Towards a national strategy for registries and cohorts

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Proliferation of databases and registries

Registries and cohorts are part of the essential data infrastructure for Switzerland’s healthcare system. The large number of registries created in recent years has led to many parallel structures of varying quality. In addition, neither an adequate financing system nor a clear regulatory framework exist for registries. In view of this situation, the association unimedsuisse has drawn up a position paper outlining the need for political action with regard to medical registries and cohorts in Switzerland (see its position paper in German and in French).

Initial political situation

The growing data needs of the Confederation and the cantons are met by a large number of databases, but the corresponding projects remain sectoral and thus contribute to the current proliferation of data collection sources. The Federal Council's health policy strategy for 2020–2030 mentions the necessity for coordinated digitisation and proposes creating favourable conditions for using health data. However, unimedsuisse thinks that this is not enough: there is an urgent need for the federal government to make strategic decisions.

The Federal Council’s strategy on education, research, and innovation for 2021–2024 proposes co-financing nationally important medical cohorts for medical research. However, the funds earmarked for this remain small. Currently only two cohorts are entitled to funds, and the funding criteria remain unclear. Fortunately, the Federal Council’s strategy for 2021–2024 also provides for the continuation of the Swiss Personalized Health Network (SPHN), which offers a platform for exchanging research data. The federal research strategy is thus heading in the right direction; however, it does not look beyond its own sector.

Thus, research funding and health policy still pursue different approaches to registries. Yet in reality, data collection and data use are increasingly moving away from segmented uses. The future lies in linking clinical registries, cohorts, biobanks, and administrative data and in using data for different purposes – for clinical treatment, quality management, tariff calculation, remuneration, policy planning and surveillance, research, and postmarketing documentation.

Future political action

It is in the interest of political decision makers to make better use of registries, cohorts, and biobanks.

unimedsuisse proposes four main lines of approach to achieve this.

1. Establish a national registry strategy

First of all, the Confederation needs to establish a national policy for registries, cohorts, and biobanks in the Swiss health system. Data collection sources in health care should be made available for research in a structured and systematic manner. The strategy should include:

- the most important health policy challenges that the data infrastructures aim to address
- an integrated view of health data that considers medical treatment, quality management, and research as well as reimbursement, government planning, and controlling
- a distinction between mandatory and recommended data collection and the definition of a uniform minimal data set
- minimum requirements for registries (see the recommendations issued by the ANQ, FMH, H+, SAMS, and unimedsuisse).

2. Define technical standards

The IT platforms that host registries, cohorts, and biobanks should be based on uniform principles and standards that allow for interoperability. Existing large biomedical IT platforms should be promoted, and the opportunities offered by the SPHN should be systematically exploited. Once harmonisation is completed, the technical solutions identified should be the subject of recommendations.

3. Coordinate with official statistics

Coordinating official statistics with registries can greatly benefit health policy. It therefore makes sense to allow officially collected data to be used with registries. This would simplify data collection processes, plausibility checks, and data quality audits as well as reduce duplicate data collection. International examples show that this can be done while also protecting personal rights.

4. Harmonise operation with sustainable financing mechanisms

Registries and biobanks should not increase healthcare expenditures. Resources can be pooled by merging registries into large biomedical platforms. In addition, uniform financing principles should be defined that not only include the cost of infrastructure and data collection but also consider the various purposes and users. The collection and use of compulsory data should be financed by the Confederation or the cantons, while the collection of optional data and research projects should be financed externally.