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RESEARCH ARTICLE

What is a trustworthy national health data space in Switzerland? A national public focus group study

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Abstract

The ongoing development of a Swiss Health Data Space (SHDS) presents an opportunity to transform health delivery and care by enabling large-scale secondary health research. The successful implementation of the SHDS depends on its trustworthiness, as public trust is closely linked to public participation in data-sharing initiatives. 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 SHDS. The participants discussed four fictitious case studies on: (1) consent management; (2) record linkage via the national social security number; (3) national data coordination center; and (4) cross-border data exchange. To best inform Swiss policy, we held a panel discussion with patient experts and healthcare professionals to translate the focus group findings into governance and public communication recommendations. Policy recommendations are proposed based on insights from the fictitious case studies discussed with participants, accompanied by guidance on implementation measures that contribute to proactively building trust in the development of the SHDS. Communication recommendations are further provided, highlighting that the success of the SHDS will depend on early and continuous trustworthy public communication efforts that actively engage the Swiss public, address their concerns, and foster support throughout its development. Overarching these efforts will be a foundational governance approach that meaningfully involves relevant stakeholders and members of the Swiss public, while allocating appropriate responsibility to maintain trustworthiness of the SHDS.

Policy Significance Statement

Access to health data for secondary use is crucial for advancing research, health care, and public health in Switzerland. To address this, the Federal Office of Public Health (FOPH) is leading the development of a *Swiss Health Data Space (SHDS)* under the fourth package of the Digisanté program. Researchers, healthcare providers and politicians alike emphasize that public trust is essential for the success of national health data-sharing initiatives. This highlights the need to clarify public and stakeholder expectations to develop widely accepted conditions for trustworthy health data use within the SHDS. This research article aims to offer actionable guidance for Switzerland's ongoing Digisanté policy and public communication developments, with a focus on shaping a SHDS grounded in public trust.

1. Introduction

Access to health data for secondary use, defined as the use of data originally collected for a different purpose, is crucial for advancing scientific research, healthcare services, and public health. An example is

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the use of anonymized electronic health records in medical research. Switzerland acknowledges the need for health data access for secondary use as part of its broader healthcare digitalization efforts. In line with the Health2030 strategy, the Digisanté program was launched to drive this transformation (Federal Office of Public Health, 2024a, 2024b). The program consists of four key strategic packages, with the fourth package, "Secondary Use for Planning, Strategic Management, and Research," focused on enabling access to health data for researchers in both the academic and private sectors. The "Data Space for Health-Related Research" project within the fourth package aims to create a Swiss Health Data Space (SHDS) that facilitates, among other data-sharing activities for primary use and planning, the secondary use of health-related data for research purposes (Federal Office of Public Health, 2025). On May 29, 2024, the Federal Assembly of the Swiss Confederation approved a commitment credit of 391.7 million CHF for the years 2025–2034 to fund DigiSanté, with the official launch of the program in January 2025 (Swiss Confederation, 2025).

Switzerland's efforts to digitalize its healthcare system align with developments in the European Health Data Space (EHDS), which aims to facilitate both the primary and the secondary use of health data across Europe. In April 2024, the European Parliament adopted the EHDS regulation, establishing a framework law for the secure and efficient use of health data across the EU, which was later adopted by the Council of Europe in January 2025 (European Commission, 2025; European Council, 2025). In both the EU and Switzerland, policymakers are calling for the development of health data spaces that are trustworthy, with the European Commission and the Swiss Federal Office of Public Health explicitly emphasizing trust as a fundamental enabler of their success (Federal Office of Public Health, 2024c; European Commission, 2024). Trust plays a central role in the successful implementation of data-sharing initiatives, as it is closely linked to public participation in data-sharing activities (Federal Office of Public Health, 2024c; European Commission, 2024).

