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Recommendations for a more integrated Swiss health data ecosystem based on lessons learned from selected use cases for data re-use in academic public health research

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Includes three case studies described in specific annexes:

1. Association of a federal data repository and the interoperability platform I14Y – Proof of concept.
   Authors: Céline Racine, Floriane Pochon-Levit, Thorsten Kühn.
   DOI : https://doi.org/10.16908/pub.2025.003
2. Health Services Research: Access to, and integration of, inpatient and outpatient health administrative data for assessing healthcare systems' performance.
   Authors: Marie-Annick Le Pogam, Murielle Bochud
   DOI : https://doi.org/10.16908/pub.2025.004
3. Occupational Health: Accessing and coding biomonitoring data acquired as part of the authorities' monitoring activities
   Authors: Hasnaa Chettou, Murielle Bochud, David Vernez
   DOI: https://doi.org/10.16908/pub.2025.005

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1. Summary

This report synthesizes findings from three case studies conducted under the DigiSanté program, which supports the digital transformation of the Swiss health systems. The proposed case studies have been specifically chosen to illustrate the practical experience, difficulties and challenges encountered by research teams at Unisanté, a Swiss academic institution of general internal medicine and public health based in Lausanne, during their public health research activities. The three case studies focus on:

1. **Data Findability and Metadata Integration** – Enhancing visibility of health-related datasets via the I14Y national data catalogue.
2. **Health Services Research** – Evaluating the impact of COVID-19 on cancer care using medico-administrative data.
3. **Occupational Health** – Aggregating biomonitoring data for chemical exposure analysis.

Despite their distinct domains, these case studies share common goals and challenges in the secondary use of health-related data for academic and public health purposes. This report highlights their shared insights and offers cross-cutting recommendations that are meant to be broadly relevant to all academic institutions working in the field of public health in Switzerland.

2. Context

2.1. Program DigiSanté and the project Data space for health-related research

DigiSanté is a strategic program of the Federal Department of Home Affairs, jointly led by the Federal Office of Public Health (FOPH) and the Federal Statistical Office (FSO). It aims at promoting the digital transformation of the Swiss healthcare system and the implementation of the Swiss Health Data Space (SHDS), in close collaboration with healthcare system stakeholders. DigiSanté establishes digital and standardised health-related services of the federal government and in doing so facilitates efficient day-to-day work. The broad use of a secure health data space by all stakeholders lends support to the high quality of treatment provided within our modern healthcare system and improves both public services and research conducted in the interests of all people.

The FOPH-project “Data space for health-related research” (DSHR) is implemented as part of the DigiSanté program package 4 on secondary use of data for planning, management and research. The project is based on the Federal Council’s report of May 4, 2022, in fulfillment of Po 15.4225 Humbel “Better use of health data for high-quality and efficient healthcare”. The Federal Council decided to further refine the suggested “national system for the reuse and linking of health data for research purposes” for implementation in the context of the SHDS.

2.2. Unisanté

Unisanté is a university center for general medicine and public health located in Lausanne, Switzerland. It employs approximately one thousand staff, including around fifty faculty members affiliated with the University of Lausanne. The institution encompasses the full continuum of healthcare and public health services—from primary care, support for vulnerable populations, and occupational medicine to health promotion and prevention, health system organisation, academic research, and university teaching.

Unisanté is committed to improving the health of individuals and communities by addressing both

medical and broader social and environmental determinants. The institution's expertise is grounded in scientific evidence and focused on innovation to respond effectively to constantly evolving public health challenges. As an academic institution, Unisanté conducts a broad range of research and educational activities in general and community medicine, as well as public and occupational health.

3. Common insights and recommendations

The three proposed case studies share common themes and insights that are detailed below, followed by general recommendations based on practical experience from concrete projects conducted during the past years within a Swiss academic institution – Unisanté, which is academically embedded within the faculty of biology and medicine of the University of Lausanne.

3.1. Secondary Use of Health Data for Public Good

All three case studies emphasize the value of reusing existing health data to inform public health, occupational safety, and healthcare policy within the Swiss fragmented health care systems. They align with DigiSanté's goals of enabling:

- Academic research (Use Case 1)
- Scientifically informed decision-making for authorities (Use Case 4)

Each project demonstrates how secondary data use can generate insights into population health, healthcare system performance, and environmental exposures that are relevant for the development and evaluation of public health policies at cantonal and federal levels and impactful public health research.

