



Public Trust in a Swiss Health Data Space

P. Daniore, F. Zavattaro, F. Gille



Imprint

© October 2024
University of Zurich

Design and infographic

Narongrit Doungmanee, iStockphoto LP

Address

Universität of Zurich
Digital Society Initiative
Rämistrasse 69
8001 Zurich

Website

<https://www.dsi.uzh.ch/en.html>

Project category	Independent study
Document	Research report
Project lead	Dr Felix Gille, Digital Society Initiative, University of Zurich
Researchers	Dr Paola Daniore & Federica Zavattaro, Digital Society Initiative, University of Zurich
Scientific advisory committee	Prof. Alfred Angerer, Zurich University of Applied Sciences; Manuel Kugler, Swiss Academy of Engineering Sciences; Mathis Brauchbar, Advocacy AG; Prof. Mélanie Levy, University of Neuchâtel; Sigrid Beer-Borst & Thorsten Kühn, Federal Office of Public Health; Prof. Viktor von Wyl, University of Zurich
Content-related support with DigiSanté Package 4	Sigrid Beer-Borst & Thorsten Kühn, Federal Office of Public Health
Funding	Novartis International AG and Sanitas Krankenversicherung (Stiftung)

Funding statement

This research project was co-initiated by Novartis and Dr Felix Gille, University of Zurich, and received financial support from Novartis International AG. The research activities and the formulation of policy recommendations were carried out independently of Novartis. In addition to Novartis International AG, the Sanitas Health Insurance foundation provided financial support for this project to initiate a broad socio-political discussion regarding the possible introduction of a Swiss health data space. Both funders had no role in the study design and research processes. The report was written independently of the funders. Outside of this work, Dr Gille receives funding from the Swiss Academy of Engineering Sciences, the Digitalisierungsinitiative der Zürcher Hochschulen, and the World Health Organization.

Acknowledgements

We would like to acknowledge our research collaboration with foraus - Forum Aussenpolitik during the early stages of this study. We thank Maximilian Rau of foraus for his efforts throughout our collaboration. We also thank Moritz Fegert, formerly of foraus, for his contributions during the early development of the study design. Additionally, we thank the advisory committee for their valuable guidance and feedback throughout the study. Special thanks go to Sigrid Beer-Borst and Thorsten Kühn from the Federal Office of Public Health, who provided content-related support in relation to DigiSanté Package 4. Finally, we thank Artemis Faulk for her assistance with support and organizational matters related to data collection for the French-speaking focus groups.

About the authors

Dr Felix Gille has a background in health policy and European public health. For over 10 years, he has been researching public trust in the health system, with a focus on health data sharing and digital health initiatives. Since 2021, Dr Gille has been a postdoctoral fellow at the Digital Society Initiative, University of Zurich. His previous workstations include roles at the Swiss Federal Institute of Technology Zurich and the University of Cambridge. He holds a PhD from the London School of Hygiene and Tropical Medicine.

Dr Paola Daniore has a background in digital health epidemiology and technology management. She is currently a policy fellow at the Center for Digital Trust, Swiss Federal Institute of Technology Lausanne. Her work focuses on enabling large-scale technology adoption in healthcare from a policy perspective. Previous workstations include roles at the Digital Society Initiative (University of Zurich), Swiss Federal Institute of Technology Zurich, and private practice. She holds an MSc from the Swiss Federal Institute of Technology Zurich, and a BEng from McGill University, Montreal. She holds a PhD from the University of Zurich.

Federica Zavattaro has a background in health policy and public health. Since 2022, she has been a PhD student in Digital and Mobile Health at the Digital Society Initiative, University of Zurich. Her current research focuses on the role of public trust in the European health data sharing policy process. Her previous work experience includes consulting at Clarivate Analytics in London. She holds an MSc from City University, London.

Table of Contents

Abbreviations	6
Glossary	6
Executive Summary (available in German, French and Italian)	7
Key Findings	15
Introduction, Challenges, Study Outcomes and Study Design	16
Why is Public Trust in Health Data Sharing Relevant?	18
Phase 1: 31 Years of Socio-Political Discourse on Health Data Sharing	19
Phase 2: Future-Oriented Case Studies for Public Focus Groups	26
Case Study 1: Consent Management	26
1.a) Informed Opt-In Consent Model for the Sharing of (Health-Related) Personal Data	26
1.b) Informed Opt-Out Consent Model for the Sharing of (Health-Related) Personal Data	27
1.c) Informed ‘Value-Based’ Opt-Out Consent Model for the Sharing of (Health-Related) Personal Data ..	27
Case Study 2: Record Linkage via the Social Security Number (AHV Number)	27
Case Study 3: National Data Coordination Centre (NDCC)	27
Case Study 4: Data Exchange	28
4.a) Monitoring of Infectious Diseases.....	28
4.b) European Research Consortium on Colorectal Cancer	28
Phase 3: Recommendations	29
3.a) Policy Recommendations	29
3.b) Communication Recommendations	33
Phase 4: Potential Application of Recommendations in Health Data Governance	35
Swiss Digital Health History: What Can We Build Upon?	35
Communication Strategy: How Can We Engage With the Public?	36
Consent Model: How Can We Combine Personal Autonomy and Feasibility?	36
Health Data Space Governance: Which Governance Structures Enjoy Public Support?	37
Record Linkage: Which Identifiers Can Be Used to Link Data?	37
International Research Collaborations: Which Conditions for International Data Use Have Public Support?	37
Methods	38
Study Phase 1	38
Study Phases 2 - 4	39
Research Ethics (Study Phases 1-3)	40
Limitations and Biases	40
References	44
Appendix	48

Tables

Table 1 Swiss Policy Documents and Events Shaping the Political Discourse on Health Data Sharing.....	20
Table 2 Thought-Provoking and Negative Events that Influenced the Socio-Political Discourse on Health Data Sharing	22
Table 3 Implementation Obstacles Identified through Stakeholder Interviews, Listed in Descending Order Based on the Frequency of Mention	23
Table 4 Description of Case Studies	26
Table 5 Consent Management - Policy Recommendations and Implementation Guidance	29
Table 6 Record Linkage - Policy Recommendations and Implementation Guidance	30
Table 7 NDCC – Policy Recommendations and Implementation Guidance.....	31
Table 8 Cross-Border Data Exchange - Policy and Implementation Guidance.....	32
Table 9 Communication Recommendations and Implementation Guidance.....	33
Table 10 Fears and Concerns Regarding the Health Data Space for Health-Related Research.....	34
Table 11 Participant Characteristics	40
Table 12 Potential Biases and Limitations	41

Figures

Figure 1 Study Phases.....	17
Figure 2 Elements Influencing the Socio-Political Discourse on Health Data Sharing.....	19

Abbreviations

ECDC	European Centre for Disease Prevention and Control
EDI	Eidgenössisches Departement des Innern (Federal Department of Home Affairs)
e-ID	Electronic Identification Services
EPD	Elektronische Patientendossier (Electronic Patient Record)
EPRA	Federal Act on the Electronic Patient Record
FMH	Foederatio Medicorum Helveticorum (Federation of Swiss Doctors)
FOPH	Federal Office of Public Health
FSO	Federal Statistical Office
GPs	General Practitioners
NDCC	National Data Coordination Centre

Glossary

AHV number	Social Security Number in Switzerland
Anonymisation	The process of removing personally identifiable information from data
Centralisation	Collection and storage of health data in a single system for easier access and analysis
Consent	Permission given by individuals for the use of their data
Cross-border data exchange	Sharing data across national borders
Data linkage	Connecting data from different sources for analysis
e-ID	Electronic identification system
Electronic patient records	Digital version of patients' medical records
Genetic data	Information about an individual's DNA
Health data space	A secure environment for sharing and using health data
Health insurance data	Information related to an individual's health insurance coverage
Health-related data	Health-related data refers to information that encompasses: a) a person's health status (e.g. clinical, genetic, insurance data); b) health determinants (e.g. tobacco use, living conditions); and c) data related to the healthcare system (e.g. service structures, costs, utilisation). It includes both individual health information (a, b) and data pertaining to healthcare institutions (c)
Health-related research	A systematic investigation of health, illness and healthcare to improve medical practices, public health and health policies
Hospital data	Information related to patients and treatments within a hospital
National Data Coordination Centre	A Swiss central authority managing national data coordination
Personal data	Any information that relates to an identified or identifiable living individual (e.g. name and surname, location data, finance and health-related data)
Personalised precision medicine	Tailored medical treatments based on individual characteristics
Pseudo-anonymised data	Data that has been processed to remove direct identifiers but can still be re-identified in certain conditions
Secondary health data use/reuse of health data	Use of existing health data (e.g. medical records) for new purposes, such as for research
Social security data	Information related to social security benefits
Tax data	Information related to an individual's taxes

Public Trust in a Swiss Health Data Space: A 2023–2024 Literature and Interview Study to Inform Policy and Governance for a Trustworthy Health Data Space for Health-Related Research in Switzerland

Executive Summary (available in German, French and Italian)

Access to health data for secondary use is crucial for advancing scientific research, healthcare services and public health in Switzerland. Over the past 30 years, efforts at both the federal and cantonal levels have been made to provide access to health data for healthcare professionals, researchers and the public. However, technical, legal and political barriers, along with societal concerns, have hindered progress in this area. In response, the Federal Office of Public Health (FOPH)—in close cooperation with the Federal Statistical Office (FSO)—is leading the project entitled ‘Datenraum für die gesundheitsbezogene Forschung’¹ as part of Package 4 on secondary data use within the DigiSanté programme (2025–2034). The goal of this project is to develop a comprehensive ecosystem for sharing health-related data for planning, strategic management and research purposes, and to establish clear guidelines for health-related research within the health data space.

Researchers and healthcare organisations emphasise that maintaining a high level of public trust is essential for the successful implementation of national health data sharing systems. Therefore, it is crucial that those responsible for designing the health data space share a common, evidence-based understanding of the criteria for the trustworthy reuse (also referred to as secondary use) of health data. This underscores the need to clarify public and stakeholder expectations in order to establish conditions for the trustworthy secondary use of data for health-related research that are accepted and supported by all relevant parties.

We conducted a multi-method assessment of 31 years of socio-political discourse on health data sharing in Switzerland, alongside a nationwide focus group interview study with Swiss citizens to capture their expectations and requirements for a trustworthy data space for health-related research. The ultimate aim is to provide actionable guidance for Switzerland’s ongoing DigiSanté policy development related to the Swiss health data space and the secondary use of data for health-related research. Our findings reveal that the digitalisation of private life in the early 2000s—and, more recently, the COVID-19 pandemic—have influenced Swiss socio-political discourse on health data sharing, raising public awareness of data use and its potential whilst also triggering policy waves on the primary and secondary use of health data. In recent years, scepticism among parts of the public and media towards national health data sharing activities appears to be increasing, largely driven by persistent negative narratives surrounding the implementation of the Electronic Patient Dossier (EPD) initiative. Given that discussions on the secondary use of health data have not yet comprehensively permeated the public discourse, Switzerland has a valuable opportunity to engage in these discussions by reflecting on the challenges that hindered the implementation of the EPD initiative and drawing lessons that can inform future health data sharing efforts. It is important to recognise that digital health experts may not necessarily see a connection between the introduction of the EPD and the establishment of a health data space. However, from a lay citizen’s viewpoint, both are closely linked since they both involve data sharing and are partially associated with the government, which is perceived as being responsible for the health data space.

¹Project title in English: «Data space for health related research»; in French: «Espace de données pour la recherche liée à la santé»; in Italian: «Spazio di dati per la ricerca in materia di salute»

To build a health data space that the public finds trustworthy, current policy efforts should focus on:

1. Implementing a user-friendly informed opt-out consent model;
2. Exploring the use of encrypted identifiers for data linkage;
3. Establishing a national data coordination centre at the federal level, with representation from politicians, academics, and the public; and
4. Setting standards for data quality and international interoperability to support cross-border data exchange.

Public communication should be central to every phase of developing and implementing the health data space through multi-channel strategies and actively engaging the public through public forums. An easy-to-understand, catchy communication strategy with relatable spokespersons is preferable. If the public does not clearly understand the benefits and risks associated with secondary data use, they will not be able to make informed decisions about data-sharing activities. These communication efforts, alongside policy recommendations, should be supported by a robust governance model that upholds data privacy, data security and public accountability.

Zusammenfassung

Der Zugang zu Gesundheitsdaten für die Sekundärnutzung ist für die Förderung der wissenschaftlichen Forschung, der Gesundheitsdienste und der öffentlichen Gesundheit in der Schweiz von entscheidender Bedeutung. In den letzten 30 Jahren wurden sowohl auf Bundes- als auch auf Kantonsebene Anstrengungen unternommen, um Angehörigen der Gesundheitsberufe, Forschern und der Öffentlichkeit Zugang zu Gesundheitsdaten zu verschaffen. Technische, rechtliche und politische Hindernisse sowie gesellschaftliche Bedenken haben jedoch den Fortschritt in diesem Bereich verlangsamt. Als Reaktion darauf leitet das Bundesamt für Gesundheit (BAG) in enger Zusammenarbeit mit dem Bundesamt für Statistik (BFS) das Projekt „Datenraum für die gesundheitsbezogene Forschung“² als Teil des Pakets 4 zur Sekundärdatennutzung im Rahmen des DigiSanté-Programms (2025–2034). Ziel dieses Projekts ist es, ein umfassendes Ökosystem für den Austausch gesundheitsbezogener Daten für Planungs-, strategische Management- und Forschungszwecke zu entwickeln und klare Richtlinien für die gesundheitsbezogene Forschung innerhalb des Gesundheitsdatenraums festzulegen.

Forscher und Gesundheitsorganisationen betonen, dass die Aufrechterhaltung eines hohen Maßes an öffentlichem Vertrauen für die erfolgreiche Umsetzung nationaler Systeme für den Austausch von Gesundheitsdaten unerlässlich ist. Daher ist es von entscheidender Bedeutung, dass die für die Gestaltung des Gesundheitsdatenraums Verantwortlichen ein gemeinsames, evidenzbasiertes Verständnis der Kriterien für die vertrauenswürdige Sekundärnutzung von Gesundheitsdaten haben. Dies unterstreicht die Notwendigkeit, die Erwartungen der Öffentlichkeit und der Interessengruppen zu klären, um Bedingungen für die vertrauenswürdige Sekundärnutzung von Daten für die gesundheitsbezogene Forschung zu schaffen, die von allen Parteien akzeptiert und unterstützt werden.