Trust can be defined as "a bet about the future contingent actions of others" (Sztompka, 2008; Gille, 2023). For health data sharing initiatives, trust has been suggested to ultimately depend on the trustor's perception of the initiative's trustworthiness, along with the influence of past positive experiences, current perceptions in the health system's ability to handle data responsibly, and future expectations of a net benefit from data use (Gille et al., 2021; Zavattaro et al., 2024). In Switzerland, this has become evident with the negative narrative surrounding the Electronic Patient Dossier (EPD), which has been compounded by recent national and international scandals. This context largely frames public trust in health data sharing today and serves as the Swiss public's reference point for national health data-sharing initiatives (Zavattaro et al., 2025). Therefore, while guaranteeing public trust in data spaces is impossible, designing a system that is perceived as trustworthy should be the central objective in order to increase the likelihood that the public will trust the system and choose to share their health data (O'Neill, 2018).

The present study aims to explore the preconditions that would make the secondary use of health data within the SHDS perceived as trustworthy by the Swiss public. This serves as a first step in developing evidence to support the broader goals of DigiSanté in developing a trustworthy health data space (Schweizeriche Eidgenossenschaft, 2023). Outside of the healthcare context, the findings can be meaningful to inform the development of other data spaces where sensitive data are shared and used, such as spaces for education data or business data (Swiss Confederation, 2023).

2. Methods

2.1. Study design and sample

The study was undertaken in two steps. First, we held four focus groups across the German-, French-, and Italian-speaking regions of Switzerland to capture nationwide public perspectives on the preconditions for developing a trustworthy health data space. For the purposes of this research study, "the public" refers to a group of participants who are reflective of the Swiss population, with no prior knowledge of or specific

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expertise in health data sharing. Among the four focus groups, two were conducted by FG, a postdoctoral researcher and the principal investigator of the study, with participants from the German-speaking region, while the remaining two were conducted by PD with participants from the French-speaking region and by FZ with participants from the Italian-speaking regions, both PhD students at the time of the study. Combined, the research team members completed over 20 focus groups prior to the conduct of this study. All focus groups were conducted in the language of the respective region, all of which were fluently spoken by the research team.

Recruitment via email, screening, and informed consent for the focus groups were conducted by foraus (Policy Kitchen—Foraus, 2025) for the first group and by gfs.bern (gfs.bern | Political and communications research, 2019) for the subsequent groups, a think tank and market research agency, respectively. Participants were purposively selected to ensure a balanced representation of different age groups, gender, and political preferences, to reflect the diverse views of the Swiss public. Specifically, recruitment for the focus group with foraus was conducted through multiple channels, including the foraus social and email platforms and relevant communities in Zurich, such as patient expert groups. From the recruited pool, participants were selected to ensure balanced representation of age, gender, and education. Recruitment from gfs.bern used stratified purposive sampling based on age, gender, language region, education, and voting behavior (gfs.bern | Surveys, 2025). Participants were drawn from proprietary panels and targeted outreach, and screened using structured questionnaires.

At the start of the focus groups, the participants were initially made aware of the study's funders along with the broader societal relevance, goals, and the guiding assumptions of the research study. After which, they were presented four fictitious, future-oriented case studies that addressed the key topics of deliberation surrounding the development of a trustworthy SHDS (Table 1). Each case study was developed based on policy documents and expert input from the project's advisory board and FOPH (detailed case

Table 1. *Case studies and descriptions*

Case study	Description
Consent through a nationally coordinated digital consent management system	Consent to the reuse of data by means of a nationally harmonized digital consent management system through three options: (1) opt-in, (2) informed opt-out, and (3) value-based opt-out models. The consent system is digitally managed by and for the individuals involved.
Use of a personal identifier as a linking variable for research	Using the Swiss social insurance number (AHV number) as a linkage variable for datasets to conduct research.
A National Data Coordination Office (NDCC) links datasets and manages the flow of data	The proposed National Data Coordination Office (NDCC) will provide the necessary technical and organizational infrastructure, along with expert support and services, to enable data exchange between stakeholders, particularly between data producers and secondary data users.
Cross-border data exchange	The EHDS is operational and connected to the SHDS, allowing data to be processed both within Switzerland and across the European Union (EU). Data access is legally secured in both regions, in compliance with data protection regulations, and is coordinated in Switzerland by the NDCC.

