifically. Link: https://www.parlament.ch/centers/eparl/curia/2015/20154225/Bericht%20BR%20D.pdf
	***Transplantation Act - Referendum**	The adoption of an opt-out solution, prompted by a referendum, has sparked discussions on consent models related to health data sharing. Link: https://www.admin.ch/gov/en/start/documentation/votes/20220515/transplantation-act.html

	The Federal Council intends to enable research to make better use of health data	The Federal Council aims to improve the framework for health data transmission and reuse in research whilst ensuring data protection. To achieve this, it instructed the EDI to develop a data system for health research, emphasising the need for secure and legally compliant data exchange. Implementation involves proposing a system for data reuse and linkage, possibly facilitated by a national data coordination service. The Federal Council has tasked the EDI, in collaboration with relevant committees and external experts, to clarify structural, procedural and application-oriented requirements in addition to assessing the necessary legal adjustments. Link: https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-88631.html
	22.3859 Ettlin Motion: Master plan for digital transformation in healthcare. Use legal standards and available data	The motion was accepted by both the Council of States (20 September 2022) and the National Council (3 May 2023), although the latter made a small change to point 2. The Council of States approved this change on 26 September 2023, and the entire motion was thus accepted. Point 1 calls for a concrete master plan to be submitted to Parliament, which illustrates the timing and content of the digitalisation goals with reliable data and explains how they can be achieved. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223859
	***22.3890 WBK_SR Motion: Framework law for the secondary use of health data**	The adoption of this motion by the Federal Council marks a significant step toward establishing a framework law to enable the secondary use of health data. This law would facilitate the rapid initiation and establishment of specific infrastructure for the secondary use of data in strategically relevant areas. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223890
	Digital transformation in healthcare: The data management expert group has started work	The COVID-19 crisis highlighted the urgent need for better data management in healthcare. To address this, the Federal Council formed an expert group in collaboration with the Conference of Cantonal Health Directors in January. Their first meeting in September gathered stakeholders from healthcare, insurance, pharmaceuticals and IT. The group aims to streamline data flows, establish standards, and drive the digital transformation of healthcare.

		Link: https://www.edi.admin.ch/edi/it/home/dokumentation/comunicati-stampa.msg-id-90422.html
	Report on digital transformation in the public service	The Federal Council recognises the critical role of efficient public services in Switzerland's digital era. To meet existing challenges, it prioritises robust telecommunications infrastructure and improved data access, including an upgrade to a minimum internet speed. The development of a code of conduct for trusted data rooms and the introduction of electronic proof of identity (e-ID) further advance digitalisation efforts, guided by sector-specific solutions and overarching strategies such as the 'Digital Switzerland' framework. Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-90645.html
	***22.4022 FDP_NR Postulate: 'Exploiting the potential of digitalisation and data management in the healthcare sector. Switzerland needs an overarching digitalisation strategy'**	The postulate calls for an overarching strategy for digitalisation and data management in the healthcare sector to be developed and submitted to Parliament. The design and implementation of the DigiSanté program fulfil this mandate, and the postulate can thus be removed from office. In November 2022, the Federal Council proposed to accept the postulate, and the National Council followed up on the proposal in December 2022. Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20224022?
	***Creation of trustworthy data rooms based on digital self-determination**	The report recommends initial steps to establish trustworthy data spaces aligned with digital self-determination, including developing a code of conduct by 2023, enhancing interoperability among data rooms and establishing a national contact point. It proposes five key principles—transparency, control, fairness, accountability and efficiency—to fulfil the Federal Council's mandate. These principles and their indicators constitute the foundation of the response, outlining the technical, legal, economic and societal requirements for creating trustworthy data spaces. Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-99268.html
	***Swiss Digital Strategy 2023**	Digitalisation in the health sector is one of the three central themes of the strategy, with a focus on the multiple uses of data. Link: https://digital.swiss/en/strategy/strategie.html