Wir haben eine multimethodische (Mixed Methods) Bewertung des 31-jährigen gesellschaftspolitischen Diskurses über die gemeinsame Nutzung von Gesundheitsdaten in der Schweiz durchgeführt, zusammen mit einer landesweiten Fokusgruppen-Interviewstudie mit Schweizer Bürgern und Bürgerinnen, um ihre Erwartungen und Anforderungen an einen vertrauenswürdigen Datenraum für gesundheitsbezogene Forschung zu erfassen. Das letztendliche Ziel besteht darin, umsetzbare Leitlinien für die laufende Entwicklung der DigiSanté-Politik der Schweiz im Zusammenhang mit dem Schweizer Gesundheitsdatenraum und der Sekundärnutzung von Daten für gesundheitsbezogene Forschung bereitzustellen. Unsere Ergebnisse zeigen, dass die Digitalisierung des Privatlebens in den frühen 2000er Jahren – und in jüngerer Zeit die COVID-19-Pandemie – den gesellschaftspolitischen Diskurs in der Schweiz über die gemeinsame Nutzung von Gesundheitsdaten beeinflusst haben. Sie haben das öffentliche Bewusstsein für die Datennutzung und ihr Potenzial geschärft und gleichzeitig politische Wellen über die primäre und sekundäre Nutzung von Gesundheitsdaten ausgelöst. In den letzten Jahren scheint die Skepsis in Teilen der Öffentlichkeit und der Medien gegenüber nationalen Aktivitäten zum Austausch von Gesundheitsdaten zuzunehmen, was vor allem auf die anhaltenden negativen Berichte über die Umsetzung der Initiative „Elektronisches Patientendossier (EPD)“ zurückzuführen ist. Da die Diskussionen über die sekundäre Nutzung von Gesundheitsdaten noch nicht umfassend in den öffentlichen Diskurs eingeflossen sind, hat die Schweizer Politik eine wertvolle Möglichkeit, sich an diesen Diskussionen zu beteiligen, indem sie über die Herausforderungen nachdenkt, die die Umsetzung der EPD-Initiative behindert haben, und Lehren daraus zieht, die in zukünftige Bemühungen um den Austausch von Gesundheitsdaten einfließen können. Es ist wichtig zu verstehen, dass Experten für digitale Gesundheit nicht unbedingt einen Zusammenhang zwischen der Einführung des EPD und der Einrichtung eines Gesundheitsdatenraums sehen. Aus der Sicht von Laien sind beide jedoch eng miteinander verbunden, da sie beide den Austausch von Daten beinhalten und teilweise mit der Regierung in Verbindung stehen, die als verantwortlich für den Gesundheitsdatenraum wahrgenommen wird.

² Projekttitel auf Englisch: „Data space for health related research“; auf Französisch: „Espace de données pour la recherche liée à la santé“; auf Italienisch: « Spazio di dati per la ricerca in materia di salute»

Um einen Gesundheitsdatenraum zu schaffen, der von der Öffentlichkeit als vertrauenswürdig empfunden wird, sollten sich die aktuellen politischen Bemühungen auf Folgendes konzentrieren:

1. Einführung eines benutzerfreundlichen Modells für eine informierte Widerspruchslösung;
2. Prüfung der Verwendung verschlüsselter Identifikatoren für die Datenverknüpfung;
3. Einrichtung eines nationalen Datenkoordinierungszentrums auf Bundesebene mit Vertretern aus Politik, Wissenschaft und Öffentlichkeit; und
4. Festlegung von Standards für Datenqualität und internationale Interoperabilität zur Unterstützung des grenzüberschreitenden Datenaustauschs.

Die öffentliche Kommunikation sollte in jeder Phase der Entwicklung und Umsetzung des Gesundheitsdatenraums im Mittelpunkt stehen, und zwar durch Mehrkanalstrategien und die aktive Einbindung der Öffentlichkeit über öffentliche Foren. Eine leicht verständliche, eingängige Kommunikationsstrategie mit glaubwürdigen Sprechern ist vorzuziehen. Wenn die Öffentlichkeit die Vorteile und Risiken der Sekundärdatennutzung nicht klar versteht, kann sie keine fundierten Entscheidungen über die gemeinsame Nutzung von Daten treffen. Diese Kommunikationsbemühungen sollten zusammen mit politischen Empfehlungen durch ein solides Governance-Modell unterstützt werden, das den Datenschutz, die Datensicherheit und die öffentliche Rechenschaftspflicht gewährleistet.

Résumé

L'accès aux données de santé pour une utilisation secondaire est crucial pour faire progresser la recherche scientifique, les services de soins et la santé publique en Suisse. Au cours des 30 dernières années, des efforts ont été déployés au niveau fédéral et cantonal pour permettre aux professionnels de la santé, aux chercheurs et au public d'accéder aux données de santé. Cependant, des obstacles techniques, juridiques et politiques, ainsi que des préoccupations sociétales, ont entravé les progrès dans ce domaine. Pour y répondre, l'Office fédéral de la santé publique (OFSP) – en étroite collaboration avec l'Office fédéral de la statistique (OFS) – dirige le projet intitulé « Datenraum für die gesundheitsbezogene Forschung »³ dans le cadre du volet de mesures 4 sur l'utilisation secondaire des données au sein du programme DigiSanté (2025-2034). L'objectif de ce projet est de développer un écosystème complet pour le partage des données liées à la santé à des fins de planification, le pilotage et la recherche, et d'établir des lignes directrices claires pour la recherche dans l'espace des données de santé.

Les chercheurs et les organismes de santé soulignent que le maintien d'un niveau élevé de confiance du public est essentiel à la réussite de la mise en œuvre de systèmes nationaux de partage des données de santé. Il est donc crucial que les responsables de la conception de l'espace des données partagent un système commun compris de tous, fondée sur des données probantes pour une réutilisation (ou « usage secondaire ») fiable des données de santé. Cela souligne la nécessité de clarifier les attentes du public et des parties prenantes afin d'établir les conditions d'une utilisation secondaire fiable des données pour la recherche liée à la santé pour qu'elles soient acceptées et soutenues par toutes les parties concernées.

Nous avons procédé à une évaluation multiméthode de 31 ans de discours sociopolitique sur le partage des données de santé en Suisse, en parallèle à une étude nationale d'entretiens de groupe avec des citoyens suisses afin de saisir leurs attentes et leurs exigences concernant un espace de données fiable pour la recherche liée à la santé. L'objectif final est de fournir des conseils exploitables pour l'élaboration de la politique DigiSanté en cours en Suisse, en rapport avec l'espace de données de santé suisse et à l'utilisation secondaire des données pour la recherche liée à la santé. Nos résultats révèlent que la numérisation de la vie privée au début des années 2000 – et, plus récemment, la pandémie de COVID-19 – ont influencé le discours sociopolitique suisse sur le partage des données de santé, en sensibilisant le public à l'utilisation des données et à son potentiel, tout en déclenchant des vagues politiques sur l'utilisation primaire et secondaire des données de santé. Ces dernières années, le scepticisme d'une partie du public et des médias à l'égard des activités nationales de partage des données de santé semble s'accroître, en grande partie en raison de remises en cause persistantes entourant la mise en œuvre du dossier électronique du patient (DEP). Étant donné que les discussions sur l'utilisation secondaire des données de santé n'ont pas encore complètement imprégné le discours public, la Suisse a une bonne opportunité de s'engager dans ces discussions en réfléchissant aux défis qui ont entravé la mise en œuvre de l'initiative DEP et en tirant des leçons qui peuvent éclairer les futurs efforts de partage des données de santé. Il est important de reconnaître que les experts en santé numérique ne voient pas nécessairement de lien entre l'introduction du DEP et la création d'un espace de données de santé. Cependant, du point de vue d'un citoyen non expert, les deux sont étroitement liés puisqu'ils impliquent tous deux le partage de données et sont partiellement associés au gouvernement, qui est perçu comme responsable de l'espace de données de santé.

Pour construire un espace de données de santé que le public juge fiable, les efforts politiques actuels devraient se concentrer sur quatre points :

1. Mise en œuvre d'un modèle pratique d'utilisation de consentement éclairé (opt-out);
2. Exploration de l'utilisation d'identifiants cryptés pour le couplage des données ;

³ Titre du projet en anglais : « Data space for health related research » ; en français : « Espace de données pour la recherche liée à la santé » ; en italien : « Spazio di dati per la ricerca in materia di salute »

3. Établissement d'un centre national de coordination des données au niveau fédéral, avec une représentation de politiciens, des universités et du public ; et
4. Définition de normes pour la qualité des données et l'interopérabilité internationale afin de soutenir l'échange transfrontalier de données.

La communication publique doit être au cœur de chaque phase du développement et de la mise en œuvre de l'espace des données de santé, grâce à des stratégies multicanaux et à l'engagement actif du public par le biais de forums publics. Il est préférable d'adopter une stratégie de communication facile à comprendre, attractive et séduisante, avec des relais de communication identifiables. Si le public ne comprend pas clairement les avantages et les risques associés à l'utilisation des données secondaires, il ne sera pas en mesure de prendre des décisions éclairées sur les activités de partage de données. Ces efforts de communication, parallèlement aux recommandations politiques, doivent être soutenus par un modèle de gouvernance solide qui défend la confidentialité des données, la sécurité des données et la responsabilité publique.

Riassunto

L'accesso ai dati sanitari per un uso secondario è fondamentale per il progresso della ricerca scientifica, il miglioramento dei servizi sanitari e della sanità pubblica in Svizzera. Negli ultimi trent'anni sono stati compiuti sforzi a livello federale e cantonale per garantire l'accesso ai dati sanitari a professionisti della salute, ricercatori e al pubblico. Tuttavia, ostacoli tecnici, legali e politici, oltre a preoccupazioni di natura sociale, hanno rallentato i progressi in questo ambito. In risposta, l'Ufficio Federale della Sanità Pubblica (UFSP), in stretta collaborazione con l'Ufficio Federale di Statistica (UST), sta guidando il progetto "Datenraum für die gesundheitsbezogene Forschung"⁴, parte del Pacchetto 4 sull'uso secondario dei dati nell'ambito del programma DigiSanté (2025–2034). L'obiettivo di questo progetto è la creazione di un ecosistema per la condivisione di dati sanitari utili alla pianificazione, gestione strategica e ricerca, oltre alla delineazione di linee guida per la ricerca sanitaria all'interno dello spazio dei dati sanitari.

Ricercatori e organizzazioni sanitarie sottolineano che il mantenimento di un elevato livello di fiducia pubblica è essenziale per il successo dell'implementazione di sistemi nazionali di condivisione dei dati sanitari. Pertanto, è fondamentale che coloro che progettano lo spazio dei dati sanitari condividano criteri basati sull'evidenza per un riutilizzo (noto anche come uso secondario) affidabile dei dati sanitari. Ciò evidenzia la necessità di chiarire le aspettative del pubblico e degli stakeholder per stabilire quali siano le condizioni accettate e sostenute da tutte le parti coinvolte che rendano affidabile il riutilizzo dei dati per la ricerca sanitaria.

Abbiamo condotto una valutazione multi-metodologica di 31 anni di discorso sociopolitico circa la condivisione dei dati sanitari in Svizzera, accompagnata da uno studio di focus group a livello nazionale con cittadini svizzeri, per comprendere le loro aspettative e richieste riguardo uno spazio dati affidabile per la ricerca sanitaria. L'obiettivo finale è fornire indicazioni concrete per lo sviluppo di politiche sanitarie per l'attuale programma DigiSanté in Svizzera, relative allo spazio dati sanitari e all'uso secondario dei dati per la ricerca sanitaria. I nostri risultati mostrano che la digitalizzazione della vita privata all'inizio degli anni 2000 e, più recentemente, la pandemia di COVID-19, hanno influenzato il discorso sociopolitico svizzero circa la condivisione dei dati sanitari, aumentando la consapevolezza pubblica sull'uso dei dati e il loro potenziale, e generando ondate di iniziative politiche sull'uso primario e secondario dei dati sanitari. Negli ultimi anni, lo scetticismo tra alcune parti del pubblico e dei media verso attività nazionali di condivisione dei dati sanitari sembra crescere, principalmente a causa delle persistenti narrazioni negative riguardanti l'implementazione dell'iniziativa della Cartella Informatizzata del Paziente (CIP). Dato che le discussioni sull'uso secondario dei dati sanitari non hanno ancora permeato pienamente il discorso pubblico, la Svizzera ha l'opportunità preziosa di partecipare attivamente a queste discussioni, riflettendo sulle sfide che hanno ostacolato l'implementazione della CIP e traendo lezioni per informare i future iniziative di condivisione dei dati sanitari. È importante riconoscere che gli esperti di sanità digitale potrebbero non vedere necessariamente una connessione tra l'introduzione della CIP e la creazione di uno spazio dati sanitari. Tuttavia, dal punto di vista del cittadino comune, i due temi sono strettamente collegati, poiché entrambi riguardano la condivisione di dati e sono parzialmente associati al governo, percepito come responsabile dello spazio dei dati sanitari.

Per costruire uno spazio dei dati sanitari che il pubblico percepisca come affidabile, gli sforzi politici attuali dovrebbero vertere su:

1. L'implementazione di un modello di consenso informato opt-out e user-friendly;
2. L'esplorazione dell'uso di identificatori criptati per il collegamento dei dati;
3. Lo stabilire un centro di coordinamento dati nazionale a livello federale, con la partecipazione di rappresentanti della politica, del mondo accademico e del pubblico;

⁴ Titolo del progetto in inglese: «Data space for health related research»; in francese: «Espace de données pour la recherche liée à la santé»; in Italiano: «Spazio di dati per la ricerca in materia di salute»

4. Lo stabilire standard per la qualità dei dati e l'interoperabilità internazionale in modo da supportare lo scambio transfrontaliero dei dati.

La comunicazione pubblica dovrebbe essere centrale in ogni fase dello sviluppo e dell'implementazione dello spazio dei dati sanitari, tramite strategie multicanale e coinvolgendo attivamente il pubblico attraverso forum pubblici. È preferibile optare per una strategia di comunicazione che sia facile da comprendere e accattivante, con portavoce riconoscibili. Se il pubblico non comprende chiaramente i benefici e i rischi associati all'uso secondario dei dati, non sarà in grado di prendere decisioni informate riguardo alle attività di condivisione dei dati. Questi sforzi di comunicazione, insieme alle raccomandazioni politiche, dovrebbero essere supportati da un solido modello di governance che garantisca la privacy e la sicurezza dei dati e la responsabilità pubblica.