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studies found in Data S1). The case studies were then translated into German, French, and Italian using DeepL Pro (deepl.com, version 1.17.1 to 2.4.0) and pilot tested to ensure clarity and comprehensibility. To ensure meaningful discussions in the focus groups, we introduced participants to the key definitions related to the case studies and gave them sufficient time to understand the concepts and ask any questions. The Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed (Data S2). The study was granted an ethics exemption by the cantonal ethics commission board in Zurich (Req-2023-01518).

Second, we held a panel discussion in German with experts including healthcare professionals, patient advocates, and patients living with chronic conditions. Panel participants were recruited through internal channels and direct outreach to patient advisory groups in Switzerland. The panel discussion served to validate and expand on the focus group findings, making sure they were comprehensive and accurately reflected the perspectives of various stakeholder groups involved in health data sharing in Switzerland. Following the panel discussion, participants received the updated findings and were given the opportunity to provide feedback.

2.2. Data collection and analysis

Data were collected between March and June 2024. Each focus group interview was conducted by a team of researchers taking on various roles, including observation, note-taking, and moderation. The first focus group was held in person at the University of Zurich, while the remaining three were conducted online via Zoom's video-conferencing platform (version 5.7.7), each lasting for approximately 120 minutes. This change in methodology was required due to difficulties in recruiting participants for in-person focus groups. Data from the in-person focus group were collected through note-taking by several members of the research team. The online focus group sessions were audio-recorded, and the resulting transcripts provided by Zoom were subsequently cleaned. For all focus groups, the data were then translated to English using DeepL (deepl.com, version 1.17.1 to 2.4.0) and imported into MaxQDA (version 10), a qualitative data analysis software (VERBI Software, 2022). Translation was examined for accuracy by bilingual research team members. The data were then coded and analyzed following a two-step inductive thematic approach (Pope et al., 2020).

In the first step, PD identified codes and subcodes, which were then grouped into overarching themes across all the focus groups. In the second step, PD and FG allocated these into themes and underlying subthemes related to policy and public communication through an iterative process. Ultimately, these were translated into policy and public communication recommendations for establishing a trustworthy SHDS. These guidelines served as the basis for the expert panel discussion, where participants were given the opportunity to review them in advance, provide written feedback, and to offer further context or engage in discussions on open topics during the online session. Throughout the study's method development, data collection, and data analysis, we were aware of potential biases that may arise. We aimed to mitigate these through rigorous pilot testing, independent analyses, external validation, and careful study design, as described in Supplementary Table S1.

Overall, this study is part of a larger project aimed at informing current policy efforts for the development of a trustworthy SHDS. A policy report with the findings was published in November 2024 (Daniore et al., 2024).

3. Results

3.1. Participant demographics

We conducted focus groups with 51 members of the Swiss public and the panel discussion with eight experts. Of the eight experts, 3 (38%) were healthcare professionals, 3 (38%) were patient advocates, and 2 (25%) were patients living with chronic diseases. An overview of the participant demographics is presented in Table 2.

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Table 2. *Participant demographics*

	Number of participants	Age range	Gender distribution
Focus group 1: In-person at the University of Zurich	17	19–76	59% women, 41% men
Focus group 2: Online, French-speaking region	9	24–66	45% women, 55% men
Focus group 3: Online, Italian-speaking region	9	23–75	55% women, 45% men
Focus group 4: Online, German-speaking region	8	20–67	50% women, 50% men
Members of the public	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

3.2. Recommendations

By combining findings from the four focus groups with insights from the experts, we identified policy and communication recommendations, as well as public concerns, to guide policymakers in developing a trustworthy SHDS. The policy recommendations are supported by implementation guidance to ensure that they are easy to understand and actionable for policymakers (Lavis et al., 2012). Next is a summary of the findings from the focus groups and expert panel that informed the development of the recommendations. Examples of quotes from the study participants are presented in Supplementary Data S3.

3.3. Policy recommendations

We identified four categories of policy recommendations aligned with the four fictitious case studies to best inform ongoing policy developments: (1) consent management, (2) record linkage, (3) national data coordination center, and (4) cross-border data exchange.

