Swiss Multiple Sclerosis Registry: A landmark project for citizen science

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Since its foundation in 1959, the Swiss Multiple Sclerosis Society (Swiss MS Society) has been supporting people living with multiple sclerosis (MS) in their daily lives. The organisation also provides funding for scientific research and serves as an independent platform for information related to MS. The quest to better understand MS and ultimately find its cure has always been a driver for innovation. Seizing the opportunities created by the emergence of data-driven medicine, the Swiss MS Society created the Swiss MS Registry – the first health registry in Switzerland owned exclusively by a patient organisation.

Still today scientists do not know the exact number of people with MS in Switzerland. The MS Registry thus aims to document the prevalence of MS in Switzerland and the number of people affected indirectly, such as relatives. The MS Registry is therefore considered a longitudinal study under the terms of the Swiss Human Research Act (HRA). The study assesses various aspects of MS, including quality of life, nutrition, work situation, pharmaceutical MS therapies, and complementary medical treatments. The scientific evaluation of these data facilitates the development of measures to improve the treatment and quality of life of those affected by MS.

MS Registry and MS Cohort: Two studies with one goal

A further objective of the MS Registry is to establish a flexible infrastructure and a network that enable interdisciplinary research with partners. An important example of this is the close cooperation with the Swiss MS Cohort Study. Both the registry and the cohort study are funded or co-funded by the Swiss MS Society.

Both initiatives aim to improve the living conditions of people with MS. Whereas the MS Cohort Study focuses on medical data collected from clinics, the MS Registry puts emphasis on people's everyday experiences and collects a large amount of data directly from participants, who may also be healthy relatives of MS patients. Data are related to participants' individual disease history, living situation, mental health, and treatment.

Due to their different approaches, the registry and the cohort complement each other almost perfectly. Participants in both studies are therefore encouraged to consent to the exchange of encoded data between the MS Cohort Study and the MS Registry.

Independence through governance and participation

With about 2500 participants as of August 2020, the MS Registry contains a massive amount of data just four years after its launch. Such a wealth of personal health data requires scientific and commercial independence. This independence is ensured by a broad-based governance organisation consisting of well-established researchers, physicians, physiotherapists, and, of course, people with MS.

The MS Registry is operated at the Epidemiology, Biostatistics and Prevention Institute (EBPI) at the University of Zurich. The registry’s project leader is Prof Viktor von Wyl from the EPBI, who has worked with his team of scientists along with expert participants from the beginning.

A special registry board convenes regularly to review project requests and discuss new topics. And this is where the key factor of the MS Registry comes into play: 25 people with MS are currently involved in all bodies and decisions. People with MS are MS experts and therefore indispensable for researchers and health professionals studying and combating MS. Without the active participation of people with MS, research would miss out to a large extent on a comprehensive MS knowledge pool. Its content-related involvement of medical laypersons and its funding through a patient organisation are what make the MS Register a unique citizen science platform in Switzerland.

Consent, user experience, and features

Participants who do not want to participate in the governance of the Swiss MS Society can just contribute and share information. On average, about thirty new participants enrol each month. The register is open to adults (at least 18 years old) with MS who reside or receive care in Switzerland; it is also open to their relatives. Participants can register online or send in a paper registration form. Along with their consent, participants submit a questionnaire, which is then processed by the registry team. Not just participants may contribute to the data collection; practitioners are also encouraged to allow access to medical records with the consent of their patients (**Figure 1**).