Key Findings

BACKGROUND

- Access to health-related data for secondary use is crucial for advancing scientific research, healthcare services and public health in Switzerland.
- The DigiSanté programme aims to foster the digital transformation of the Swiss health system between 2025 and 2034 with a total budget of 623 m CHF (development loan 391.7 m CHF).
- DigiSanté's Package 4 ('Secondary use for planning, strategic management and research') aims to establish the necessary conditions for secondary data use in the Swiss health data space.

31 YEARS OF POLICY AND PUBLIC DISCOURSE ON HEALTH DATA SHARING

- Two policy waves shaped health data sharing in Switzerland: the first laid the groundwork for regulating health data sharing for primary purposes; the second, catalysed by the COVID-19 pandemic, centred around creating the legal framework for the secondary use of health data.
- Two categories of events influenced the socio-political discourse in Switzerland: thought-provoking events, centred on the digitalisation of private lives and the COVID-19 pandemic; and negative events, primarily driven by the slow implementation of the Electronic Patient Dossier (EPD) initiative in Switzerland.
- Lessons from past data-sharing initiatives can inform the trustworthy implementation of projects within the DigiSanté programme.

POLICY RECOMMENDATIONS

- Consent Management: Implement an informed opt-out consent model with clear communication and user-friendly systems, including annual reminders to be able to opt-out and options for post-mortem data control. Allow for data removal upon request. The informed consent model (opt-in) is considered time-consuming and relies on individual motivation to engage in consent processes.
- Record Linkage: Define standards for encryption of the Social Security Number (AHV number) and implement safeguards against misuse.
- National Data Coordination Centre: Ensure financial sustainability and efficiency through synergies with existing data-sharing networks. Maintain governance independence, transparency and public accountability by incorporating diverse professional and public input through an advisory board. Establish governance at the federal level.
- Cross-Border Data Use: Apply Swiss data governance rules and ensure high data quality when using data from abroad. International data use should be aligned with Swiss values.

COMMUNICATION RECOMMENDATIONS

- Multi-Channel Communication: Employ different communication channels to reach diverse segments of the public.
- Public Engagement: Use public exchange forums to enable direct dialogue between the public and experts.
- Content Clarity: Use clear, accessible language tailored to various age and population groups, incorporate patient success stories, and maintain honesty and transparency when addressing public concerns.
- Trusted Spokespersons: Involve general practitioners and other relatable figures whom the public trusts as spokespersons.
- Managing Challenges: Anticipate potential challenges, such as language barriers and low public interest, whilst recognising that unusually high communication coverage may raise public suspicion.

Introduction, Challenges, Study Outcomes and Study Design

Introduction

The ability to access and reuse health data is essential for effective health system management and improvement, the digital transformation of healthcare, disease prevention, biomedical research and the development of drugs and health technologies. For over 30 years, Switzerland has recognised the need for digital transformation within its health system. However, this recognition has not yet resulted in the implementation of solutions that provide comprehensive access to health data for both healthcare professionals and patients at the national level. In addition to technical, legal and political obstacles, societal concerns are considered key barriers (Lingg & Lütschg, 2020; Martani et al., 2021). Researchers and healthcare organisations emphasise that maintaining high levels of public trust is crucial for the successful implementation and acceptance of health data sharing systems (Ghafur et al., 2020; Horn & Kerasidou, 2020; Williams & Fahy, 2019). The public places trust in the health system and its actors, expecting health data to be used in a way that generates a net benefit for both the health system and society. Public trust in health data sharing is crucial since it leads to public acceptance and support for these activities (Gille, 2023).

To advance the digital transformation of the Swiss health system, the Federal Department of Home Affairs (*Eidgenössisches Departement des Innern*, EDI), in collaboration with the Federal Office of Public Health (FOPH) and the Federal Statistical Office (FSO), has developed and initiated the DigiSanté programme. With a total budget of CHF 623 million (development loan of CHF 391.7 million), the DigiSanté programme aims to support and accelerate the transformation of the health system from 2025 to 2034 across four areas: Package 1 'Prerequisites for the Digital Transformation'; Package 2 'National Infrastructure'; Package 3 'Digitising Government Services'; Package 4 'Secondary Use for Planning, Steering and Research' (Die Bundesversammlung, 2024; FOPH, 2024). Package 4 focuses on designing the framework conditions for the efficient, secure, legally and ethically acceptable secondary use of health-related data for planning, steering and research purposes within the health data space (Federal Office of Communications, 2023).

Challenges

Although the Swiss political sphere emphasises the importance of public trust and trustworthiness in its healthcare system digitalisation efforts, there is limited evidence of how past experiences with data-sharing have shaped current public trust, and how the Swiss public perceives trustworthy secondary use within a health data space (Schweizerische Eidgenossenschaft, 2023). This knowledge gap poses a challenge to the evidence-based development of a trustworthy data space for health-related research in Switzerland.

Study Outcomes

This report presents the following:

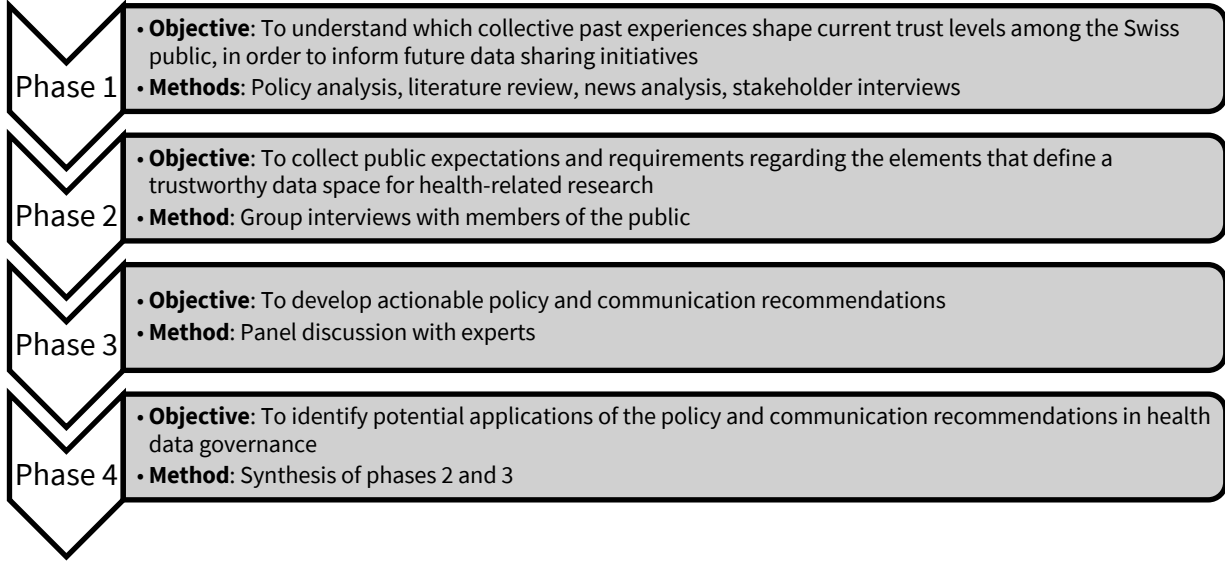
- An overview of 31 years of socio-political discourse on health data sharing in Switzerland (p. 19)
- Policy recommendations for building a trustworthy data space for health-related research (p. 29)
- Recommendations for effectively communicating about a trustworthy data space for health-related research (p. 33)
- Next steps for health data governance, based on policy and communication recommendations (p. 35)

Study Design

A research team from the Digital Society Initiative at the University of Zurich, Switzerland (study lead: Dr. Felix Gille) conducted a multi-method study in 2023/2024, placing Swiss civil society and relevant stakeholders at the centre of the research project. The study design followed four phases (**Figure 1**), which were informed by a multi-stakeholder workshop in June 2022 with 14 participants from politics, industry, patient groups, research, and civil society. The methods used for this project are presented in the **Methods** section, pages 38-40.

As a key qualitative research method, interview studies can offer rich insights into participants' experiences and perceptions, making them essential for understanding complex phenomena such as trust in health data spaces. Their strength lies in the in-depth exploration of views. However, their typically small sample sizes (when compared to national surveys) tend to limit the generalisability of their results. Qualitative research prioritises depth and context over broad representation. To enhance generalisability following this study, future research should incorporate quantitative methods, replication and triangulation.

Figure 1 Study Phases



Why is Public Trust in Health Data Sharing Relevant?

Public trust in the health system is fundamental to the successful introduction of national health data sharing initiatives, such as national electronic health record systems or health data spaces, which can be used to share data for both primary and secondary use. Unlike a private individual or a professional, the term ‘public’ refers to the entire community of individuals within a nation. When the public trusts the health system and its actors with their health data, they are more likely to support and participate in health data sharing initiatives. In contrast, public suspicion and low levels of trust can lead to health system inefficiencies, prolonged implementation processes, increased costs or even the failure of such initiatives.

In the broad context of health data sharing and digital health, public trust is built in anticipation of a net benefit, comprising personal, societal and health system benefits. For example, the public shares their health data for research purposes with the anticipation that the research outcomes will improve care quality, enhance efficiency or lead to the development of new treatment methods. This benefits not only a single patient but also the wider present and future society, including health system actors themselves. In the spirit of communal benefit, it is important to consider that data donation or sharing activities can be driven by public altruism. Therefore, when altruistically shared data are used by private companies for their own research and development, it is crucial to maintain a central focus on demonstrating how the research generates a wider positive societal impact beyond company profits or other interests (Gille, 2023).

In the public sphere, public trust develops through open public discourse about trust issues (Gille et al., 2017). These discussions occur in the news media, on social media and in public fora, where personal and collective experiences—alongside opinions on wider health system issues—contribute to shaping a collective understanding of trust. Recent examples include media coverage of the introduction of the Electronic Patient Dossier (EPD) and discussions about measures taken during the COVID-19 pandemic in Switzerland, where trust was a central theme in the public sphere. Since information exchange is the lifeblood of trust building, clear and targeted communication strategies are critical for successful trust building. Without truthful information that conveys clear benefits whilst addressing public fears and potential risks associated with new health system activities, public trust will not flourish.

The public builds trust based on positive past experiences with comparable health system activities, present perceptions of the health system’s ability to use data beneficially, and future expectations of beneficial outcomes from health data use. The close relationship between past experiences and trust is explained by a trust culture arising from ‘the collective and shared experiences of societal members over time’, defining trust culture as ‘a product of history’ (Sztompka, 1999, p. 99). Conferring trust requires consideration of all previous experiences since it can only be placed in a familiar setting (Luhmann, 1979). The public is likely to trust the health system with their data only if the conditions they associate with trustworthiness—derived from past experiences, present perceptions and future expectations—are met. Although common conditions for trustworthiness in the digital health domain centre around privacy protection, personal autonomy and data security (Gille, 2023), these conditions vary depending on the specific context and application.

In summary, public trust can be described as follows:

Public trust grows in the public sphere from open public discourse, legitimising the actions of the healthcare system. Public trust builds on information equally relating to past experiences, present perceptions and future expectations. Public trust is established in anticipation of a net benefit for both the public and the health system.

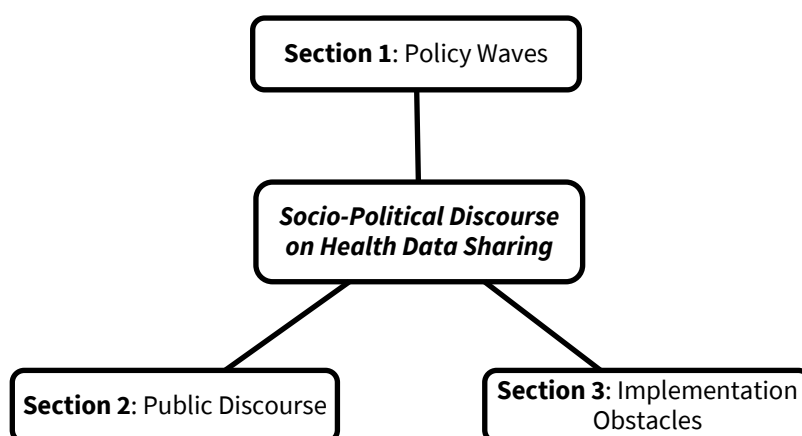
Phase 1: 31 Years of Socio-Political Discourse on Health Data Sharing

Past experiences with comparative digital health initiatives and other governmental digitalisation efforts outside the health system are crucial for understanding what potentially shapes public trust today. This is because positive past experiences with the health system can be ‘thought-provoking’ for the public, shaping their perceptions of data-sharing initiatives and, in turn, increasing their likelihood of trusting the health system in the future. Research suggests the existence of spillover effects, where individuals transfer their willingness to place trust from one societal context to another—even when the contexts are unrelated (Gille, 2023). For example, if the public perceives that the government can effectively protect data in the context of public administration and e-governance, they may be more inclined to trust the government with their health data in the digital health context.

Past collective experiences that influence public trust are largely shaped by three factors: media coverage, expert opinions and policies. The news narrative shapes public trust through the framing of topics, tone of reporting and story selection (Gunther, 1998; Mutz & Soss, 1997). Expert opinions also offer valuable insights into complex issues, contributing to the formation of public trust. On the other hand, conflicting expert opinions or controversies within the expert community can undermine public trust (Page et al., 1987; Greve-Poulsen et al., 2023). Policies and subsequent health system interventions are often the source of trust-related issues. At the same time, policies can enhance public trust by fostering a sense of security, certainty and predictability among the public. This perceived secure and predictable environment alleviates concerns and reinforces trust in the system (De Benedetto et al., 2020; Rochel, 2023).

Understanding how past collective experiences are formed is essential to adequately inform trust-building measures in current and future digital health initiatives, such as the proposal for establishing a Swiss data space for health-related research. Phase 1 of this study aims to inform the trustworthy implementation of the affected projects in DigiSanté by tracing the evolution of socio-political discourse around health data sharing in Switzerland from 1992 to the present. The findings are presented in three sections (**Figure 2**).

Figure 2 Elements Influencing the Socio-Political Discourse on Health Data Sharing



Section 1: Policy Waves Defining Data Sharing in Switzerland

Out of 86 policy documents identified in the policy analysis (description and references in **Appendix 1**), 44 were selected as key political milestones that, in our assessment, have shaped the discourse on health data sharing in Switzerland (**Table 1**). These policies are presented chronologically to provide an overview of the political

trajectory and evolving discourse on health data sharing in the country. We identified *two policy waves* that have shaped the country’s data-sharing developments.