4. Consent management

Across all focus groups and the expert panel, discussions on consent management revolved around the fundamental need for individuals to have transparency regarding how their personal health data are used, the entities who have access to it, and the purposes for which it is used (Table 3). Accordingly, the consent models discussed in order of increasing degree of informed decision making were: (a) the opt-in model, (b) the "value-based" opt-out model, and (c) the opt-out model. Across all focus groups, a consistent pattern was observed in which participants initially favored more transparent opt-in models, such as dynamic consent, which would require individuals to be informed of each data-sharing request and to provide approval on a case-by-case basis. However, as discussions progressed, participants raised concerns about the feasibility of these models in achieving the broader societal goals of nationwide health data sharing. This led to a shift by many participants in preference toward the "value-based" opt-out model, where individuals can, for example, communicate their general preferences regarding data sharing on an annual basis, and their data are then used and shared for research purposes in accordance with those preferences. To allow for such a solution to work, participants emphasized the importance of clearly communicating the project's purpose and intended impact in an accessible and understandable manner, ensuring that individuals can make informed decisions to opt-out based on their values. This approach converged to an "informed value-based opt-out model," which became the preferred choice of both focus group participants and expert panelists.

5. Record linkage

The use of Switzerland's social security identifier, the AHV number, as the primary linking variable for connecting records was met with significant skepticism (Table 4). These concerns were mainly focused on privacy, specifically the risk of re-identifying individuals if anonymization procedures were not

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Table 3. *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	The consent management system should clearly state how privacy is protected within the datasets 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.
Consent model	
Design the consent management system to be user-friendly	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.
Adopt an informed value-based opt-out consent model since this is favorable from both the public and research perspectives	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.
Alternative: Implement an informed dynamic consent model (opt-in) for individuals willing to invest time in consent decisions over an extended period	The consent management system should notify individuals when there are updates regarding the use of their data and offer them the option to reconfirm or withdraw their consent.
Reminders	
Send annual reminders to the public to remind them of their right to review and update their consent preferences	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.
Data use after death	
Provide data control options allowing individuals to set conditions for data use after death, or set an expiry date for their consent	The consent management system should provide an option for individuals to set a deadline (i.e., expiry date) for the use of their data.
Data removal	
Incorporate the ability to remove data as part of the consent management system	The consent management system should provide the option for individuals to request the complete removal of their data from the data space.

undertaken properly. While focus group participants recognized the logical use of the AHV number to link data from all Swiss residents, there was broad agreement that necessary safeguards must be put in place to protect privacy. These discussions emphasized the need for a governance framework or a charter of principles for the SHDS that clearly defines the security measures in place for linking identifiers, such as the AHV number. Building on this, expert panelists recommended that the governance structure or charter

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Table 4. *Record linkage: policy recommendations and implementation guidance*

Policy recommendations	Implementation guidance
Record linkage	
AHV number	
Establish a unique and secure identifier for data linkage	A unique identifier system, such as an encrypted AHV number or alternative identifier, should be established to facilitate the linkage of various datasets
Establish and enforce measures to prevent the misuse of AHV numbers by NDCC staff	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 anonymized form

of principles should outline how these security measures will be made transparent, as well as detail the specialists and controls in place to prevent re-identification.

6. National data coordination center

Overall, there was general consensus on the role of the NDCC as a center of expertise, and requirement that it should be supported by external oversight to ensure transparency, efficiency, and adherence to best practices, while preserving public trust and accountability (Table 5). Most discussions surrounding the NDCC centered on its governance. Both the public participants and expert panelists emphasized that in the spirit of open governance, governance measures and designated contact information for all relevant areas should be made publicly available and transparent. Discussions also centered on the public preference for the NDCC to remain independent, be established at the federal level, and be governed by an oversight committee that represents both the Swiss population and relevant stakeholders involved in health data sharing, including university representatives. An important point raised by the expert panel and in focus groups was the preference for the NDCC to establish a self-sustaining financing model, to ensure that the costs associated with the NDCC and the SHDS overall are not transferred to the public.