2023	**23.3002 Motion SIK_SR - Improve the security of Switzerland's most important digital data**	The Federal Council aims to enhance the security of vital digital data across governmental and critical infrastructure sectors. Proposed measures include defining criteria for identifying sensitive data, establishing rules for its management and prioritizing Swiss companies, in collaboration with universities, for infrastructure design. Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20233002
	***DigiSanté 2024–2034 - Program to promote digital transformation in the health system - Commitment credit**	On 22 November 2023, the Federal Council sent the Federal Assembly a message concerning a commitment credit intended for a program to promote digital transformation in the health system for the years 2025 to 2034. Commitment Credit Link: https://www.parlament.ch/fr/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20230076 Aim: To promote digital transformation in healthcare. Package 4 'Secondary Use for Planning, Strategic Management, and Research' aims to facilitate access to this data for researchers from the academic and private sectors and optimise databases to address health-related issues. 'Data space for health-related research' is one of seven projects in Package 4. Program Link: https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategien/digisante.html#115324384
	The computerised patient record will become a pillar of the healthcare system	With targeted measures, the Federal Council intends to further develop the EPD with the aim of increasing its benefits for patients, doctors, nurses, hospitals, nursing homes and all other healthcare facilities. In the future, the EPD will be used by all healthcare professionals—not only in the inpatient sector, but also in doctors' practices, pharmacies and outpatient therapies. Furthermore, its opening will be free for all people residing in Switzerland. To this effect, at its meeting on 28 June 2023, the Federal Council put a revision of the federal law on the EPD out for consultation. Link: https://www.bag.admin.ch/bag/en/home/das-bag/aktuell/medienmitteilungen.msg-id-96137.html
	***Code of conduct for managing trustworthy data spaces based on digital self-determination**	The code of conduct contributes to the data sharing discourse by concretising the design of reliable data spaces based on four fundamental principles to establish trust and the corresponding implementation measures.

		Link: https://www.bakom.admin.ch/bakom/en/homepage/digital-switzerland-and-internet/strategie-digitale-schweiz/data-policy/code_of_conduct.html
	*** SR 235.1 - (New) Federal Act on Data Protection (nFADP)**	Introduction of the 'Privacy by Design' and 'Privacy by Default' principles, along with mandatory regulations requiring the maintenance of a register of processing activities to enhance transparency in the use of personal data. Link: https://www.fedlex.admin.ch/eli/cc/2022/491/en
	Federal Council lays foundations for a Swiss data ecosystem	The potential of data should be better exploited in Switzerland. To this end, the Federal Council wants to create a Swiss data ecosystem and promote it sustainablility. The Swiss data ecosystem consists of trustworthy data spaces that can be interconnected in this system according to clear rules. The Federal Council has adopted several measures to promote a Swiss data ecosystem. The main measures are: - Implementation of Motion 22.3890 'Framework law for the secondary use of data'. The consultation draft is to be submitted to the Federal Council by the end of 2026. - Code of conduct for trustworthy data spaces. The Federal Council has approved the code of conduct. - Establishment of a central contact point for the Swiss data ecosystem starting from the end of 2024. Link: https://www.bk.admin.ch/bk/en/home/digitale-transformation-ikt-lenkung/datenoekosystem_schweiz.html
	Digital Switzerland Strategy 2023	The Digital Switzerland Strategy sets the guidelines for the country's digital transformation and is binding for the Federal Administration. For other stakeholders, including the cantons, communes, businesses, academia and civil society, it serves as a framework aimed at maximising the opportunities presented by digital transformation for all. The 2023 Digital Switzerland Strategy is structured around five long-term domains, each with associated indicators: education and skills; security and trust; frameworks for business and society; infrastructure; and digital public services. The focus areas, determined by the Federal Council, are digitisation in the healthcare sector, legislation supportive of digitalisation, and digital sovereignty. Link: https://www.bk.admin.ch/dam/bk/en/dokumente/dti/StrategieDCH/strategie-digitale-schweiz-