This *first wave* of policies focused on establishing the legal foundation for the use of health data for primary purposes. This wave began in 1992 with the publication of the Federal Act on Data Protection, which categorised health data as ‘sensitive personal data’ and introduced the concept of explicit consent for the processing of personal data. Additionally, the Federal Statistics Act regulated the linkage of personal data across different databases. These were followed by the Health Insurance Act in 1994, which regulated the secondary use of data among multiple stakeholders for the first time. In 2001, five Swiss university hospitals launched the ‘Patient Dossier 2003’ initiative, which aimed to improve the use of computers in managing data and standardising the sharing of patient records. This marked the first systematic attempt to promote the use of digital patient files. 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. In 2007, the first Swiss eHealth Strategy was published, aiming to enhance the efficiency, quality, and security of electronic health services. This strategy responded to an assessment of Switzerland’s eHealth implementation status, conducted following the release of the European eHealth Action Plan in 2004. A key objective of the strategy was the gradual introduction of electronic patient records. In 2010, the Humbel Postulate 10.3327 urged the Federal Council to present the necessary legal basis to support the implementation of the eHealth strategy, leading the Federal Council to instruct the Federal Department of Home Affairs to establish the legal framework for the implementation of electronic patient records by September 2011. These policy developments culminated in the publication of the Federal Act on Electronic Patient Records (EPRA) in 2015, which provided a legal framework for data sharing for primary use in Switzerland.

The *second wave* of policy developments was catalysed by the COVID-19 pandemic, which highlighted Switzerland’s lag in healthcare digitalisation and underscored the need for a comprehensive healthcare digitalisation strategy and the use of data for research purposes, as reported in motion 20.3243 FDP_SR. In January 2022, the FOPH published a report on improving data management in healthcare, drawing on lessons from the pandemic and outlining seven guiding principles for future data management. In May 2022, the Federal Council responded to the 2015 Humbel postulate 15.4225, which called for improved health data reuse by directing the EDI to define the processes for the health data system and make the necessary legal adjustments. This led to several political initiatives, including the adoption of motion 22.3890 WBK_SR 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 November 2023, the Federal Council submitted a request for commitment credit to the Federal Assembly to finance the DigiSanté programme, which aimed to promote digital transformation in the healthcare system. This request was approved in May 2024, with Package 4 (‘Secondary use for planning, strategic management, and research’) focusing on establishing the necessary conditions for secondary data use within the Swiss health data space.

Table 1 Swiss Policy Documents and Events Shaping the Political Discourse on Health Data Sharing

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)
	Foundation 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 Ettlín Motion - Digital transformation in healthcare. Finally catch 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
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

Section 2: Events that Influenced the Public Discourse on Health Data Sharing

Between 1992 and the present, we identified a series of prominent events, including scandals, which influenced the socio-political discourse on health data sharing in Switzerland (**Table 2**). These events were viewed both positively (thought-provoking events) and negatively (negative events) by stakeholder interviewees.

Table 2 Thought-Provoking and Negative Events that Influenced the Socio-Political Discourse on Health Data Sharing

Thought-Provoking Events in the Socio-Political Discourse
1. Early 2000s: Digitisation of private life raised awareness about personal data-sharing
2. 2020: COVID-19 pandemic showed the potential benefits of a digital health system
3. Before 2021: 'Myvaccination' platform was a well-accepted digital solution
4. 2023: DigiSanté programme demonstrated commitment to advancing digital health
Negative Events in the Socio-Political Discourse
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 EPD initiative (2015–2024)
3. COVID-19 pandemic uncovered digitalisation gaps in the Swiss health system

Thought-Provoking Events in the Socio-Political Discourse

A major driver of the supportive discourse surrounding data-sharing initiatives has been the *digitalisation of private life*, which began in the early 2000s. This digitalisation, marked by the widespread use of the internet and mobile devices, increased public awareness of data flows and their implications. The *COVID-19 pandemic* then underscored the crucial role of digitised health data and, as noted by one interviewee, served as the '*awakening of the politicians*' (P04), prompting efforts to accelerate digitalisation within the Swiss health system. A prominent example is the SwissCovid Digital Contact Tracing App, which was viewed by some as a success due to its rapid development and high privacy standards. Following the pandemic, the '*meineimpfungen/Myvaccination*' solution and the decision to finance the establishment of the *DigiSanté programme* further contributed to the supportive discourse as they demonstrated the practical benefits of health data sharing and Switzerland's commitment to advancing its digital health infrastructure.

Negative Events in the Socio-Political Discourse

Factors that fuelled public scepticism about data-sharing developments were primarily driven by *scandals* both within Switzerland and globally. Among them, the 2013 Edward Snowden intelligence leak (Greenwald et al., 2013), along with data protection investigations into the 'Myvaccination/meineimpfungen' platform in 2021 (Trezza, 2021) and the 'Organ Donation/Swisstransplant' breach in 2022 (Le Temps, 2022) were mentioned by stakeholders as the most prominent scandals that negatively influenced the socio-political discourse on health data sharing in Switzerland. Additionally, the Electronic Identification Services (e-ID) referendum was noted for sparking debates around government involvement in the governance of sensitive data. Stakeholders, rather than the general public, viewed the outcome of this referendum as a negative development since it revealed a lack of public trust in the state. Nevertheless, stakeholders also noted that these harmful events did not significantly penetrate the wider public discourse. The 'Myvaccination' platform serves as an example of a digital

health initiative that was initially viewed positively but later shifted to having negative public perception. This pattern can be observed throughout the last 31 years of digital health policy in Switzerland, where high expectations from healthcare professionals and the public were unmet for various reasons.

A prominent example of initial expectations and positive discourses that shifted into negativity is the *slow implementation of the EPD*. The EPD emerged as a major, if not the single largest, factor contributing to widespread scepticism about data sharing in the Swiss public discourse. The extensive reach of this sentiment is highlighted by a stakeholder who noted the following in an interview: *‘It’s not really a scandal; it’s just a 1000-time repeated story and myths about the EPD. I think it’s not doing good for the system’* (P05). An analysis of news articles from 1998 to 2023 revealed a generally negative tone when reporting on health data sharing, with a gradual shift towards more negativity after the publication (2015) and enforcement (2017) of the EPRA. Articles reported delays in implementation, inefficiencies, security concerns and the accusation that the federal government and the cantons lacked a *‘holistic vision’* (Birrer, 2023), referring to the EPD initiative as *‘the small failure of a modern state’* (Zürcher & Schaad, 2023). A similar trend was observed in expert opinion papers, where the tone became increasingly negative from 2016 to 2021. For instance, a 2016 editorial from the Federation of Swiss Doctors (Foederatio Medicorum Helveticorum - FMH) criticised the high regulatory requirements of the newly published EPRA (Gilli, 2016) and labelled the EPD as a *‘monster that will never work’* (Huber, 2022). However, by the end of 2022, the tone became more neutral in response to EPRA revisions (Zimmer, 2022) and the launch of a national awareness campaign to accompany the introduction of the EPD (Zimmer, 2023).

Lastly, while the *COVID-19 pandemic* fostered supportive discourse around data-sharing, exemplified by the SwissCovid app, it also revealed significant scepticism by exposing the Swiss healthcare system’s heavy reliance on paper-based practices, highlighting the considerable work required to advance its digitalisation efforts.

Section 3: Implementation Obstacles for Swiss Data Sharing Initiatives Over the Past 31 Years, with a Focus on the EPD

This section outlines the obstacles identified concerning the implementation of past health data-sharing initiatives in Switzerland. These obstacles are grouped into four areas (**Table 3**), which can help inform the implementation efforts of the affected projects of the DigiSanté programme. The EPD was by far the most frequently cited data sharing initiative in stakeholder interviews. Although the EPD pertains to the sharing of data for primary use rather than for health-related research, as envisioned for the Swiss health data space, it remains the first and only nationwide health data sharing initiative familiar to Swiss stakeholders, making it natural for them to refer to this initiative.

Table 3 Implementation Obstacles Identified through Stakeholder Interviews, Listed in Descending Order Based on the Frequency of Mention

Implementation Obstacles for Swiss Data-Sharing Initiatives Over the Past 31 Years – Focus on the EPD
Policy
- Misalignment of stakeholder interests with power dynamics among various actors
- Cultural attitudes and individualistic approaches towards data-sharing
- Pace disparity: policy process lagging behind digitisation
- Challenges posed by federalism
- Lack of obligation to consent for data-sharing initiatives
- Limited public involvement in policymaking
- Absence of legal framework for the secondary use of health data
- Insufficient funding for the implementation of initiatives

Public
- Lack of public awareness regarding the potential use 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 involvement in the policy process Lack of direct financial incentives to support their digital transition
Technical
- Challenges with interoperability (unstructured/siloed data)

Over the past 31 years, *policy obstacles* stem from the mismatch between the rapid pace of technological advancements and slower policymaking processes, leading to difficulties in policy implementation. Conflicting stakeholders' interests and decentralised governance structures have resulted in disagreements over common standards and the absence of a unified strategy. Cultural resistance to data-sharing, driven by individualistic motivations and a lack of understanding of broader benefits, has also emerged as a significant obstacle. Furthermore, voluntary participation in the EPD, coupled with limited public involvement in the policymaking process, has led to inconsistent adoption. Finally, the lack of a legal framework for the secondary use of health data, compounded by limited funding resources, presents significant obstacles to the implementation of large-scale data sharing initiatives such as the EPD.

A lack of *public* awareness regarding the benefits and opportunities of data sharing initiatives presents a significant obstacle to their implementation. Compared to neighbouring countries, Switzerland is only beginning to engage in public discourse around data sharing for primary use, with information campaigns on the EPD targeting healthcare professionals starting in June 2023 and the public only in 2024 (Zimmer, 2023b). This delay represents a missed opportunity for policymakers to effectively address public concerns and shape the dialogue at an early stage. Stakeholders reported that no substantial public discourse on health data sharing for secondary purposes exists in Switzerland. However, from the limited public input collected so far, key concerns regarding health data sharing initiatives include privacy and security issues, including fears that sensitive health data could be accessed by entities with questionable intentions, such as insurance companies seeking to profit from this information. Overall, stakeholders pointed to a cultural resistance to change among the Swiss public, given the highly functioning Swiss healthcare system. This, along with the non-user-friendly interface and the complex registration process, were reported as barriers to the implementation of the EPD, as highlighted by one stakeholder: *'The opening of an EPD is considered to be very complicated. [...] I think people just want a very easy-going, convenient solution. As long as that's not offered, and of course, free of charge, then people will just not go [for it]'* (P05).

Healthcare professionals, particularly physicians, serve a pivotal role in the implementation of health data sharing initiatives since they directly influence both health policy processes and public opinion. From the perspective of healthcare professionals, four main obstacles to the implementation of health data sharing initiatives in Switzerland were identified: the limited perceived benefits of the initiative, their poor involvement in policymaking, the absence of appropriate direct financial incentives, and concerns about the trust relationship with

patients being endangered by data sharing initiatives. Interviewees reported that healthcare professionals remained reluctant to support the EPD, with many inconsistently advocating for it to their patients, which in turn erodes patients' trust in the EPD.

Lastly, *technical obstacles*—mainly in the form of a lack of interoperability between software systems—remain a significant obstacle, as highlighted by a stakeholder commenting on generic data use: *'[In Switzerland, there are] still silos [...] you cannot use this data for secondary use because the semantic model is unclear. It's bound to the data silos; so that's the situation from 1998 until today' (P10)*. The quality and unstructured nature of data were also cited as obstacles to data-sharing, underscoring the importance of establishing competence centres to harmonise this data.

Conclusion

The ongoing sceptical discourse around the EPD, compounded by national and international scandals, largely frames public trust in health data sharing at present in Switzerland. Notably, this serves as the Swiss public's reference point for national health data sharing initiatives. Since discussions on the secondary use of health data have not yet entered the public sphere, it is crucial to learn from the obstacles faced during the EPD implementation process and extract valuable lessons that can be applied to upcoming health data sharing initiatives. It is important to recognise that digital health experts may not necessarily see a connection between the introduction of the EPD and the establishment of a health data space. However, from a lay citizen's viewpoint, both are closely linked since both of these initiatives involve data sharing and are partly associated with the government, which is perceived as responsible for the health data space.

At the policy level, it is recommended that the coordination of the initiative be centralised at the federal level whilst fostering active collaboration among stakeholders to align interests and promote cooperative efforts towards common goals. At the public level, a comprehensive engagement strategy is advised, focusing on implementing effective, user-friendly solutions that provide citizens with autonomy of choice. Additionally, monitoring the narrative surrounding the initiative and adopting a proactive approach to trust-building are essential steps. Healthcare professionals should be involved in the development of the solution and policymaking process from the outset and should receive financial incentives to support their digital transition.

Phase 2: Future-Oriented Case Studies for Public Focus Groups

A visualisation of how a health data space may operate in the future is necessary to guide meaningful discussions on the conditions that would make the health data space trustworthy from the public’s perspective. To facilitate this explorative process with members of the public, we introduced the interview group participants to four fictitious case studies that do not reflect current practice but address critical aspects of health data sharing for secondary purposes. These aspects include 1) different consent management systems, 2) the use of personal identifiers for record linkage, 3) the roles and governance of a hypothetical national data coordination centre (NDCC) that links, facilitates and controls the flow of data, and 4) health data sharing across borders. These case studies were developed by the research group based on discussions with project advisory group members from the FOPH, with a focus on data sharing and specifically on promoting secondary data use in a national health data space. The case studies were also informed by policy documents and further input from the broader advisory panel. Each case study aimed to describe potential future scenarios for a data space that supports and facilitates health-related research, using fictional scenarios to make the concepts more understandable and tangible for the lay public. Key terms were explained to participants. Text, images and verbal explanations were used to ensure that they all understood the case studies discussed in the focus groups. The case studies are outlined in **Table 4** and described below.

Table 4 Description of Case Studies

Case study	Description
1) Consent Management	Consent to the reuse of data by means of a nationally harmonised digital consent management system
2) Record Linkage via Social Security Number (AHV number)	Using a personal identifier as a linkage variable for research
3) National Data Coordination Centre (NDCC)	An NDCC links, facilitates and controls the flow of data
4) Cross-Border Data Exchange	Cross-border data exchange takes place through the NDCC

Case Study 1: Consent Management

In this case study, three potential consent management models were presented and discussed with focus group participants.

1.a) Informed Opt-In Consent Model for the Sharing of (Health-Related) Personal Data

A nationwide digital consent management system facilitates the collection of electronic consent for data sharing within the health data space. To use this system, individuals require a smartphone or computer and must log in via an app or website using their Swiss-ID. The system allows them to view their health-related data, such as electronic patient records, alongside other personal data (e.g. tax information).

