

How to make biomedical research datasets interactive

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Personalized Health Informatic. Credit: SIB / Christian Lovis, UNIGE

The concept of interoperability describes the ability of different systems to communicate. This is a major challenge in biomedical research, and in particular, in the field of personalized medicine, which is largely based on the compilation and analysis of numerous datasets. For instance, the COVID-19 pandemic has shown that even when the technical, legal and ethical constraints are lifted, the data remain difficult to analyze because of semantic ambiguities. Under the auspices of the Swiss Personalized Health Network (SPHN) and in close collaboration with representatives from all five Swiss university hospitals and eHealth Suisse, a team of



scientists from the University of Geneva (UNIGE) and the University Hospitals of Geneva (HUG), in collaboration with the SIB Swiss Institute of Bioinformatics and the Lausanne University Hospital (CHUV), have developed the strategy for a national infrastructure adopted by all Swiss university hospitals and academic institutions. With its pragmatic approach, this strategy is based on the development of a common semantic framework that does not aim to replace existing standards, but to use them in a synergistic and flexible way according to the needs of the research and the partners involved. The implementation of this strategy, which has already started, marks a crucial step to stimulate research and innovation for a truly personalized medicine in Switzerland.

Personalized medicine is based on the exploitation and analysis of large quantities of data whether genomic, epidemiological or from <u>medical</u> <u>imaging</u>, to extract meaning. To be able to do this, cross-referencing and aggregating mutually intelligible data is compulsory, even when they come from very different sources.

With this in mind, the Swiss government created in 2017 the Swiss Personalized Health Network (SPHN), an initiative placed under the leadership of the Swiss Academy of Medical Sciences in collaboration with the SIB Swiss Institute of Bioinformatics that aims to promote the use and exchange of health data for research. "Despite major investments over the past decade, there are still major disparities", says Christian Lovis, director of the Department of Radiology and Medical Informatics at the UNIGE Faculty of Medicine and head of the Division of Medical Information Sciences at the HUG. "This is why we wanted, with our partners and the SPHN, to propose a strategy and common standards that are flexible enough to accommodate all kinds of current and future databases."

A three-pillar strategy



We communicate on three main standards: the meaning we give to things, because we must agree on a common basis for understanding each other; a technical standard—the sound, with which we speak; and finally, the organization of the meaning and sound with sentences and grammar to structure the communication in an intelligible way. "In terms of data, it's the same thing, explains Christophe Gaudet-Blavignac, a researcher in the team led by Christian Lovis. You have to agree on a semantic, to represent conceptually what has to be communicated. Then we need a compositional language to combine these meanings with all the freedom required to express everything that needs to be expressed. And finally, depending on the projects and research communities involved, this will be 'translated' as needed into data models, which are as numerous as the languages spoken in the world."

"Our aim has therefore been to unify vocabularies so that they can be communicated in any grammar, rather than creating a new vocabulary from scratch that everybody would have to learn anew", says Christian Lovis. "In this sense, the Swiss federalism is a huge advantage: it has forced us to imagine a decentralized strategy, which can be applied everywhere. The constraint has therefore created the opportunity to develop a system that works despite local languages, cultures and regulations." This makes it possible to apply specific data models for only the last step to be adapted to the formats required by a particular project—the Food and Drug Administration (FDA) format in the case of collaboration with an American team, for example, or any other specific format used by a particular country or research initiative. This constitutes a guarantee of mutual understanding and a huge time saving.

No impact on data protection

However, data interoperability does not mean systematic data sharing. "The banking world, for example, has long since adopted global interoperability standards, stresses Christophe Gaudet-Blavignac. A



simple IBAN can be used to transfer money from any account to any other. However, this does not mean that anyone, be they individuals, private organizations or governments, can know what is in these accounts without a strict legal framework." Indeed, a distinction must be made between the instruments that create interoperability and their implementation, on the one hand, and the regulatory framework that governs their accessibility, on the other hand.

Strategy implementation

This strategy has been implemented stepwise in Switzerland since the middle of 2019, in the framework of the Swiss Personalized Health Network. "Swiss university hospitals are already following the proposed strategy to share interoperable data for all multicentric research projects funded by the SPHN initiative", reports Katrin Crameri, director of the Personalized Health Informatics Group at SIB in charge of the SPHN Data Coordination Centre. Further, some hospitals are starting to implement this <u>strategy</u> beyond the SPHN initiative.

More information: Christophe Gaudet-Blavignac et al, A National, Semantic-Driven, Three-Pillar Strategy to Enable Health Data Secondary Usage Interoperability for Research Within the Swiss Personalized Health Network: Methodological Study, *JMIR Medical Informatics* (2021). DOI: 10.2196/27591

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