7. Cross-border data exchange

There was general agreement on Switzerland's prominent role in research and academia, and the importance of its participation in international research efforts to maintain this position (Table 6). Members of the public and expert panelists alike regarded the SHDS as a key enabler for Switzerland to participate in such efforts. Discussions primarily focused on the importance of establishing appropriate measures to align data quality standards within the SHDS with those of data originating from international sources. With ongoing developments with the EHDS, discussions highlighted the importance of designing governance structures aligned with those of the EHDS to facilitate their integration and avoid duplication of efforts in the future.

7.1. Public concerns regarding the trustworthy development of an SHDS

While members of the public and expert panelists expressed overall support for the SHDS, concerns were raised regarding its trustworthy development (Table 7). Concerns primarily centered on the centralization of decision making within the SHDS, particularly regarding its potential impact on privacy preservation, the assurance that data would be used solely for its intended purposes, and the security of the data against bad actors. Given the stalled progress with the implementation of Switzerland's national electronic health record system (EPD), concerns were raised about decision-makers' ability to overcome political and

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Table 5. *NDCC: policy recommendations and implementation guidance*

Policy recommendations	Implementation guidance
National Data Coordination Center (NDCC)	
Finance	
Ensure that the NDCC is financially self-sustaining	A self-sustaining financing model should be established to ensure that the costs of the NDCC, including the SHDS itself, are not passed onto the public.
Leverage synergies within the NDCC to enhance efficiency	Synergies can be sought with other ongoing digitalization efforts, such as the EPD system.
Governance	
Ensure that the NDCC operates independently and maintains neutrality	No parties with a conflict of interest should be involved in NDCC governance.
Establish the NDCC as a public entity	The NDCC should be governed as a public institution and be accountable to the public.
Ensure that the NDCC governance body includes public representatives and diverse professional groups, such as general practitioners (GPs), researchers, IT specialists, and politicians	NDCC governance should comprise public representatives and patient experts to ensure a diversity of perspectives. Provisions for external independent oversight can be included.
Ensure that governance procedures are transparent and publicly accessible	The governance model of the NDCC should state: - at which points in the data-sharing process actors are involved and for which duties; - the anonymization procedures undertaken; - the relevant certifications required to perform certain tasks; and - the access control measures in place. Provisions should be made to state a designated contact person for each specialized area from which data may be requested.
Federal level	
Establish the NDCC at the federal level	The NDCC should be governed at the federal level, with additional considerations made to ensure meaningful involvement of the cantons.
Evaluate the potential risks associated with centralizing the NDCC	Considerations should be made to determine whether centralized governance carries the risk of a power monopoly.

cultural barriers to data sharing for the broader societal benefit through the SHDS. Key questions were also raised regarding whether decisions, such as those made through an "informed value-based opt-out model," would be developed and made accessible in a way that can effectively reach all population groups, with adequate onboarding measures in place to ensure informational self-determination.

7.2. Communication recommendations

Study participants generally agreed that addressing public concerns would be best supported by a well-informed and effective public communication strategy. A set of communication recommendations was formulated based on the discussions with the focus groups and experts (Table 8). It was emphasized that

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Table 6. *Cross-border data exchange: policy and implementation guidance*

Policy recommendations	Implementation guidance
Cross-border data exchange	
Data governance	
Apply data governance rules from the SHDS to all data access requests originating from foreign countries	Requests for foreign data access should be subject to the same control procedures as those for national data access.
Data quality	
Ensure that data from foreign countries meets high-quality standards	Checks (e.g., through a checklist or certification) should be implemented to ensure that the data quality standards for international data are met.
Value systems of collaborating countries	
Ensure that the public values and norms of Switzerland are upheld by foreign countries that utilize Swiss data	Foreign data access requests and their evaluation should include assessments of research, societal values, and norms.