		2023.pdf.download.pdf/Digital%20Switzerland%20Strategy%202023.pdf
	Approval of code of conduct for managing trustworthy data spaces	The Federal Council has approved the Code of Conduct, which serves as a recommendation for the Federal Administration; however, it is not legally binding. It provides guidance for other stakeholders in the private, scientific, civil society, and business sectors, and is open to their signatures. Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-99268.html
2024	*** DigiSanté 2024–2034 - Federal Decree on the commitment credit for a program to promote digital transformation in the healthcare sector for the years 2025–2034**	On 29 May 2024, the Federal Assembly of the Swiss Confederation approved a commitment credit of 391.7 million CHF for the years 2025–2034 to fund the DigiSanté program, which aims to promote digital transformation in the healthcare sector. Link: https://www.fedlex.admin.ch/eli/fga/2024/1333/it
Ongoing	***Revision of the Federal Act on the Electronic Patient Record (EPRA)**	Among other revisions is the possibility for patients to give express consent to making non-anonymised medical data in their EPR available for research purposes. Link: https://www.bag.admin.ch/bag/en/home/strategie-und-politik/nationale-gesundheitsstrategien/strategie-ehealth-schweiz/umsetzung-vollzug/weiterentwicklung-epd.html#-1105949232
	***Revision of the Epidemics Act to better manage future public health crises**	This review aims to allow the Confederation and the cantons to collaborate closely to protect the health of the population from future threats represented by communicable diseases or resistance to antibiotics by promptly adopting preventive measures. Link: https://www.mcid.unibe.ch/about_us/events/symposium_on_the_revision_of_the_swiss_epidemics_act/index_eng.html
	***Revision of the HRA**	On 7 June 2024, the Federal Council approved and adopted amendments to the ordinances under the HRA to enhance participant protection and improve the regulatory framework for researchers. The amendments take effect on 1 November 2024, except for transparency provisions, which come into force on 1 March 2025. Link: https://kofam.ch/en/research-on-humans/hra-revision-ordinances

		At the same time as adopting the partial revision of the HRA ordinances, the Federal Council instructed the EDI to revise the HRA and submit a draft bill to it by the end of 2026. Link: https://www.bag.admin.ch/bag/en/home/medizin-und-forschung/forschung-am-menschen/revision-verordnungen-hfg.html-hfg.html
	***Implementation of 22.3890 WBK-SR Motion**	According to the motion text, the Federal Council is tasked with establishing, through a framework law, a legal basis that allows for the rapid development and implementation of specific infrastructures for the secondary use of data in strategically relevant sectors. The Federal Department of Justice and Police will draft the legal basis for the secondary use of data. The consultation project must be submitted to the Federal Council by the end of 2026. Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-99268.html

Appendix 6

Opinion-shaping events positively influencing the socio-political discourse on health data sharing – Interview data	
1. Early 2000s – Digitisation of private life	“P*eople are aware that when they're using Apple watches or other tools, those data are going everywhere*” (P10)
2. 2020 – COVID-19 pandemic - Increased awareness regarding the potential of health data within	
a) The public	*“The pandemic represents a point where awareness, so to speak, of data use, has changed something in the public” (P06)*
b) The political sphere	*“[…] I think the real cause for pushing this now forward is the awakening of the politicians saying 'Hey, this needs to be governed by a proper strategy, data reuse, and all of the infrastructures that are needed for that and everything around doesn’t emerge by itself” (P04).*
- Rapid development of SwissCovid Tracing App with high standard	“*The covid app was developed here in Switzerland pretty fast, and we were one of our first to set it up with a really high standard” (P11)*
3. Before 2021 – ‘Myvaccination’ solution	*“[…] I think it was very positive, […] people gave me positive feedback” (P05*)
4. 2023 – DigiSanté program	*“[…] we knew that the FOPH and the statistical office would set up a program they have now. So, we can see things moving on and really happening. I think that's positive. That's really a good development” (P08)*

