

MIDATA Platform

- Contribute to the development and improvement of the open source MIDATA IT platform
- Make applications and use cases developed for the platform available to other MIDATA cooperatives
- Commission, on a yearly basis, a security audit of the local instance of the MIDATA IT platform and its operation's organization by an at least nationally recognized office/firm
- Identify, with a high level of quality, each user of the platform, to avoid fake accounts and reduce misuse of the platform
- Conclude from the start and for the first period of operation a support agreement with the Swiss MIDATA.coop

Governance

- Agree to the not-for-profit nature of MIDATA cooperatives
- Agree not to introduce financial incentives for data sharing
- Integrate in its local MIDATA Articles of Association the parts considered as mandatory by the Swiss MIDATA.coop and later, once created, by the international MIDATA.coop Association
- Let the Swiss MIDATA.coop and later, once created, the international MIDATA.coop Association review the local Articles of Association before they are promoted for the first time.
- Let the Swiss MIDATA.coop and later, once created, the international MIDATA.coop Association audit the implementation of the governance model before the local platform goes live for the first time
- Co-develop and improve the cooperate governance model and the universal articles of association

Corporate Design and Communication

- Agree to use the MIDATA.coop brand name (registered trademark)
- Use xy.midata.coop for local cooperatives
- Co-develop an international corporate design with high recognition value
- Assure a positive communication at the local level
- Communicate at the international level only in agreement with now the Swiss MIDATA.coop and later, once created, the international MIDATA.coop Association

Contacts

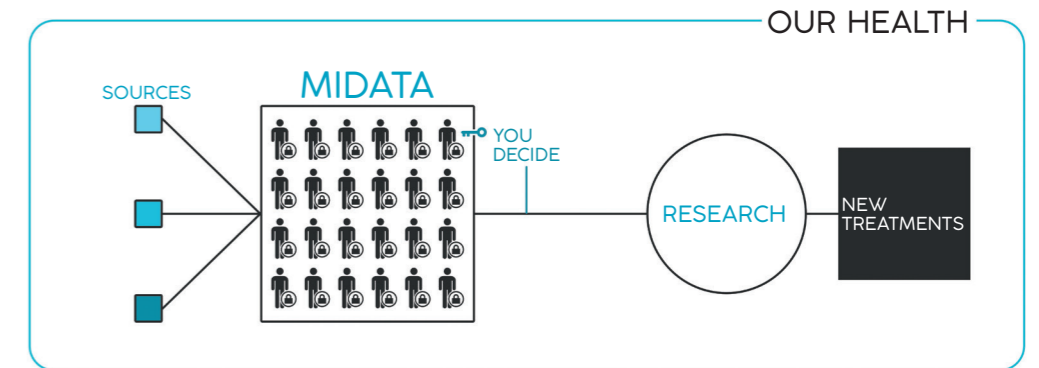
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Supported by



**MIDATA Cooperatives:
 Citizens take control of their
 personal data**



Mission

MIDATA cooperatives enable citizens to securely store, manage and control access to their personal data by helping them to establish and own national/regional not-for-profit MIDATA cooperatives.

MIDATA's initial focus will be on health related data since these are most sensitive and valuable for one's personal health.

MIDATA cooperatives act as the fiduciaries of their account holders' data. As MIDATA account holders, citizens can visualize and analyze their personal data. As cooperative members, they govern the cooperative. They can actively contribute to medical research and to clinical trials by providing access to sets of their personal data across cooperatives.

First MIDATA cooperative in Switzerland

The first MIDATA cooperative was founded in Switzerland, in 2015. It already runs several pilot projects with Swiss university hospitals, supporting patient outcomes research and clinical trials.