Table 7. *Public concerns related to the SHDS*

Public concerns
- Data misuse fears
- Data security fears
- Data theft fears
- Delays in implementation due to prolonged political deliberation
- 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 centralized NDCC governance
- Privacy concerns
- Protection of minors
- Record linkage fears
- Swiss data being accessed by non-EU states
- Unequal access

for the SHDS to actively foster public trust, an ongoing two-way dialog between the public and the stakeholders involved in its development is needed. This involves clear and targeted communication with relevant members of the public, meaningfully highlighting the societal benefits of nationwide health data sharing, with some participants comparing it to the act of donating blood. The choice of trusted spokespeople, such as general practitioners or other individuals with whom the Swiss public can identify, is essential. This should be paired with leveraging awide range of communication channels capable of reaching all members of the Swiss population, such as a website where individuals can provide feedback and social media. Furthermore, two-way public communication involves actively engaging the public at key stages of the SHDS development, gathering feedback through forums, and incorporating it into

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Table 8. *Public 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	Public communication campaigns should use messaging analogous to initiatives such as blood donation campaigns to emphasize the societal relevance of the health data space across various media channels. Successful projects using data from the SHDS 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 toward population groups that are underrepresented in health research in Switzerland.
Use public exchange forums to engage the public and offer them the opportunity to speak directly with experts	Public exchange forums should be held at key stages of the SHDS' development, from the early definition phase to the implementation stage. These forums 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 hard-to-reach population groups to gather insights into their requirements and expectations for participation in the SHDS.
Content	
Use tangible and understandable language tailored to different age and population groups to address public concerns	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.
Leverage patient success stories	Patient success stories should be included in communications to illustrate the benefits of data sharing and use.
Ensure honesty and transparency in all communications	Communication should be honest and transparent.
Spokesperson	
Involve GPs and individuals whom the public identifies with	Tangible and relatable spokespersons should be selected to communicate about the health data space so that the public can more easily identify with them
Caution	
Overcome challenges in reaching larger segments of the public by addressing language barriers and low levels of interest	Communication strategies should consider how to engage hard-to-reach population groups and those demonstrating little or no interest in health data sharing

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relevant efforts. Overall, all study participants emphasized the importance of ensuring that public communication is built on honesty and transparency.

8. Discussion

Based on a large sample of the Swiss public and experts, this study identified key elements regarding consent management, data linkage, the establishment of a national data coordination center, and cross-border data exchange that would contribute to making the SHDS trustworthy. Based on feedback from the public and validation from experts, the policy and communication recommendations presented in this study offer an initial reference for policymakers and relevant stakeholders involved in the development of a trustworthy SHDS. These recommendations can also be applicable to other countries, including those participating in the EHDS, to guide efforts in establishing trustworthy nationwide health data-sharing frameworks for secondary use.

Incorporating the elements identified in this study that contribute to making the SHDS trustworthy should be complemented by policy efforts aimed at building and maintaining public trust. This can be accomplished by clearly embedding public trust and trust-building principles into national legislation, to allow for policy implementers to adopt trust-building measures at various stages of health data-sharing policy process. A recent framework analysis identified that these principles have been incorporated only to a limited degree within Swiss, Italian, French, and EU health data-sharing legislations, reflecting a missed opportunity to prioritize these efforts from the outset (Zavattaro et al., 2024). These can be complemented by the application of indicators that are routinely monitored to evaluate whether outcomes related to public trust are being achieved (van der Schee et al., 2006; Gille et al., 2024). This approach mirrors the use of performance metrics applied in healthcare systems for accountability and quality control of health system activities (Braithwaite et al., 2017). Clearly defining public trust as a key objective, along with establishing a roadmap to monitor progress throughout the policy lifecycle, offers a concrete opportunity for policymakers to actively contribute to building public trust in the SHDS and other national health data-sharing initiatives.