Appendix 7

Events negatively influencing the socio-political discourse on health data sharing – Interview data	
1. Scandals - 2013: Edward Snowden leaked intelligence data from the US National Security Agency - 2018: Cambridge Analytica's unauthorised processing of personal data from Facebook - 2021: Data breach of 'Myvaccination' platform exposed Swiss citizens' vaccination records; Rejection of the Electronic Identification Services (e-ID) referendum - 2022: Data breach of the Swiss Organ Donation register - 2022: Online leak of medical files in Neuchâtel, Switzerland	"*The various data thefts from hospitals using ransomware blackmail certainly had a negative impact, as did the scandal at meineimpfungen.ch mentioned earlier. But I'm sure that for most people, these have strengthened their desire to do better rather than do even less*" (P11)
2. Slow implementation of the Swiss EPD initiative (2015–2024)	*"It's not really a scandal it's just 1000 times repeated story and myths about the EPD. I think it's not doing good to the system. […] So, the good stories are mostly really within the professionals and the bad story is EPD. That's a visible thing"* (P05)
3. Switzerland's reliance on paper-based systems revealed by the COVID-19 pandemic	"*The beginning of the Covid pandemic, it was embarrassing, as I would say, to see how data is shared among different players in Switzerland nowadays, I mean using fax as a kind of means to exchange data is not worthy of the 20 first century and that had negative effects in the sense of we can't go on like this*" (P09)

Appendix 8

Experts' opinion papers and news articles on health data sharing and scandals	# of articles and tone
Experts' opinion papers on scandals ('My Vaccination' and 'Organ Donation')	3 67% red 33% yellow
News articles on scandals ('My Vaccination' and 'Organ Donation')	52 57% red, 42% yellow 1% green
Experts' opinion papers on 'health data', 'Patientendossier'	24 13% red 21% yellow 66% green
News articles on 'health data', 'Patientendossier'	476 39% red 38% yellow 23% green

Appendix 9

Obstacles to the implementation of health data sharing initiatives – Interview data	
Policy	
-Misalignment of stakeholder interests with power dynamics among various actors	*"I would say that there was a lot of questions surrounding the different views of the stakeholders towards the use of data, and how it should be gathered, how it should be secured […] not a lot of consensus on how to do that, because there are so many different stakeholders involved which have different political, economic goals, […]My impression was also that it was a little bit of a power game to control how this thing should be used"* (P09)
-Cultural attitudes and individualistic approaches toward data sharing	*"I think still the main obstacle is personal or, let's say, cultural aptitudes, the willingness to share from researchers, but also health institutions like hospitals, because there's of course a lot of potential risks […] also for trying to keep the benefits more for yourself and not recognizing the benefits for sharing data to a large extent, yet"* (P01)
-Pace disparity: policy processes lagging behind digitisation	"*I think the problem is that we are lagging the technology development. So, we have to be faster, the political process has to be faster"*" (P10)
-Challenges posed by federalism	*"In our federal system, health is the responsibility of the cantons. However, effective data exchange would require coordination at national level, at least when it comes to defining data standards. […] That's one of the biggest problems"* (P11) *"What has been really an issue is that there wasn't one clear strategy which we want to achieve"* (P07)
-Voluntary participation in data sharing initiatives	*"[…] today have a system which is hardly functioning because of voluntary participation so people don't need to sign up to this at least at the moment"* (P09)
-Limited public involvement in policy making	*"I think what is also a little bit missing is that all this digital let's say digital legislation is done without the public. That that's also a big point. So because what we're seeing right now and then patient dossier, we have to ask the patients or the citizens how such a portal should be implemented. […] We have to engage more the citizens here in Switzerland when we are talking about inventing new digital tools"* (P10)