MIDATA key objectives

MIDATA cooperatives exist

- to provide its members and the general population with a digital platform (“MIDATA platform”) for secure storage, management, and sharing of personal data of any kind, in particular health and education data, and connected services;
- to provide those services to natural persons who participate in the MIDATA platform as data account holders and to use their data according to the account holders, directions and their explicit informed consent;
- to promote account holders becoming cooperative members, thus partaking in the governance of the cooperative, and to help members building communities around common purposes;
- to promote the digital self-determination of the population by enabling account holders to use their personal data as self-determining agents and as they wish, in particular for research purposes;
- to promote the collective interests of the account holders and to enable the utilization of their personal data as a common resource. This is achieved by enabling account holders to accept requests for the analysis of their data and to give explicit informed consent, and to make the results or the data themselves available to third parties in return for an economic remuneration to the cooperative;
- to foster research projects that benefit society; and
- to employ the scientific results and income derived from the secondary usage of personal data in the framework of the aforementioned objectives.

MIDATA Values

CITIZEN OWNED

Copies of personal data are stored in citizen-owned and citizen-controlled MIDATA cooperatives. Account holders profit from data analysis, visualization and interpretation tools. In this way, account holders will increasingly be able to take control over their own health.

NOT FOR PROFIT

In the same way that blood banks and citizen science platforms work best when no financial incentives are offered, MIDATA cooperatives are not-for-profit. Revenues will be reinvested into

services on the platform and into research projects for the benefit of society.

OPEN SOURCE

MIDATA cooperatives offer an innovation platform (APIs) for third parties by providing a secure sandbox in which to develop data analytics and visualization services on account holders’ data without having to establish their own data storage environment.

TRANSPARENT

Transparency is ensured by the fact that the governance principles of MIDATA cooperatives are public. Account holders are encouraged to become cooperative members and take part in the governance of the cooperative. Account holders are in control of their data. They can withdraw their personal data at anytime.

SECURE

Data are multiply encrypted and only the account holders possess the key to their data. Every data access is logged. Secure citizen-controlled data access across different national cooperatives will be established to permit global research projects and clinical trials.

REGIONAL

The MIDATA model enables the construction of regional/national cooperatives which, by a set of common rules, permit global research projects to be set up and carried out in a fair and democratic manner.

Conditions for Setting up MIDATA Cooperatives in Other Countries

Background

MIDATA.coop has over the past 3 years developed a functional open source IT platform for the secure storage, management and sharing of personal data of any sort. The platform has undergone 3 independent security checks before the first personal data have been stored. MIDATA.coop has also established a clear trust-promoting governance framework that is currently being implemented in the articles of Association of the MIDATA cooperative in Switzerland. A first pilot project in collaboration with the University

Hospital in Bern supporting patient outcome and clinical research has been started successfully. Further projects are planned. The MIDATA data governance model has been publicized nationally and internationally in scientific papers, white papers and conferences. It has received widespread acceptance. The Swiss MIDATA cooperative and its pilot project have been covered in the national daily newspapers and radio.

After these 3 years of research and development work to establish the MIDATA cooperative in Switzerland, MIDATA.coop is interested in supporting the development of MIDATA cooperatives in other countries and is actively collaborating with international partners to set-up MIDATA cooperatives in the framework of defined use cases.

This document lists the terms and conditions under which the Swiss MIDATA.coop supports and contributes to the establishment of MIDATA cooperatives in partner countries/regions.

Support from MIDATA.coop Switzerland

- Technical training and support in setting up a productive local instance of the MIDATA IT platform with a local cloud provider at cost-covering costs
- Ethical and legal framework for sharing personal data
- Template of the MIDATA Articles of Association (part considered by MIDATA.coop as mandatory and part to be adapted to the local cooperative law and other local considerations compatible with the mandatory part)

Terms and Conditions

International MIDATA.coop Association

Agree to become a founding member of an International MIDATA.coop Association that oversees:

- the development of MIDATA cooperatives
- their ethical and legal framework
- the open source MIDATA IT platform development
- the establishment of a SWIFT-like secure data exchange platform between cooperatives
- the communication at the international level