Interview participants were presented with two possible consent options:

- *General Consent:* One-time consent for research on data collected in the present and future, including: a) electronic patient records, b) genetic data, c) health insurance data, d) social security data, and e) tax data. This general consent permits the use of their data within the health data space.
- *Dynamic Consent:* A model offering ongoing control over data access. Individuals receive requests for consent for each research project involving their data. Without their explicit consent, their data will not be shared.

Additionally, individuals can donate extra data through an online portal if they believe the data are relevant for research, such as physical activity data or data on their consumption behaviour.

1.b) Informed Opt-Out Consent Model for the Sharing of (Health-Related) Personal Data

With the appropriate legal basis, an opt-out system allows for pseudonymised data to be made available within the health data space through the NDCC to researchers upon request, even after an individual's death. These data include a) electronic patient records, b) genetic data, c) health insurance data, d) social security data, and e) tax data.

If individuals choose not to consent to this data sharing, they have the option to object and opt-out. From that point onward, their data will no longer be accessible for research within the health data space. However, any data already released for secondary use prior to the objection will continue to be processed within the respective projects until their completion.

Additionally, individuals can donate extra data through an online portal if they believe the data are relevant for research, such as physical activity data or data on their consumption behaviour.

1.c) Informed 'Value-Based' Opt-Out Consent Model for the Sharing of (Health-Related) Personal Data

With the appropriate legal basis, the following pseudonymised data will be made available within the health data space, through the NDCC, to researchers upon request—even after an individual's death. These data include a) electronic patient records, b) genetic data, c) health insurance data, d) social security data, and e) tax data.

If individuals choose not to agree with this data sharing, they can file an objection for a specific data use purpose (e.g. studies on insurance premiums or university cancer research). From that point onward, their data will no longer be accessible within the health data space for that particular research purpose. However, any data already released for secondary use prior to the objection will continue to be processed within the respective projects until their completion.

Additionally, individuals can donate extra data through an online portal if they believe the data are relevant for research, such as physical activity data or data on their consumption behaviour.

Case Study 2: Record Linkage via the Social Security Number (AHV Number)

A research team from the University of Geneva, in collaboration with a Swiss health insurance company, requests a dataset from the NDCC to assess social inequalities in healthcare provision. The study specifically aims to determine whether social status and income influence patient treatment. The dataset includes a) hospital care data and b) tax data, which are compiled by the NDCC. The Social Security Number (AHV number) is used to link the records, thereby ensuring the accurate matching of information from both data sources for each individual.

The research director submits a request to the NDCC. The request is reviewed by the NDCC for feasibility from legal, ethical, scientific, and technical perspectives, including an assessment of the data provider's consent (if required). After a positive evaluation in all four areas, the research director is granted access to the requested anonymised dataset within the secure infrastructure of the health data space, meaning no primary records are sent out. The NDCC charges for this service.

Case Study 3: National Data Coordination Centre (NDCC)

The NDCC oversees data flow within the health data space and links records for health-related research. A start-up in Basel is developing a comprehensive digital care infrastructure for cancer treatment, with the goal of enabling personalised precision medicine to improve cancer prevention, early detection and treatment. For this

research, the start-up requires a dataset consisting of a) electronic patient records, b) genetic data, and c) insurance data.

The research director searches the NDCC's data catalogue and identifies the necessary data sources. The research director submits a request to the NDCC. The request is reviewed by the NDCC for feasibility from legal, ethical, scientific and technical perspectives, including an assessment of the data provider's consent (if required). After a positive evaluation in all four areas, the research director is granted access to the requested anonymised dataset within the secure infrastructure of the health data space, meaning no primary records are sent out. The NDCC charges for this service.

Case Study 4: Data Exchange

4.a) Monitoring of Infectious Diseases

The European Centre for Disease Prevention and Control (ECDC) in Stockholm collects and analyses anonymised health data to monitor the spread of infectious diseases within the European Union. Surveillance systems provide information that is used to track trends in communicable diseases and help identify risk factors and areas requiring intervention. This information supports the prioritisation, planning, implementation, resource allocation and evaluation of prevention programmes and control measures. In collaboration with the Swiss FOPH, Switzerland is integrated into the monitoring system. Anonymised data, including doctor and laboratory reports, is transmitted from the Swiss mandatory reporting system for infectious diseases to the ECDC. The FOPH has been routinely collecting this type of data for years, and data records are transmitted weekly within a secure infrastructure.

4.b) European Research Consortium on Colorectal Cancer

A European research consortium comprising university research groups and pharmaceutical companies aims to study colorectal cancer to develop better treatment methods. The consortium is led by three research groups based at universities in England, Switzerland and Poland, and is funded by public and industrial grants. The participating pharmaceutical companies operate globally, with headquarters in Switzerland and England.

For the research project, information from a) electronic patient records, b) genetic data, c) health insurance data, d) social security data, and e) hospital care data are linked using a personal identifier and then anonymised. The data integration is conducted in Switzerland by the NDCC, and the data records are provided within a secure infrastructure. The combined dataset is deleted after the project's completion.

Phase 3: Recommendations

3.a) Policy Recommendations

Based on discussions from the focus groups with members of the public, as well as a panel discussion with experts, we developed four main categories of policy recommendations following the structure used in the four fictitious case studies. These recommendations are supported by implementation guidance to assist policy-makers in effectively translating them into practice. Importantly, the policy recommendations were developed under the assumption that the health data space and data reuse activities adhere to the following principles:

- Economic self-sustainability
- The highest security and privacy protection standards
- Legal compliance
- Public accountability (including a sanction system for misconduct)
- Research ethics
- Research standards

As outlined in **Table 5**, the first category of policy recommendations, along with its implementation guidance, focuses on consent management.

Table 5 Consent Management - Policy Recommendations and Implementation Guidance

POLICY RECOMMENDATIONS	IMPLEMENTATION GUIDANCE
CONSENT MANAGEMENT	
Informed	
Ensure that the public is adequately informed to enable them to make appropriate choices	<i>The consent management system should clearly state how privacy is protected within the data sets that research teams are granted access to, who the research actors involved are, the overall purpose of the research study for which the data are required, and whether the consent is valid for existing data, future data, or both.</i>
Consent Model	
Design the consent management system to be user-friendly	<i>The consent management system should ensure an easy user experience by using appropriate language and tone. Additional support must be provided for individuals who face difficulties in giving consent or those lacking the capacity to do so.</i>
Adopt an informed value-based opt-out consent model since this is favourable from both public and research perspectives	<i>The consent management system should be opt-out by default, with the public being duly informed about the general nature of the research for which their consent is valid. Interested individuals can log in to the consent management system and deselect the areas of research they do not wish to participate in based on their personal preferences.</i>
Alternative: Implement an informed dynamic consent model (opt-in) for individuals willing to invest time in consent decisions over an extended period	<i>The consent management system should notify individuals when there are updates regarding the use of their data and offer them the option to re-confirm or withdraw their consent.</i>
Reminders	
Send annual reminders to the public to remind them of their right to review and update their consent preferences	<i>The consent management system should send annual reminders to individuals, informing them that they can update their consent preferences. Information about achievements made from data in the data space could be included to update the public.</i>
Data Use After Death	
Provide data control options allowing individuals to set conditions for data use	<i>The consent management system should provide an option for individuals to set a deadline (i.e. expiry date) for the use of their data.</i>

after death, or set an expiry date for their consent	
Data Removal	
Incorporate the ability to remove data as part of the consent management system	<i>The consent management system should provide the option for individuals to request the complete removal of their data from the data space.</i>

The public representatives who participated in the focus group discussions, as well as the experts consulted in the panel discussion, emphasised the importance of transparency from the actors involved in seeking consent for their research project. They highlighted the need to clearly communicate the project’s purpose and intended impact in an understandable and accessible manner to ensure that individuals can opt-out based on their values and an informed understanding. Additionally, there was a strong emphasis on making the consent management system easily accessible to all individuals through methods such as providing information in different languages and formats. The consent models discussed in the focus groups were the a) opt-in consent model (general consent versus dynamic consent), b) opt-out model, and c) ‘value-based’ opt-out model. Discussions centred on dynamic consent- and value-based opt-out models, with both being perceived as interesting and useful options. However, when considering feasibility and the need to aggregate large datasets at the population level, focus group participants often favoured the value-based opt-out model. Importantly, similar to being fully informed during a traditional informed consent process—as typically conducted prior to participation in a research study—the value-based opt-out model also requires a similar level of accompanying information. Hence, we refer to this as an *informed value-based opt-out model*.

As shown in **Table 6**, the second category of policy recommendations, along with its implementation guidance, focuses on record linkage.

Table 6 Record Linkage - Policy Recommendations and Implementation Guidance

POLICY RECOMMENDATIONS	IMPLEMENTATION GUIDANCE
RECORD LINKAGE	
AHV Number	
Establish a unique and secure identifier for data linkage	<i>A unique identifier system, such as an encrypted AHV number or alternative identifier, should be established to facilitate the linkage of various datasets.</i>
Establish and enforce measures to prevent the misuse of AHV numbers by NDCC staff	<i>Consider using AHV numbers under strict protective measures and implement controls to ensure that NDCC staff cannot access the data unless it is in an anonymised form.</i>

Overall, there was a general consensus that the governance structure or charter of principles for the health data space must clearly outline the security measures implemented for identifiers, such as the AHV number. The use of AHV numbers for data linkage was controversially discussed in the interviews. Participants’ opinions ranged from supporting its use as a logical option due to its widespread distribution to expressing concerns about using the AHV number at all since it is perceived as highly personal information. The governance structure should include details on how these security measures are made transparent, and how specialists and controls are in place to prevent re-identification. Additionally, the scope of record linkage and the actors involved must be communicated transparently. Providing traceability for individuals to track their own data and its access was suggested as a means to enhance transparency and accountability.

As outlined in **Table 7**, the third category of policy recommendations, along with its implementation guidance, focuses on the NDCC.

Table 7 NDCC – Policy Recommendations and Implementation Guidance

POLICY RECOMMENDATIONS	IMPLEMENTATION GUIDANCE
NATIONAL DATA COORDINATION CENTRE (NDCC)	
Finance	
Ensure that the NDCC is financially self-sustaining	<i>A self-sustaining financing model should be established to ensure that the costs of the NDCC, including the data space, are not passed onto the public.</i>
Leverage synergies within the NDCC to enhance efficiency	<i>Synergies can be sought with other ongoing digitalisation efforts, such as the EPD system.</i>
Governance	
Ensure that the NDCC operates independently and maintains neutrality	<i>No parties with a conflict of interest should be involved in NDCC governance.</i>
Establish the NDCC as a public entity	<i>The NDCC should be governed as a public institution and be accountable to the public.</i>
Ensure that the NDCC governance body includes public representatives and diverse professional groups, such as general practitioners (GPs), researchers, IT specialists and politicians	<i>NDCC governance should comprise public representatives and patient experts to ensure a diversity of perspectives. Provisions for external independent oversight can be included.</i>
Ensure that governance procedures are transparent and publicly accessible	<i>The governance model of the NDCC should state:</i> <ul style="list-style-type: none"> - <i>at which points in the data sharing process actors are involved and for which duties;</i> - <i>the anonymisation procedures undertaken;</i> - <i>the relevant certifications required to perform certain tasks; and</i> - <i>the access control measures in place.</i> <i>Provisions should be made to state a designated contact person for each specialised area from which data may be requested.</i>
Federal level	
Establish the NDCC at the federal level	<i>The NDCC should be governed at the federal level, with additional considerations made to ensure meaningful involvement of the cantons.</i>
Evaluate the potential risks associated with centralising the NDCC	<i>Considerations should be made to determine whether centralised governance carries the risk of a power monopoly.</i>

The NDCC should be a centre of expertise, with external oversight to ensure that its operations remain transparent, efficient and in line with best practices whilst maintaining public trust and accountability. Overall, there was a general consensus that governance should reside primarily within the public administration. For the NDCC to be perceived as trustworthy, emphasis was placed on the involvement of public representatives within the NDCC governance body. However, it was also recognised that other actors, such as university representatives, should be involved at appropriate stages, particularly during implementation. Additionally, designated contact persons should be available for handling data requests.

As outlined in **Table 8**, the fourth category of policy recommendations, along with its implementation guidance, focuses on cross-border data exchange.

Table 8 Cross-Border Data Exchange - Policy and Implementation Guidance

POLICY RECOMMENDATIONS	IMPLEMENTATION GUIDANCE
CROSS-BORDER DATA EXCHANGE	
Data Governance	
Apply Switzerland’s data governance rules to all data access requests originating from foreign countries	<i>Requests for foreign data access should be subject to the same control procedures as those for national data access.</i>
Data Quality	
Ensure that data from foreign countries meets high quality standards	<i>Checks (e.g. through a checklist or certification) should be implemented to ensure that the data quality standards for international data are met.</i>
Value Systems of Collaborating Countries	
Ensure that the public values and norms of Switzerland are upheld by foreign countries that utilise Swiss data	<i>Foreign data access requests and their evaluation should include assessments of research, societal values and norms.</i>

Among public representatives in focus groups and experts, discussions primarily centred on ensuring high standards of data quality and protection across all stakeholders. The essential role of the NDCC in enforcing these standards whilst facilitating data transfers was also emphasised. It will be essential to ensure governance conformity for cross-border data exchange between the Swiss health data space and the European Health Data Space.

3.b) Communication Recommendations

Communicating truthful information about the benefits and risks of the health data space is fundamental to building public trust. Without well-planned and appropriate communication strategies, public trust cannot be established. Based on discussions from the focus groups and with experts, a set of communication recommendations was developed, as outlined in **Table 9**. These recommendations are accompanied by implementation guidance to assist policymakers in effectively implementing them.