- Absence of legal framework for secondary use of health data	*"There's some regulatory hurdles, sometimes it's not clear who can -under what circumstances- use what data so we really also ask for kind of a framework law on secondary data usage"* (P08)
-Insufficient funding for the implementation of the initiative	*"I think another big obstacle which hasn't been talked about a lot is the pure funding aspect. We're talking about a huge change in how health data is used in Switzerland, a huge public health change, and the funding from the Federal or the cantons is very, very little. […] It's just not enough money from the public side"* (P09)
Public	
-Lack of public awareness of the potential of their data and the benefits of the solution being implemented	*"Most people in politics, but also in health, and especially in the public don't really see the broader approach and benefits of really a good [digital] health state arena for them"* (P11)
-Lack of public discourse on health data sharing for secondary purposes	*"I think societally we have not yet had that broad discussion on the promises of data sharing and data use at scale"* (P01)
-Resistance to change in a functioning healthcare system	*"Our healthcare system is still one of the best in the world. The quality is high, access is guaranteed, and the costs are still affordable for our country. Therefore, the pressure to change something is very low"* (P11)
-Data security and privacy concerns	*"In the public there's a kind of worry about this data going to insurance companies and changing how insurance will work. […] But I would say, if you put an initiative to vote now, the majority would be fine with using health data in this way, because they're not so conscious about the necessity for privacy"* (P09)
-Non-user-friendly interface and complex registration process	*"I think people are hoping for easygoing tools, and as long as it's not easily accessible... the opening of an EDP is considered to be very complicated. […] I think people just want a very easy going, a convenient solution. As long as it's not offered, and of course, free of charge, then people will just not go on"* (P05)
Healthcare Professionals	
-Lack of support from physicians, negatively impacting patient adoption of the solution being implemented	*"I feel like the most detrimental factor […] is that practitioners and all stakeholders in the health care sector they don't agree on the EPD, and I think that the sense that something is not right with the EPD, and that it's not of use, and that hospitals don't wanna use it […] of course you're not gonna trust it if your doctor doesn't trust it"* (P02)
- Physicians serving as trust anchors for patients, creating a sense of accountability in data handling	*"Medical practice assistants say: 'for us it's very important to not share data because patients are trusting us. We are their trust anchor. And they give us data. So, it must be very clear that data*

	sharing comes from the patient and not from the healthcare professional'" (P10)
- Limited perceived benefits from the health data sharing solution being implemented	"*But as a matter of fact, at least as I understood, doctors were not seeing that benefit because basically, it was a kind of a storage system for PDFs"* (P09)
- Lack of direct financial incentives to support their digital transition	*"[…] We need incentives. Incentives could be a new tariff for using such systems, so that the healthcare professionals can make the proper investments into the new technology"* (P10)
Technical Obstacles	
-Challenges with interoperability (unstructured/siloed data)	*"And another problem is that all the primary systems, they were developed as data silos, they were not prepared to exchange data, so every vendor has its own data model. […] They still have silos, and even if you have a good infrastructure which enables you to share all those data to others, the data are not useful there, you cannot use this data for secondary use because the semantic model is unclear it's bound to the data silos and so that's the situation from 1998 until today"* (P10)

Appendix 10

Key Lessons for the future – Interview data	
Policy	
-Align stakeholders' interests	*"Now is precisely the time for the different actors who have political interests to come together to advance the entire system"* (P06)
-Establish a legal framework for secondary health data use	*"We must have a concept that takes into account the legal situation; [...] we need a law for secondary use, but it's very complicated"* (P06)
-Centralise the coordination of the initiative at federal level	*"[...] the way of using data or using health systems in Switzerland is very inefficient and there's of course a clash between autonomy and centralization, but maybe this needs to change in certain areas. Regarding public health, some autonomy needs to go to the Federal level and cannot be on the cantons anymore because otherwise it's just impossible to...We're such a small country and this kind of small borders, they mean nothing with regard to public health, so why keep them up artificially because of these political reasons? [...] It's a very hard pill to swallow, probably for the Swiss public"* (P09)
-Increase funding available to promote the implementation of health data sharing solutions	*"Another lesson is that we need to put much more money into this issue if we want to make it work"* (P09)
-Separate bodies for data storage and use to avoid conflicts of interest	*"And so, those who regulate the access of the data shouldn't use the data"* (P11)
- Set political priorities after the system's functionality has been successfully demonstrated	*"The solution [has to] take into account legal, medical, infrastructure, and data security factors. And then [...] we must showcase how this system works, and then comes politics that must set priorities, not us, I mean it's politics that says 'Ah okay, we understand, this is the system, now we want this, this, this [to be] done first'"* (P06)
- Accelerate policymaking to match pace of technology development	"*I think we have to change the process of making laws in the new digital era, because that does not work right now. You cannot wait... DigiSanté has 400 million Swiss francs, but it has a scope of 10 years! All the technology will be specified now and will be put in place in 10 years. So that will not work because technology changes faster. So, we have to adapt our processes to the development of digital technologies"* (P10)