3.2. Data Fragmentation and Interoperability Challenge

A recurring issue is the fragmentation of data across institutions and systems:

- The I14Y proof-of-concept addressed this by developing a harvester to integrate metadata from institutional repositories into a national catalogue, improving data discoverability.
- In the TOCCATA project, hospital and insurance data could not be linked due to legal and technical constraints, limiting the ability to track patient care trajectories.
- The occupational health case faced difficulties combining datasets from SUVA, SHeS, and SKIPOGH due to inconsistent coding and lack of standardized metadata.

These examples underscore the need for interoperable systems and standardized metadata to enable meaningful data integration.

3.3. Legal, Ethical, and Administrative Barriers

All case studies encountered or highlight significant regulatory and administrative hurdles:

- **Strict anonymization requirements** (e.g., under the nFADP) limited data granularity and linkage.
- **Complex data access procedures** delayed research timelines (e.g., 3.5 years for TOCCATA).

- **Lack of clear governance** for data reuse, especially from enforcement agencies like SUVA, hindered access.

These barriers reduce the timeliness and impact of research and highlight the need for a **coherent legal framework** for secondary data use.

3.4. Metadata Quality and Data Documentation

Poor metadata quality and inconsistent documentation were cited as major obstacles:

- The **I14Y project** focused on improving metadata interoperability through mapping between DDI and DCAT-CH standards.
- In the **TOCCATA study**, lack of data dictionaries and inconsistent variable naming complicated analysis.
- The **occupational health case** noted the need for harmonized coding systems (e.g., ISCO, FoodEx) to enable cross-database analyses.

Improving metadata quality is essential for data reuse, discoverability, and integration.

3.5. Need for Infrastructure and Governance Reform

All three case studies call for systemic improvements:

- A **federal health data trust center** is proposed to enable secure, privacy-compliant data linkage.
- **Standardized metadata catalogues** like I14Y can enhance health-related data findability and reuse.
- **Legal and technical frameworks** must evolve to balance privacy with public health research utility.

3.6. Shared Recommendations

Based on the common findings, the following cross-cutting recommendations emerge:

1. **Develop a national legal and ethical framework for secondary data use**
    - Establish clear legal and ethical guidelines for data reuse.
    - Harmonise data access procedures and clarify the legal basis for data reuse across federal, cantonal, and private actors.
    - Define governance roles for enforcement agencies (e.g. SUVA) and academic institutions.
2. **Develop a federal health data trust center**
    - Enable privacy-preserving record linkage across datasets and data analyses in secure environments.

- Serve as a coordinating entity for linking administrative, clinical, and population data in a legally and technically secure manner.

3. **Standardize metadata and coding systems**
    - Adopt and enforce international standards (e.g., ISCO, ICD-10, FoodEx).
    - Ensure consistent variable naming and documentation by providing harmonized metadata templates and dictionaries across datasets.
4. **Facilitate data access procedures**
    - Streamline approval processes and reduce administrative burden.
    - Simplify ethics and access procedures through shared legal tools and data use agreements.
    - Deploy APIs and automated harvesting (e.g., I14Y integration) for data discoverability.
5. **Promote technical capacity and support**
    - Support secure data environments (e.g., clean rooms, trusted centers).
    - Encourage institutions to host data stewards and offer training in metadata management.
    - Provide resources for metadata mapping and repository integration.
    - Enhance computational resources for large-scale data analysis.
6. **Foster interdisciplinary and inter-institutional collaboration**
    - Engage researchers, policymakers, data custodians, and IT experts.
    - Promote co-development and sharing of tools, standards and secure data infrastructures.

4. Conclusions

These case studies illustrate both the obstacles and transformative potential of secondary health data use in Switzerland. Realising this potential requires a coherent legal framework, robust infrastructure, standardised metadata practices, and strategic governance. The recommendations provided here offer a blueprint to build a trusted, FAIR-aligned, and impactful national health data ecosystem supporting research, policymaking, and population health.