Table 9 Communication Recommendations and Implementation Guidance

COMMUNICATION RECOMMENDATIONS	IMPLEMENTATION GUIDANCE
Format	
Use different communication channels (e.g. TV, print news, social media, information webpage) to reach different segments of the public	<i>Public communication campaigns should use messaging analogous to initiatives such as blood donation campaigns to emphasise the societal relevance of the health data space across various media channels. Successful projects using data from the health data space can be showcased in these campaigns. A designated website for the health data space should regularly provide updates on its progress and associated projects, and offer members of the public the opportunity to provide feedback. Targeted communication efforts should be directed towards population groups that are underrepresented in health research in Switzerland.</i>
Use public exchange fora to engage the public and offer them the opportunity to speak directly with experts	<i>Public exchange fora should be held at key stages of the health data space's development, from the early definition phase to the implementation stage. These fora should involve relevant stakeholders, including patients, patient experts, members of the public, researchers, medical professionals, nursing staff, medical practice assistants, pharmacists and IT experts. Smaller-scale public involvement initiatives should be undertaken with harder-to-reach population groups to gather insights into their requirements and expectations for participation in the health data space.</i>
Content	
Use tangible and understandable language tailored to different age and population groups to address public concerns (see Table 10)*	<i>Communication content should be developed to alleviate public concerns (e.g. through a frequently asked questions section on a website) covering topics such as data security, record linkage and the informed consent (opt-in) versus opt-out approach. Information should be made available in multiple languages to reflect the diversity of the Swiss public.</i>
Leverage patient success stories	<i>Patient success stories should be included in communications to illustrate the benefits of data-sharing and use.</i>
Ensure honesty and transparency in all communications	<i>Communication should be honest and transparent.</i>
Spokesperson	
Involve GPs and individuals whom the public identifies with	<i>Tangible and relatable spokespersons should be selected to communicate about the health data space so that the public can more easily identify with them.</i>
Caution	
Overcome challenges in reaching larger segments of the public by addressing language barriers and low levels of interest	<i>Communication strategies should consider how to engage harder-to-reach population groups and those demonstrating little or no interest in health data sharing.</i>
Avoid unusually high communication coverage to prevent raising public suspicion	<i>Excessive communication may backfire and undermine the objectives of the communication strategy since unusually high coverage can be met with suspicion.</i>

Public representatives and experts emphasised the need to maintain an open dialogue between the public and key actors within the health data space, including organisations responsible for secondary data use for research purposes. It was highlighted that clearly communicating both the societal and individual relevance of projects emerging from the health data space is crucial. Regular public engagement to gather feedback on the work being done within the health data space should be prioritised, with communication strategies adapting in response to public feedback. This includes addressing public concerns and fears, as well as emphasising the benefits of the research conducted within the health data space. The spokesperson for communication efforts must be trustworthy, with suggestions indicating that GPs could serve as key communication channels with their patients. Politicians were also identified as important figures in public communication efforts. Fears and concerns regarding the data space for health-related research are presented in **Table 10**.

Table 10 Fears and Concerns Regarding the Health Data Space for Health-Related Research

FEARS & CONCERNS*
- Data misuse fears
- Data security fears
- Data theft fears
- Delays in implementation due to prolonged political deliberation
- Equal access
- Fears of NDCC misconduct
- Fears of unnecessarily large sample sizes for research
- Financial burden
- Forcing the entire population to consent to data-sharing
- Hyper bureaucracy
- Medical staff burden
- Power monopoly concerns due to centralised NDCC governance
- Privacy concerns
- Protection of minors
- Record linkage fears
- Swiss data being accessed by non-EU states

Public concerns largely focus on the concentration of power that centralising the governance of a potential NDCC would place in the hands of federal authorities. This sentiment aligns with previous policy recommendations, which emphasised the importance of involving relevant stakeholders, including representatives from politics, academia and the public, in the governance of the health data space to ensure balanced oversight and protect public interests. Public concerns also focus on privacy protection within the health data space, whether the data will be used solely for its intended purposes, and the security of the data against theft once it is centralised. These issues underscore the need for strict safeguards and responsible data practices. Communication strategies must address these concerns proactively. Lastly, concerns extend to the financial burden of developing, implementing and maintaining the health data space, along with fears that its introduction may be delayed by excessive bureaucratic processes.

Phase 4: Potential Application of Recommendations in Health Data Governance

Drawing from the insights gathered through this project—and in combination with existing scientific knowledge—this section explores potential applications of the study’s findings for the governance of a health data space in Switzerland. The aim is to stimulate discussions among stakeholders responsible for the design and implementation of the health data space.

Swiss Digital Health History: What Can We Build Upon?

In December 2023, the Federal Chancellery Digital Switzerland (*Bundeskanzlei Digitale Schweiz*) stated the following in their monitoring report: ‘Switzerland is still in the early stages of digitalising its healthcare system and is not very developed’ (Swiss Confederation, 2023). Past experiences with the health system and national digital health initiatives influence current public trust building. The last 31 years of digital health history in Switzerland have provided us both with opportunities and great challenges. The most significant challenge identified in our project, as well as in other comparative studies on trust building, is the cumbersome introduction of the EPD, which has left members of the public puzzled about the ability of the government to manage and implement large-scale national digital health initiatives. From an expert perspective, the introduction of the EPD is not necessarily linked to the establishment of a national health data space or the improvement of conditions for secondary data use. However, from a lay person’s perspective, both may be perceived as interconnected efforts by the government to build a national infrastructure for health data sharing. In the present study, focus group participants discussed the extent to which a functional EPD system is essential to the success of a meaningful health data space since the EPD provides a valuable dataset for research.

In the interviews, we frequently observed that many participants considered the topic of health data sharing and the secondary use of health data as largely uncharted territory. Stakeholders noted that discussions on the secondary use of health data have yet to penetrate the public sphere. Considerable knowledge gaps also exist, making it difficult for lay people to form an informed (i.e. evidence-based) opinion on data sharing initiatives. As a result, a substantial portion of the interviews had to be dedicated to explaining key concepts with the help of infographics, thus confirming that the general topic of this study is not part of common public knowledge. A 2022 study suggests that self-rated digital literacy is 72% among Swiss citizens (Holenweger, 2022); however, knowledge about and use of digital health applications in Switzerland is declining (Golder et al., 2023). Moreover, several recent studies have shown that the public is willing to share various types of health data for different research purposes, provided that privacy, anonymisation, public health benefits and the trustworthiness of data processing institutions are upheld. In line with this, in a 2022 survey, 74% of the Swiss population reported that they are willing to share their data for medical research (Pletscher et al., 2022). Similarly, a 2021 study found that 53.6% of survey respondents expressed their willingness to participate in personalised health research studies (Brall et al., 2021).

Beyond the context of health data sharing and medical applications (e.g. digital health apps), and considering the potential for spillover effects in trust building, it is important to note that the Swiss public may not be accustomed to e-governance or high levels of digitalisation in their interactions with local government authorities. One example is the prolonged implementation of the e-ID. If other government sectors relevant to the daily lives of citizens outside of the health system were consistently digitised, we anticipate that positive overall experiences could support new government-led digital health initiatives.

We can conclude that the complex landscape of public understanding and support for health data sharing and research in Switzerland indicates that trust-building efforts related to the establishment of a health data space a) cannot rely on a foundation of positive collective public experiences, and b) require careful planning and

communication to address public opinion shaped by previous digitalisation efforts in Switzerland and the resulting biases.

Communication Strategy: How Can We Engage With the Public?

Effectively communicating easy-to-understand and truthful information about the direct benefits and potential risks associated with the secondary use of health-related data within a health data space infrastructure is of critical importance. The communication recommendations outlined above provide initial insights into what focus group participants believe can make the health data space trustworthy. Previous research further supports these findings, proposing that the following steps are considered when designing a communication campaign aimed at building trust in a digital health initiative:

1. 'Understand the present and historical context, as well as the actors involved in the health system.
2. Understand the mechanisms that are fundamental to building public trust.
3. Understand how public trust-building actions are embedded within the wider societal and political context.
4. Communicate via credible and reputable spokespersons.
5. Make the information easily understandable and tangible, and tailor it to different target audiences.
6. Convene public discussion fora.
7. Meaningfully engage and involve responsible actors when developing a consistent communication strategy.
8. Provide opportunities for public engagement and feedback when developing and implementing communication strategies.
9. Consider the potential impact of conspiracy and misinformation on the public trust-building processes.
10. Develop a contingency plan for events that may erode public trust.' (Gille, 2023, pp. 90–91)

Consent Model: How Can We Combine Personal Autonomy and Feasibility?

In the present study, we primarily explored three different consent models during focus groups with members of the public: a) the opt-in consent model (general consent versus dynamic consent); b) the opt-out model; and c) the 'value-based' opt-out model. Although other consent models exist, we focused on these three, assuming they represent workable solutions for the Swiss health data space. In the interviews, discussions were predominantly focused on the dynamic consent- and value-based opt-out models. This does not imply that the opt-out model was disregarded, but rather that the other two models were viewed as more appealing.

We observed reflective discussions about the different consent models, where focus group participants weighed their personal views against public and research interests, along with broader societal perspectives and practical feasibility. Although several interviewees initially favoured the dynamic consent model, they reconsidered their position whilst also reflecting on the potentially high workload and need for continuous engagement and self-motivation required by the dynamic consent process. Interviewees questioned whether a significant portion of the Swiss public is sufficiently motivated and willing to participate in such a model over an extended period. Despite these discussions being hypothetical, towards the end of the case studies we consistently witnessed an opinion shift towards favouring the value-based opt-out model. Under the pre-conditions of being fully informed, having an easy user experience with the consent system and receiving reminders about the option to revoke consent for specific research topics or entirely, the value-based opt-out model was considered a feasible consent solution for the health data space. Additional features of the consent model should include the ability for users to make decisions about data use after death and the deletion of their data.

Health Data Space Governance: Which Governance Structures Enjoy Public Support?

To build public trust, it is essential to view it as a foundational element of health data governance. Building public trust will require leadership, commitment and resources at the executive level. Maintaining a sustained focus on public trust through active engagement with the Swiss public during the design, implementation, provision and evaluation phases of health data space governance is crucial for effectively building and maintaining public trust. Without this ongoing commitment, fostering meaningful public trust becomes significantly more challenging. The deep integration of public trust as a design principle and performance indicator of high-quality health data space governance is essential. It may also be beneficial to include public trust as an indicator in the performance appraisal of the health data space governance board itself.

In this study, focus group participants identified independence, the representation of all stakeholders, financial self-sustainability, efficiency, public ownership and transparency as key considerations for trust building. Whilst participants unanimously agreed that a governance structure located at the federal level appeared to be the most effective, they emphasised that such centralisation should be implemented with careful attention to power balance and the inclusion of stakeholder interests.

Record Linkage: Which Identifiers Can Be Used to Link Data?

After consent models, data linkage was the most frequently discussed topic during the focus groups. Interestingly, we observed that many discussions, which initially began on a critical note, shifted to a more positive tone once participants were provided with additional information on data protection measures. Once again, this highlights the importance of effective communication strategies.

Despite the need for protective measures to prevent potential data misuse during the data linkage process itself, a key issue raised was the choice of identifiers for linking data. In the case study, we introduced the use of the AHV number to interviewees, which elicited a range of responses from full support to rejection. This leaves three options for the choice of identifiers for data linkage: a) to use the AHV number in an encrypted, untraceable format (hashing) through standardised algorithms; b) to develop an effective communication strategy that clearly conveys the benefits of using the AHV number and alleviates public concerns; or c) to consider alternative identifiers.

International Research Collaborations: Which Conditions for International Data Use Have Public Support?

International research collaborations that utilise data accessible in the health data space were regarded as a natural and logical step. When data access is controlled by the NDCC, the same conditions apply to both international and national research. Additionally, if the data are accessible to researchers in countries with similar societal norms and values, no objections were raised in the interviews.

Methods

Study Phase 1

A multi-method study was conducted to trace the evolution of the socio-political discourse surrounding health data sharing in Switzerland from 1992 to 2023. Our approach 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; and
- C) a news search and analysis across Swiss newspapers to trace the evolution of media narratives.

The analysis followed an iterative process. We integrated insights from the interview data with the policy analysis and the review of opinion papers to identify I) the policy process 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 II) thought-provoking events and III) harmful events that influenced the public discourse on health data sharing, as well as IV) the implementation obstacles of past data sharing initiatives. Where appropriate, we conducted the data analysis in German, French, Italian and English, with all of the aforementioned languages being fluently spoken by research team members.

A.I) Stakeholder Interviews

Eleven stakeholders were purposively sampled for 30-minute online interviews. These included representatives from academia (two interviewees), the pharmaceutical industry (one interviewee), the FOPH (one interviewee), the FSO (one interviewee), the Swiss Personalised Health Network (one interviewee), the Swiss Institute of Bioinformatics (one interviewee), the Swiss Medical Association (one interviewee), politics (two interviewees), and journalism (one interviewee). All potential participants were invited via an email (sent in February 2024), which provided a brief introduction to the research team and the study aim. Interview questions were formulated based on the team's prior research and in line with Pope and Mays' guide to designing a topic guide in qualitative research (Pope et al., 2020), which were aligned with the study's objectives (**Appendix 3**). The online interviews were conducted in English, audio-recorded and then transcribed using the online software Zoom. Transcripts were then uploaded to MaxQDA24 (software used for qualitative research), manually reviewed to remove identifying information (e.g. names, institutions and cities) and coded using reflexive thematic analysis to identify emerging themes (Braun et al., 2018). To ensure the quality of the analysis, all members of the research team reviewed the codes and reached an agreement on the main themes.

A.II) Review of Expert Opinion Papers

A scoping review of editorials and viewpoints was conducted to trace the evolution of expert opinions on health data sharing in Switzerland from 1998 to 2023. A comprehensive search strategy was developed for PubMed, Scopus, Embase and Cochrane in collaboration with a specialised librarian from the University of Zurich (**Appendix 2**). Given the geographical focus of the study, the following online medical journals were also included in the scoping review: Swiss Health Web, Swiss Medical Forum, and Swiss Medical Weekly. Keyword searches were conducted 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, the keywords 'Swisstransplant', 'Meineimpfungen' ('Myvaccination' in German), and 'Patientendossier' ('patient dossier' in German) were researched since these emerged from the interviews as events that influenced public perceptions of health data sharing in Switzerland (**Appendix 2**). Articles were coded based on topic, date and tone using color-coded indicators. Colour coding was based on the original language text to capture the nuances of tone in each language.

B) Policy Analysis

Relevant policy documents from 1992 to 2023 were searched on the Swiss Government and Parliament websites (<https://www.bag.admin.ch/bag/de/home>, www.parlament.ch) to trace the political development of the discourse around health data sharing in Switzerland. These searches involved using the key terms ‘data’ and ‘health data’ in Italian (‘dati’, ‘dati sanitari’) and German (‘Daten’, ‘Gesundheitsdaten’), and by identifying relevant cross-references within the identified policies. We identified broad search terms and included various types of documents, such as acts, strategies, motions, referenda, mandates, press releases, interpellations and postulates to gain a comprehensive overview of the relevant political developments on health data sharing.

C) News Analysis

News searches were conducted using the digital archives of seven leading newspapers in Switzerland across the three language regions: Italian (‘Corriere del Ticino’, ‘La Regione’), French (‘Le Temps’ and ‘Tribune de Genève’) and German (‘Der Bund’, ‘Tages-Anzeiger’ and ‘Neue Zürcher Zeitung’). Additionally, news searches were conducted on Medinside and Inside IT, two Swiss digital news platforms that cover healthcare and technology topics, respectively. 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 that emerged from the interviews during that period (**Appendix 2**). Articles were coded based on topic, date and tone using color-coded indicators. Colour coding was based on the original language text to capture nuances of tone in each language.