Public	
-Illustrate to the public the benefits of the health data sharing initiative being implemented	*"[...] it also needs to show the benefit, the true benefits for people. I mean having everything in one place sounds like a nice thing. But in the end, what does it do? [...] give me some proper use cases, in everyday life where this benefits me"* (P09)
-Improve public communication (use of ambassadors)	*"I believe the most important thing that we need to do in the future is that we will also try to become active in this filed is to really inform more*" (P08) *"But I think, also to all the organization, especially for cancer, for breast cancer, and so forth, I think that they have a lot of credibility in the public. I think that's where we maybe should actually start to have as ambassadors for sharing the data because and if you can get them on board, they see the benefits for contributing" (P07)*
-Involve the public in policymaking	*"I think, what is also a little bit missing is that all this digital legislation is done without the public"* (P10)
Healthcare Professionals	
- Involve health care professionals from the start in developing the health data sharing solution	*"Whatever the healthcare system will look like in the future, doctors will kind of need to be there to translate between health and also digital sphere and if they're not part of it, that will be a problem"* (P08)
-Explain benefits of the health data sharing solution to healthcare professionals	"[…] *they do not see any benefit for them as these... That's how the argument goes. So I really don't understand how in the future they cannot see any benefit for them, or also in the administration and their patient administration" (P08)*
- Provide financial support to healthcare professionals	*"We don't have a tariff for any digital application like e-prescription like medication plan, and so on also. And this a problem and this should be solved very soon. We need incentives" (P10)* *"An incentive could also be let's say, a punishment if you don't send them e-prescription, then you have to pay for it"* (P10)
- Consider a patient-centric approach to data sharing	*"I think you can't put the health care professional in the role to say 'Okay, so there is a lot of patient data, let's share the data'. Of course, patients have to know what data will be shared. And it's better to use technologies that patients directly share their data with others. I*

	would suggest to exclude the healthcare professionals from that" (P10)
Data Sharing Solutions	
-Data security & privacy	
Acknowledge risks and enhance data protection measures	*"[…] just to be very vigilant with the data privacy and the data protection issues. I think the risk can never be put down to 0, but one can show that it did what was technically and reasonably possible that also helps retain trust, even if let's say, through criminal activities or so breaches happen" (P01)*
Use an external third-party for data oversight and ensure transparency on data access	*"[…] something that is essential for trust is that, if you want, you could always check who has actually used your data. […] And then you also want to have something like a state surveillance like for the banks. […] I think these are the elements that will help public trust"* (P03)
Store data in Switzerland	"*People want to have the data stored inside the country, especially health data*" (P10)
-Technical Features	
Align taxonomy of health data	*"[…] we must have a common definition that then allows everyone to do their job, but also allows the secondary use of data*" (P06)
Use patient identifiers to optimize the secondary use of health data	"*We must have patient identification; otherwise, it doesn't work*" (P06)
Demand for high-quality data from the source	*"An important point is data capture at source because you need good high-quality data at source that can be shared. Competency centers [are needed] to ensure the quality of the data" (P10)*
-Ensure the solution works, benefits all actors, and is easy to use	"*[…] First of all, it needs to work. I mean, you cannot build trust on products that do not work"* (P08)
-Establish trust with eID before adding health data – without imposition	"*We first have to get the aid on a stable basis and a trustworthy base where people say, Oh, that's cool. I trust that. And then you can start with the health data. […] We absolutely suppose that everybody we see in the public has a phone number, […] and a smartphone. […] There is absolutely no law for it. So, we don't need a mandatory eID, but if it works, the eID will be at 90% in in a few years'*" (P11)
-No one-size-fits-all solution due to diverse public composition	*"We really don't need a one-fix all approach. There would be, let's say, about 12 profiles from one extreme, let's say, a paranoid profile, […] and on the other end you will have people who say: 'If some company can use my fitness data to improve their skin care solution, I couldn't care*

	less'. And in the middle, you have people who would say: Hey, if a university wants to use my health data for research, I agree. But if no commercial company has to use them. […] If you provide a dozen of such profiles, the people will find themselves in one of them and they can say: Hey, you can use my health data according to this profile" (P11)