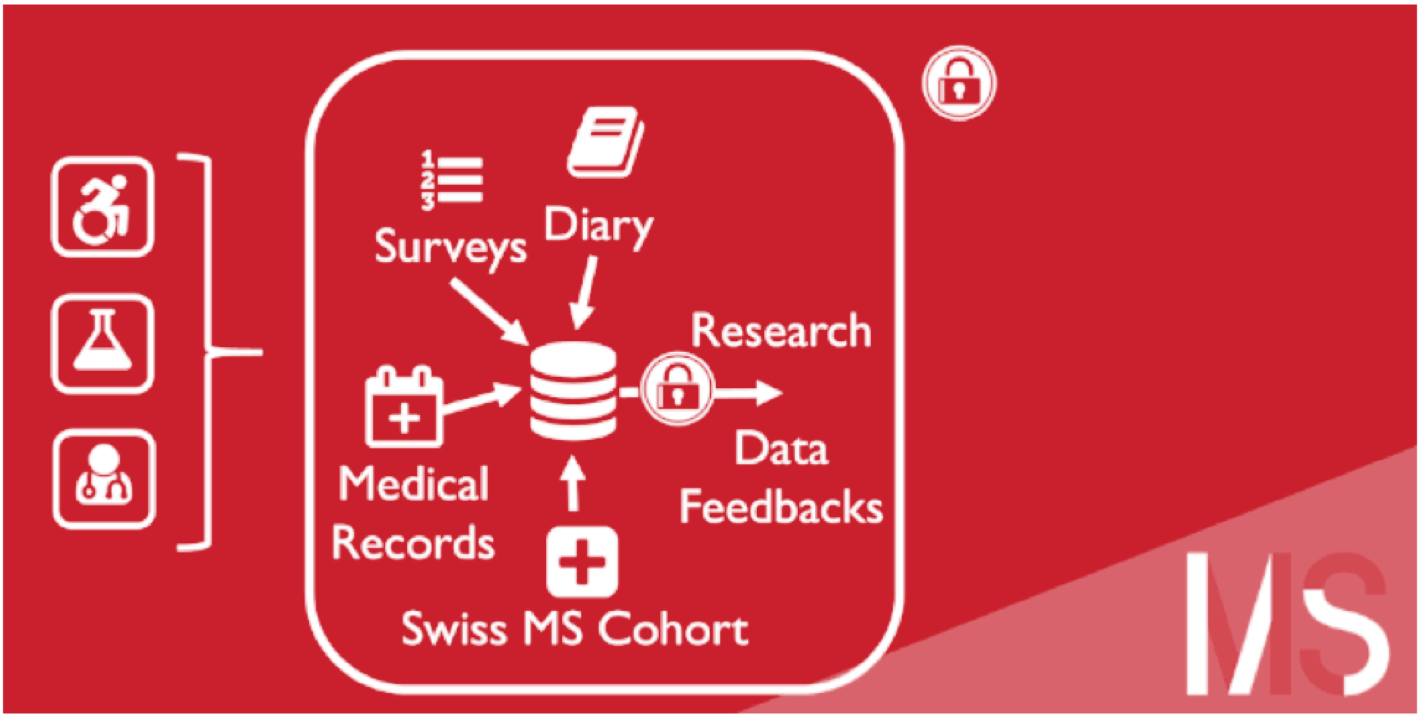

Figure 1: MS Registry’s data sources

Once the initial data has been transferred into the digital universe, enrollees can use the registry’s mobile app to complete regular surveys. The app also includes a diary (**Figure 2**), in which participants can record their personal state of health, activities, and more on a daily basis.

Participants may obtain single-source access to information about MS written in language that is easy to understand. However, they must devote some time to the process. Online or paper questionnaires need to be filled out every six months and take up to an hour to complete.

Wie ist ihr Wohlbefinden heute

100 ist das beste Wohlbefinden und 0 das schlechteste Wohlbefinden, das Sie sich vorstellenkönnen

Wie ist Ihre Stimmung heute?

Figure 2: MS Registry's diary function on its mobile app

Participants are rewarded for their time and effort, because research results are published regularly and reveal valuable practical findings. For example, a team of scientists recently established that only about half of all patients receive their MS diagnosis within three months of their first visit to the doctor. This means that the other half has to wait – sometimes much longer – in a burdensome state of uncertainty. Such findings provide a basis for practical guidelines for doctors.

Regulatory environment and data security

Unlike the harmonised cancer registries in Switzerland, which are governed by federal law, the MS Registry has no specific statutory basis. This does not imply, however, that it operates in an unregulated area. On the contrary, as a longitudinal human research project it is subject to approval by an ethics committee and must comply with data protection regulations. Furthermore, it is regulated by the rules applicable to public bodies in general in the Canton of Zurich and to the university in particular.

Another crucial topic is IT security. All data made available to the MS Registry are encrypted and stored in the IT environment at the university. The relation between data and persons can only be established by means of a key, which is protected and accessible only to selected registrars at the university. Moreover, the MS Registry’s team members are subject to confidentiality rules.

Conclusion

Like other registries or biobanks, the MS Registry faces challenges. One issue is data quality, which depends to a large extent on the accuracy of the information provided by participants. In addition, long-term financing must be secured. In the highly competitive field of Swiss fundraising, funds from members are no guarantee for financial stability. Nevertheless, the Swiss MS Society is set to continue the success story of the Swiss MS Registry.