Study Phases 2 - 4

We conducted four focus groups across the German-, French- and Italian-speaking regions of Switzerland to identify public expectations and requirements related to the attributes that define a trustworthy health data space for health-related research. The participants discussed four fictitious case studies: 1) Consent Management; 2) Record Linkage via the Social Security Number (AHV Number); 3) NDCC; and 4) Cross-Border Data Exchange. Each case study was developed based on policy documents and expert input, translated into German, French and Italian, and pilot-tested for understandability. After completing the four focus groups, we held a panel discussion with experts, conducted in German, to validate and expand the focus group findings. The interviewed experts comprised three (3/8, 38%) healthcare professionals, three (3/8, 38%) patient experts (i.e. patients who advocate based on lived experience of a medical condition) and two (2/8, 25%) patients. We recruited and interviewed a total of 51 unique participants. An overview of the data collected is presented in **Table 11**.

Table 11 Participant Characteristics

	Number of participants	Age range	Gender distribution
Focus group 1: in-person at the University of Zurich, local recruitment	17	19–76	59% women, 41% men
Focus group 2: online, French-speaking region	9	24–66	44% women, 55% men
Focus group 3: online, Italian-speaking region	9	23–75	55% women, 44% men
Focus group 4: online, German-speaking region	8	20–67	50% women, 50% men
Public representatives	43	19–76	52% women, 48% men
Expert panel discussion: online, German-speaking region	8	N/A	37% women, 63% men
Overall total	51	19–76	49% women, 51% men

Of the four focus group discussions, the first was conducted in person at the University of Zurich, while the remaining three were conducted online using the Zoom videoconferencing platform. This shift in methodology was necessary due to recruitment challenges for in-person focus groups. Current research does not provide conclusive evidence about the advantages and disadvantages of in-person versus online interviews (Menary et al., 2021; Jones et al., 2022), which aligns with our own research experience. We changed the method and pilot-tested the online focus group setup prior to data collection. Thus, we do not foresee biases arising from this methodological change. Recruitment, screening and informed consent for the focus groups were managed by foraus Forum Aussenpolitik for the in-person focus group and by gfs.bern for the online focus groups. Participants (gfs.bern recruitment pool) were carefully selected to ensure a balanced representation of different age groups and political preferences to reflect the diverse views of the Swiss public. The transcripts were independently coded inductively by two researchers and translated into themes, which were then used to develop policy and public communication recommendations. These recommendations were further discussed in a panel with patient experts, healthcare professionals and patients to validate the proposed recommendations and co-develop examples to guide their implementation.

Research Ethics (Study Phases 1-3)

This study was conducted in compliance with the Declaration of Helsinki and received the 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 in the stakeholder interviews and focus groups.

Limitations and Biases

As a type of qualitative research method, interview studies offer rich and detailed insights into interview participants' experiences and perceptions regarding the researched topic. This makes interview studies invaluable for understanding complex and emerging phenomena. The strength of this method lies in its ability to explore participants' views in depth and comprehensively. However, qualitative research prioritises depth and context over statistical representation, resulting in valuable context-specific insights that may not be universally applicable. To increase generalisability, a national survey study is advisable to test and validate the findings of this study.

Throughout the study phases, we were aware of potential biases, which we aimed to mitigate through rigorous pilot testing, independent analyses, external validation and careful study design (**Table 12**).

Table 12 Potential Biases and Limitations

Biases	Explanation	Mitigation
Focus Group and Stakeholder Interviews		
Acquiescence Bias	Participants might agree with others' opinions to avoid conflict.	<ul style="list-style-type: none"> - Focus Groups: We employed neutral and open-ended questions, encouraged diverse opinions and maintained a non-judgmental atmosphere throughout the focus group discussions. - Stakeholder Interviews: Not applicable since they were conducted individually.
Confirmation Bias	Moderator focuses on interview answers supporting his/her own opinions.	<ul style="list-style-type: none"> - Focus Groups & Stakeholder Interviews: We employed neutral, open-ended questions and structured questioning techniques. In the focus group, we included an additional co-moderator to introduce diverse perspectives during the moderation process. Both the stakeholder interviews and focus groups were pilot-tested to identify and rectify any questions or moderation techniques that might inadvertently influence participants' responses. Coding frameworks were applied to ensure that responses were analysed objectively.
Dominance Bias	One interviewee dominates the interview.	<ul style="list-style-type: none"> - Focus Groups: We set clear ground rules from the outset, emphasising the value of everyone's input and encouraging equal participation. We prompted quieter participants to contribute, rotated who spoke first, and politely intervened with dominant voices when necessary. An inclusive atmosphere was fostered, and summarisation techniques were employed to refocus the discussion on other participants. - Stakeholder Interviews: Not applicable since they were conducted individually.
Group Thinking	Participants withhold their own thoughts for the sake of harmony, leading to a lack of diverse opinions being discussed during the interview.	<ul style="list-style-type: none"> - Focus Groups: We emphasised the importance of diverse opinions at the outset of the session, making it clear that all viewpoints were valued. We encouraged individual contributions by directly asking quieter participants for their perspectives and rotating who spoke first to avoid dominance by particular individuals. Additionally, the moderator used probing questions to explore alternative views and gently challenged the consensus by introducing devil's advocate scenarios. - Stakeholder Interviews: Not applicable since they were conducted individually.

Hawthorne Effect	Participants change their answers because they are being observed.	<ul style="list-style-type: none"> - Focus Groups & Stakeholder Interviews: We assured participants that the focus group was a safe and confidential environment where honest and candid feedback was encouraged. We emphasised that responses would remain anonymous and that their input would not be evaluated based on individual performance. Additionally, we used a neutral, non-intrusive moderation style to minimise the feeling of being observed, thereby helping participants feel more comfortable and natural in their responses.
Interpretation Bias	Researcher misinterprets results based on their own views.	<ul style="list-style-type: none"> - Focus Groups & Stakeholder Interviews: We involved a second researcher to independently review the data, thereby reducing the influence of individual perspectives. Additionally, regular discussions between researchers helped to cross-check interpretations and ensure that multiple viewpoints were considered.
Moderator Bias	Moderator influences participants' opinions.	<ul style="list-style-type: none"> - Focus Groups & Stakeholder Interviews: We used neutral, open-ended questions to avoid leading participants towards specific answers and maintained a non-judgmental tone throughout the discussions. A co-moderator was involved to provide an additional perspective, ensuring a balanced approach to facilitation. We also pilot-tested the stakeholder interviews and focus groups to identify any biases in questioning or moderation techniques and made adjustments as needed.
Sampling Bias and Selection Bias	Participants do not represent the broader society and are chosen to favour certain opinions.	<ul style="list-style-type: none"> - Focus Groups: For three out of the four focus groups, we employed an external party to handle the sampling process and collect participant consent, thereby ensuring an impartial and objective approach. Participants were carefully selected to ensure a balanced representation of different age groups and political preferences, reflecting the diverse views of the Swiss public. For the fourth focus group, participants were sampled through various channels, with similar demographics to those of the other three groups. Additionally, all focus groups were conducted in the respective regional languages (i.e. German, French and Italian) to ensure that participants could express their views comfortably and naturally, thereby reducing potential biases related to language barriers. - Stakeholder Interviews: Participants were purposively sampled to ensure diverse perspectives from stakeholders in Switzerland, resulting in a

		balanced representation of key actors rather than favouring specific opinions.
Social Desirability Bias	Participants say what is socially acceptable and not their own views.	- Focus Groups & Stakeholder Interviews: We assured participants that their responses would remain confidential and anonymous, thereby creating a safe environment for them to express their true opinions without fear of judgment. We also used neutral, non-leading questions to avoid steering participants towards answers they might perceive as more socially acceptable. Additionally, moderators maintained a non-judgmental and neutral tone throughout the discussions to encourage honesty.
Technical Bias	Technology affects participants' answers.	- Focus Groups & Stakeholder Interviews: We ensured that all participants had access to reliable and familiar technology during the focus groups or interviews, thereby minimising the potential for technological difficulties to impact their responses. Participants were provided with clear instructions and support before the sessions to ensure they were comfortable with the digital tools being used. Additionally, the moderation process remained flexible, allowing for breaks or adjustments if any technical issues arose whilst ensuring that participants were not rushed or influenced by technological interruptions.
Case Studies		
Simplification	Oversimplification of complex issues, leading participants to overlook nuances.	We developed four case studies balancing content precision against usability in a focus group format with participants. Case studies were also supported by a discussion of all relevant definitions to ensure the participants' understanding of the more complex topics. Prior to their use, the case studies were reviewed by the advisory board and pilot-tested.
Topic Complexity	Missing knowledge among participants to discuss the case studies in an informed manner.	The topic discussed was highly technical and not part of the general knowledge of citizens. To address this, we introduced the case studies providing clear definitions of the relevant technical terms. Participants were first given a few minutes to read through the case studies independently. To further aid understanding, we incorporated icons and images to help participants visualise the scenarios. The moderator then summarised the scenarios using simple and straightforward language to ensure clarity. This approach supported various learning styles. Participants were also encouraged to ask questions about the case studies to clarify any doubts or potential misinterpretations.

References

- Birrer, R. (2023, September 26). Wir leisten uns zu viel Luxus im Gesundheits-wesen. *Tages-Anzeiger*.
<https://www.tagesanzeiger.ch/leitartikel-zum-praemienschock-wir-leisten-uns-zu-viel-luxus-175648144529>
- Brall, C., Berlin, C., Zwahlen, M., Ormond, K. E., Egger, M., & Vayena, E. (2021). Public willingness to participate in personalized health research and biobanking: A large-scale Swiss survey. *PLOS One*, 16(4), e0249141. <https://doi.org/10.1371/journal.pone.0249141>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2018). *Thematic analysis*. Handbook of Research Methods in Health Social Sciences . Springer, Singapore. https://doi.org/10.1007/978-981-10-2779-6_103-1.
- De Benedetto, M., Lupo, N., & Rangone, N. (2020). *The crisis of confidence in legislation*. Nomos Verlagsgesellschaft.
- Die Bundesversammlung. (2024, March 7). *Nationalrat spricht Millionenkredit für digitales Gesundheitswesen*.
https://www.parlament.ch/de/services/news/Seiten/2024/20240307111005672194158159026_bsd088.aspx
- Federal Office of Communications. (2023, December 8). *Code of conduct for operating trustworthy data spaces*.
<https://www.bakom.admin.ch/bakom/en/home/digital-und-internet/strategie-digitale-schweiz/datenpolitik/verhaltenskodex.html>
- Federal Office of Public Health. (2024). *DigiSanté: Förderung der digitalen Transformation im Gesundheitswesen*. <https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategien/digisante.html>
- Ghafur, S., Dael, J. V., Leis, M., Darzi, A., & Sheikh, A. (2020). Public perceptions on data-sharing: Key insights from the UK and the USA. *The Lancet Digital Health*, 2(9), e444–e446. [https://doi.org/10.1016/S2589-7500\(20\)30161-8](https://doi.org/10.1016/S2589-7500(20)30161-8)
- Gille, F. (2023). *What is public trust in the health system?: Insights into health data use*. Policy Press.
<https://doi.org/10.51952/9781447367352>
- Gille, F., Smith, S., & Mays, N. (2017). Towards a broader conceptualisation of ‘public trust’ in the health care system. *Social Theory & Health*, 15(1), 25–43. <https://doi.org/10.1057/s41285-016-0017-y>

- Gilli, Y. (2016) Le dossier électronique du patient traverse une phase critique, Swisshealthweb. Available at:
<https://saez.swisshealthweb.ch/fileadmin/assets/SAEZ/2021/bms.2021.19754/bms-2021-19754.pdf>
- Golder, L., Keller, T., Schena, C., & Schäfer, S. (2023, May). *Im Notfall alle Daten verfügbar: Mehrheit der Bevölkerung unterstützt EPD*. Cockpit gfs.bern AG. <https://cockpit.gfsbern.ch/de/cockpit/ehealth-bevoelkerung-2023/>
- Greenwald, G., MacAskill, E., & Poitras, L. (2013, June 11). Edward Snowden: The whistleblower behind the NSA surveillance revelations. *The Guardian*. <https://www.theguardian.com/world/2013/jun/09/edward-snowden-nsa-whistleblower-surveillance>
- Greve-Poulsen, K., Larsen, F. K., Pedersen, R. T., & Albæk, E. (2023). No gender bias in audience perceptions of male and female experts in the news: Equally competent and persuasive. *The International Journal of Press/Politics*, 28(1), 116–137. <https://doi.org/10.1177/19401612211025499>
- Gunther, A. (1998). The persuasive press inference: Effects of mass media on perceived public opinion. *Communication Research*, 25(5), 486–504. <https://doi.org/10.1177/009365098025005002>
- Horn, R., & Kerasidou, A. (2020). Sharing whilst caring: Solidarity and public trust in a data-driven healthcare system. *BMC Medical Ethics*, 21(1), 110. <https://doi.org/10.1186/s12910-020-00553-8>
- Huber, F. (2022, February 8). *Das BAG soll keine weiteren Kompetenzen mehr erhalten*. <https://www.swiss-healthweb.ch/de/article/doi/saez.2022.20526/>
- Jones, J.E., Jones, L.L., Calvert, M.J., Damery, S.L. and Mathers, J.M. (2022). A Literature Review of Studies that Have Compared the Use of Face-To-Face and Online Focus Groups. *International Journal of Qualitative Methods*, 21. doi:<https://doi.org/10.1177/16094069221142406>.
- Le Temps. (2022, January 18). *Enquête ouverte après des failles informatiques concernant le registre national du don d'organes—Le Temps*. <https://www.letemps.ch/suisse/enquete-ouverte-apres-failles-informatiques-concernant-registre-national-don-dorganes>
- Lingg, M., & Lütschg, V. (2020). Health system stakeholders' perspective on the role of mobile health and its adoption in the Swiss health system: Qualitative study. *JMIR mHealth and uHealth*, 8(5), e17315. <https://doi.org/10.2196/17315>
- Luhmann, N. (1979). *Trust and power: Two works*. Wiley.