Policymakers should demonstrate that the national health data-sharing system for secondary use would benefit society and should actively work toward alleviating public concerns about data use and reuse. An important observation from our study is the broad consensus among both the Swiss public and experts that the establishment of a national health data-sharing system for secondary use would benefit society. Nevertheless, the benefit emerging from data sharing and use needs to be visible and understandable to the general public. If it is not clear how data-sharing benefits the society and wider system, it will be difficult to build trust. This aspect was made evident by the widespread criticism and lack of public trust surrounding the rollout of the electronic patient dossier (EPD), Switzerland's national electronic health record system (Zavattaro et al., 2025; Daniore et al., 2025). In particular, skepticism has focused on the fact that the benefits of the EPD are not apparent to many users due to the system's complexity, with multiple competing platforms making participation confusing and difficult in practice. This lack of clarity and advocacy from healthcare professionals has resulted in low public uptake and low trust in the EPD. In comparison with neighboring countries, Switzerland is among the lowest in public trust in its EPD, alongside Germany and France, where concerns are shaped by issues of privacy and government oversight. In contrast, public trust in Austria is higher, as its unified system (ELGA) is perceived to offer clear benefits and easy access to personal health data (Papadopoulos et al., 2025).

A central point raised by our study's participants is the importance of implementing appropriate measures that foster public trust that focus on alleviating their concerns (Holland et al., 2022). Using the EPD as a reference for the SHDS could be a valuable first step, by ensuring from the outset that its benefits are clearly communicated and made tangible to the public, that the system itself is easy to access and use, and that data privacy is safeguarded. Early evidence from Finland indicates high public acceptance of health data sharing within the national health data infrastructure, Findata, which is largely due to public understanding of its benefits and the presence of a robust regulated environment for health data sharing (Cascini et al., 2024). This calls for the establishment of a two-way communication channel between the public and the stakeholders involved in the development of the SHDS (Zawati and Lang, 2024; Intemann,

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2023). Achieving this requires a structured approach to ensure meaningful public involvement activities are planned at key stages of the SHDS development, as proposed in a recent perspective paper (Daniore et al., 2025). This can be facilitated through strategies such as hosting public forums to gather feedback on new developments, providing an accessible website that clearly explains progress with the SHDS where the public can provide input, and offering clear communication through trusted spokespeople, to allow the public to form informed opinions on the SHDS (Lee and Li, 2021). If done right, it can contribute to increased social cohesion, public support, and encourage public participation in activities related to the SHDS (Council et al., 2014). When this is not the case or, if public trust is lost, the opposite may happen as a result of conflicts over privacy rights and self-determination, coupled with fears of data misuse, which could potentially undermine the success of the SHDS (Raab et al., 2023).

At the core of building public trust through policy and public communication is the underlying governance of the SHDS (de Ruijter et al., 2024). Building public trust requires thoughtful leadership, sustained commitment, and adequate resources at the executive level, all of which should be clearly defined within a comprehensive governance framework (Burgess, 2014). The governance framework must prioritize balanced oversight and the protection of public interests by meaningfully including relevant stakeholders and public representatives across all key phases of development of the SHDS. This should be paired with clear accountability measures to support trust-building efforts (Bartlett et al., 2024). As previously suggested with the trust performance indicators to monitor the implementation of trust-building measures, a similar set of indicators could also be developed and used for performance appraisal of the SHDS governance board itself. Importantly, the governance framework should be designed to align with the EHDS, to facilitate future cross-border data exchange without unnecessary duplication of efforts (Terzis and Santamaria Echeverria, 2023).

9. Conclusion

Given that the SHDS is still in its early stages, it is now a crucial time to implement public feedback related to consent management, data linkage, the establishment of a national data coordination center, and cross-border data exchange that have been identified as essential for making the SHDS trustworthy. Central to this will be the public communication efforts and stakeholder engagement that foster public trust and address their concerns as the SHDS develops. Policymakers should prioritize early engagement with the public and relevant stakeholders in shaping both the dialog and implementation of the SHDS, supported by clearly defined measures to build public trust. This needs to be supported by systematic evaluations to assess whether these measures are being met to ensure that fostering public trust becomes an integral, foundational aspect of the SHDS. Ultimately, systematically prioritizing policy, public communication, and governance in a way that fosters public trust from the outset gives the SHDS the best chance of developing into a meaningful initiative that the Swiss public is more likely to support and participate in.

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Data availability statement. Data for this study are stored on the University of Zurich infrastructure, but are not available or deposited publicly in order to protect the privacy of the individuals who were interviewed.

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