- Martani, A., Geneviève, L.D., Egli, S.M., Erard, F., Wangmo, T. and Elger, B.S. (2021). Evolution or Revolution? Recommendations to Improve the Swiss Health Data Framework. *Frontiers in Public Health*, 9. doi:<https://doi.org/10.3389/fpubh.2021.668386>
- Menary, J., Stetkiewicz, S., Nair, A., Jorasch, P., Nanda, A.K., Guichaoua, A., Rufino, M., Arnout R.H. Fischer and Jessica A.C. Davies (2021). Going virtual: adapting in-person interactive focus groups to the online environment. *Emerald open research*, 1(6). doi:<https://doi.org/10.1108/eor-06-2023-0008>.
- Mutz, D., & Soss, J. (1997). Reading public opinion: The influence of news coverage on perceptions of public sentiment. *Public Opinion Quarterly*, 61(3), 431–451. <https://doi.org/10.1086/297807>
- Page B. I., Shapiro R. Y., Dempsey G. R. (1987) What Moves Public Opinion? *The American Political Science Review* Volume 81 , Issue 1 , March 1987 , pp. 23 - 43 DOI: <https://doi.org/10.2307/1960777>
- Pletscher, F., Mändli-Lerch, K., & Glinz, D. (2022). Willingness to share anonymised routinely collected clinical health data in Switzerland: A cross-sectional survey. *Swiss Medical Weekly*, 152(23-24). doi:<https://doi.org/10.4414/smw.2022.w30182>.
- Pope, C., Ziebland, S., & Mays, N. (2020). Analysis. In *Qualitative research in health care* (pp. 111–133). John Wiley & Sons, Ltd. <https://doi.org/10.1002/9781119410867.ch9>
- Rochel, J. (2023). Error 404: looking for trust in international law on digital technologies. *Law, Innovation and Technology*, pp.1–37. doi:<https://doi.org/10.1080/17579961.2023.2184139>.
- Schweizerische Eidgenossenschaft. (2023, December). *BBl 2023 2908—Botschaft zum Verpflichtungskredit für ei...* Fedlex. <https://www.fedlex.admin.ch/eli/fga/2023/2908/de>
- Swiss Confederation. (2023, December 8). *Monitoring Report on Digital Switzerland Strategy 2023*. <https://www.bk.admin.ch/dam/bk/en/dokumente/dti/StrategieDCH/monitoringbericht-strategie-dch-2023.pdf.download.pdf/Monitoring%20Report%20on%20Digital%20Switzerland%20Strategy%202023.pdf>
- Sztompka, P. (1999). *Trust: A sociological theory*. Cambridge University Press.
- Trezzini, M. (2021, March 23). Swiss online vaccine registry probed for data security issues. *Swissinfo.Ch*. <https://www.swissinfo.ch/eng/politics/swiss-online-vaccine-registry-probed-for-data-security-issues/46471504>

- Williams, G. A., & Fahy, N. (2019). Building and maintaining public trust to support the secondary use of personal health data. *Eurohealth*, 25 (2), 7 - 10. European Observatory on Health Systems and Policies, World Health Organization. Regional Office for Europe. <https://iris.who.int/handle/10665/332521>
- Zimmer, A. (2022, November 30). *Das Digitale Gesundheitssystem: Achtung Baustelle*. <https://www.swiss-healthweb.ch/de/article/doi/saez.2022.21300/>
- Zimmer, A. (2023, November 17). *Ein bewegtes Jahr zur Ende*. <https://saez.swisshealthweb.ch/de/article/doi/saez.2023.1282904944/>
- Zimmer, A. (2023b) *Jahresrückblick | saez.ch, saez.swisshealthweb.ch*. Available at: <https://saez.swiss-healthweb.ch/de/article/doi/saez.2023.1282904944/> (Accessed: 21 June 2024).
- Zürcher, C., & Schaad, F. (2023, October 7). Warum das Patientendossier ein Murks ist. *Tages-Anzeiger*. <https://www.tagesanzeiger.ch/digitalisierung-des-gesundheitswesens-warum-das-patientendossier-ein-murks-ist-816824845132>

Appendix

Appendix 1, Phase 1

* Documents or events included in Table 1 were selected as the key 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	<p>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.</p> <p>Link: https://www.news.admin.ch/news/message/attachments/2886.pdf</p>
	*04.3243 Noser Motion - E-Health. Use of electronic means in healthcare	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?Af-fairId=20043243</p>
2005	Revision of the 1998 Information Society Strategy by the Interdepartmental Information Society Committee	<p>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.</p> <p>Link: https://www.news.admin.ch/news/message/attachments/1731.pdf</p>
2006	* Strategy of the Federal Council for an Information Society in Switzerland (Updated from 1998)	<p>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.</p> <p>Link: https://www.news.admin.ch/news/message/attachments/1727.pdf</p>
2007	* AS 2007 479 - Ordinance on the Insurance Card for Compulsory Health Insurance (VVK)	<p>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).</p> <p>Link: https://www.fedlex.admin.ch/eli/oc/2007/101/it</p>
	*eHealth Swiss Strategy 2007-2015	<p>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.</p>

		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

		<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-29610.html</p>
	Introduction of the eHealth Barometer	<p>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.</p> <p>Link: https://e-healthforum.ch/barometer/</p>
2010	*SR 818.101 – Epidemics Act (entered into force in 2016)	<p>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.</p> <p>Link: https://www.fedlex.admin.ch/eli/cc/2015/297/en</p>
	*10.3327 Humbel Postulate - Implementation of the e-Health Strategy	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20103327</p>
	*Electronic health record: mandate for the development of legal bases	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-36567.html</p>

2011	Draft of the Federal Law on Electronic Patient Records: Start of the consultation procedure	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-41209.html</p>
	*SR 810.30 - Human Research Act (HRA) (entered into force in 2014)	<p>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.</p> <p>Link: https://www.fedlex.admin.ch/eli/cc/2013/617/en</p>
2012	*Federal Strategy for Switzerland’s Digital Future	<p>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.</p> <p>Link: https://www.admin.ch/gov/en/start/dokumentation/medienmitteilungen.msg-id-43694.html</p>
	Electronic patient records: The Federal Council orders the drafting of the dispatch to the new law	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-44170.html</p>
2013	Health2020 Report	<p>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.</p> <p>Final goals: innovation, transparency and administrative efficiency.</p> <p>Link: https://www.bag.admin.ch/dam/bag/en/dokumente/nat-gesundheitsstrategien/gesundheit2020/g2020/bericht-gesundheit2020.pdf.download.pdf/report-health2020.pdf</p>

	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	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-61068.html</p>
	Federal Council strategy for a digital Switzerland	<p>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.</p> <p>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</p>
2017	Introduction of the computerised patient record is underway	<p>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.</p> <p>Link: https://www.edi.admin.ch/edi/it/home/dokumentation/comunicati-stampa.msg-id-66071.html</p>
	*Establishment of the Swiss Personalised Health Network (SPHN)	<p>First federal government initiative aimed at creating interconnected data infrastructure to make relevant health information interoperable in Switzerland.</p> <p>Link: https://sphn.ch/organization/about-sphn/#:~:text=The%20Swiss%20Personalized%20Health%20Network,and%20omics%20data%20for%20research.</p>
2018	Electronic patient file: adaptation of the accreditation procedure	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-69642.html</p>
	*eHealth Swiss 2.0 (2018–2024)	<p>Aim: to promote the adoption of electronic patient dossiers and coordinate digitalisation efforts around the EPD.</p>

		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/geschaefft?AffairId=20184102

	<p>*18.4328 Wehrli Postulate - Electronic patient record. What else can be done to ensure that it is fully used?</p>	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?Af-fairId=20184328</p>
<p>2019</p>	<p>Open Government Data Strategy 2019–2023</p>	<p>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.</p> <p>The 2019–2023 OGD strategy has five objectives:</p> <ol style="list-style-type: none"> 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. <p>Link: https://www.bfs.admin.ch/bfs/en/home/services/ogd/documentation.assetdetail.16164831.html</p>
	<p>Computerised patient record: Federal Council opens to larger providers</p>	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/it/home/das-bag/aktuell/medienmitteilungen.msg-id-74239.html</p>
	<p>*Health Policy Strategy 2020–2030 (Health 2030)</p>	<p>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 programme is envisioned, as well as the establishment of data rooms for health-related research.</p>

		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 Programme 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/strategiech2020.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 digitalization of its healthcare system. The 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 Ettlín 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.

		<ul style="list-style-type: none"> - 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. <p>Link: https://www.parlament.ch/en/ratsbetrieb/suche-curia-vista/geschaefft?AffairId=20213957</p>
	*21.4373 Silberschmidt Motion - Introduction of a unique patient identifier	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaefft?AffairId=20214373</p>
	21.4374 Silberschmidt Motion - Introduction of digital patient administration	<p>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.).</p> <p>Link: https://www.parlament.ch/en/ratsbetrieb/suche-curia-vista/geschaefft?AffairId=20214374</p>
2022	*Report from the FOPH on improving data management in the healthcare sector	<p>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.</p>

	<p>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</p> <p>https://www.bag.admin.ch/bag/de/home/das-bag/aktuell/medienmitteilungen.msg-id-86762.html</p>
<p>Protection of patient data and protection of policyholders - Additional report following up on 08.3493 Heim postulate</p>	<p>From the report, it emerged that compliance with data protection regulations has become widespread, and they are now largely 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.</p> <p>Link: https://www.news.admin.ch/news/message/attachments/70400.pdf</p>
<p>22.3015 SGK_NR Motion - Electronic patient records. Make them practical and secure them financially</p>	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223015</p>
<p>The Federal Council intends to further develop the computerised patient record</p>	<p>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.</p> <p>Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-88245.html</p>
<p>*Report from the Federal Council following up on 15.4225 Humbel postulate</p>	<p>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.</p> <p>Link: https://www.parlament.ch/centers/eparl/curia/2015/20154225/Bericht%20BR%20D.pdf</p>

<p>*Transplantation Act - Referendum</p>	<p>The adoption of an opt-out solution, prompted by a referendum, has sparked discussions on consent models related to health data sharing.</p> <p>Link: https://www.admin.ch/gov/en/start/documentation/votes/20220515/transplantation-act.html</p>
<p>The Federal Council intends to enable research to make better use of health data</p>	<p>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.</p> <p>Link: https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-88631.html</p>
<p>22.3859 Ettlín Motion: Master plan for digital transformation in healthcare. Use legal standards and available data</p>	<p>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.</p> <p>Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223859</p>
<p>*22.3890 WBK_SR Motion: Framework law for the secondary use of health data</p>	<p>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.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223890</p>
<p>Digital transformation in healthcare: The data management expert group has started work</p>	<p>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.</p>

		Link: https://www.edi.admin.ch/edi/it/home/dokumentation/comunicati-stampa.msg-id-90422.html
	Report on digital transformation in the public service	<p>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.</p> <p>Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-90645.html</p>
	*22.4022 FDP_NR Postulate: 'Exploiting the potential of digitalisation and data management in the healthcare sector. Switzerland needs an overarching digitalisation strategy'	<p>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 programme fulfil this mandate, and the postulate can thus be removed from office.</p> <p>In November 2022, the Federal Council proposed to accept the postulate, and the National Council followed up on the proposal in December 2022.</p> <p>Link: https://www.parlament.ch/it/ratsbetrieb/suche-curia-vista/geschaefft?AffairId=20224022?</p>
	*Creation of trustworthy data rooms based on digital self-determination	<p>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.</p> <p>Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-99268.html</p>
	*Swiss Digital Strategy 2023	<p>Digitalisation in the health sector is one of the three central themes of the strategy, with a focus on the multiple uses of data.</p> <p>Link: https://digital.swiss/en/strategy/strategie.html</p>
2023	23.3002 Motion SIK_SR - Improve the security of Switzerland's most important digital data	<p>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</p>

	<p>and prioritizing Swiss companies, in collaboration with universities, for infrastructure design.</p> <p>Link: https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20233002</p>
<p>*DigiSanté 2024–2034 - Programme to promote digital transformation in the health system - Commitment credit</p>	<p>On 22 November 2023, the Federal Council sent the Federal Assembly a message concerning a commitment credit intended for a programme to promote digital transformation in the health system for the years 2025 to 2034.</p> <p>Commitment Credit Link: https://www.parlament.ch/fr/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20230076</p> <p>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.</p> <p>Programme Link: https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategien/digisante.html#115324384</p>
<p>The computerised patient record will become a pillar of the healthcare system</p>	<p>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.</p> <p>Link: https://www.bag.admin.ch/bag/en/home/das-bag/aktuell/medienmitteilungen.msg-id-96137.html</p>
<p>*Code of conduct for managing trustworthy data spaces based on digital self-determination</p>	<p>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.</p> <p>Link: https://www.bakom.admin.ch/bakom/en/homepage/digital-switzerland-and-internet/strategie-digitale-schweiz/data-policy/code_of_conduct.html</p>
<p>* SR 235.1 - (New) Federal Act on Data Protection (nFADP)</p>	<p>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.</p> <p>Link: https://www.fedlex.admin.ch/eli/cc/2022/491/en</p>

	<p>Federal Council lays foundations for a Swiss data ecosystem</p>	<p>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 its sustainability. The Swiss data ecosystem consists of trustworthy data spaces that can be interconnected in this system according to clear rules.</p> <p>The Federal Council has adopted several measures to promote a Swiss data ecosystem. The main measures are:</p> <ul style="list-style-type: none"> - 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. <p>Link: https://www.bk.admin.ch/bk/en/home/digitale-transformation-ikt-lenkung/datenoesystem_schweiz.html</p>
	<p>Digital Switzerland Strategy 2023</p>	<p>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.</p> <p>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.</p> <p>The focus areas, determined by the Federal Council, are digitisation in the healthcare sector, legislation supportive of digitalisation, and digital sovereignty.</p> <p>Link: https://www.bk.admin.ch/dam/bk/en/dokumente/dti/StrategieDCH/strategie-digitale-schweiz-2023.pdf.download.pdf/Digital%20Switzerland%20Strategy%202023.pdf</p>
	<p>Approval of code of conduct for managing trustworthy data spaces</p>	<p>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.</p> <p>Link: https://www.admin.ch/gov/it/pagina-iniziale/documentazione/comunicati-stampa.msg-id-99268.html</p>
<p>2024</p>	<p>* DigiSanté 2024–2034 - Federal Decree on the commitment credit for a</p>	<p>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</p>

	programme to promote digital transformation in the healthcare sector for the years 2025–2034	DigiSanté programme, 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 2, Phase 1

Search String/Keywords	Database	Results	Excluded	Included
Editorials				
((((((((("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 'editorial' from 1999	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	Cochrane	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	InsidelT			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 3, Scoping review of editorials and news search)

Appendix 3, Phase 1

Five interview questions presented 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 to 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 in the future?*