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MIDATA Cooperatives – Democratizing the Personal Data Economy

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The emergence of a large personal data economy generates new digital dependencies. The value of aggregated personal data increases exponentially with the number of related data sets. Analyses of the aggregated personal data are vital to health and medical research. Organized as collectives, individuals have the potential to become important self-determined actors in a new personal data economy in which access to personal data is controlled by the individual and negotiated by a non-profit organization representing the interests of the individuals. The MIDATA cooperative provides the democratically governed fair data infrastructure for this new citizen-controlled personal data ecosystem. MIDATA acts as the fiduciary of its users' data assets.

The MIDATA cooperative operates a secure cloud-based IT platform that enables citizens to securely store, manage and control access to their personal data. As MIDATA account holders, citizens can visualize and analyse their personal data and profit from data services provided on the platform by third parties. With their data, they can actively contribute to medical research and to clinical trials as citizen scientists.

The Swiss MIDATA cooperative has been established in 2015. The cloud-based MIDATA platform has been designed and built with by experts from ETH computer science (Prof. Donald Kossmann) and Institute for Medical Informatics, Bern University of Applied Sciences BFH (Prof. Serge Bignens). The platform has undergone three independent security checks. The first clinical research project on patient-reported outcome after bariatric surgery in collaboration with the Bern University Hospital has been complete in 2016.

Currently there are more than a dozen clinical and health-related citizen science projects running or in preparation with different university hospital groups and a large insurance company. MIDATA has successfully partnered with university institutions in other countries (Charité, Germany; Leiden University Medical Center, Netherlands; Oxford University Hospital Foundation Trust, UK) to initiate the set-up of MIDATA cooperatives in these countries.
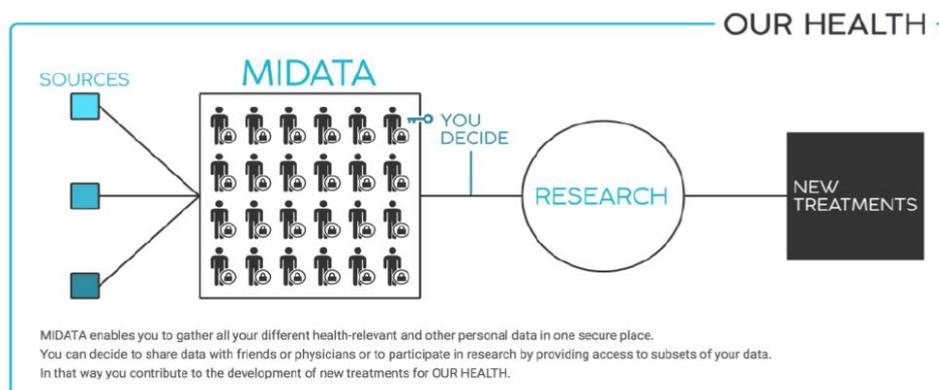

Figure 1: The MIDATA cooperative provides a novel trust framework for citizen-controlled data aggregation and data access control. It enables new research and data services based on aggregated data. Access to a citizen's data is under the exclusive control of the citizen.

Introduction and Context

Personal data are a highly valuable resource[1]. In exchange for free internet or app based services, personal data are often given away unknowingly. This has led to the emergence of a large personal data economy generating new digital dependencies and raising the question how individual privacy and self-determination can be protected, while at the same time the data can be put to use for society and progress. The MIDATA framework provides an answer as to how this dilemma can be solved.

Data can be copied at near zero marginal costs and, according to the new EU General Data Protection Regulation (GDPR), individuals have a right to obtain digital copies of their personal data (data portability)[2]. Only individuals have the ability to aggregate all their different types of personal data including medical, non-medical, health-related and educational data. In particular health and medical data are mostly stored in incompatible silos. The value of aggregated personal data increases exponentially with number of related data sets. Therefore, organized as collectives, individuals have the potential to become important self-determined actors in a new personal data economy in which access to personal data is controlled by the individual and negotiated by an organization representing the interests of the individuals and giving them the possibility to participate with their data in research, if they so wish. The MIDATA cooperative provides the democratically governed fair data infrastructure for this new citizen-controlled personal data ecosystem. MIDATA acts as the fiduciary of its users' data assets.

1. Market and Customers

The size of the market for personal data can be appreciated from the valuation of data companies like Google and Facebook. It has been estimated that in 2020 the personal data market in Europe will generate a value of € 1 trillion, not including medical data that is under strong data protection laws[3]. Since data can be copied and individuals will have a right to a copy of all their personal data according to article 20 on data portability of the EU General Data Protection Regulation directive, an entirely new personal data market can emerge in which citizen control access and can aggregate data that hitherto has been locked in different silos (e.g. medical, mobile-health and genome data). While MIDATA's initial focus is on health, since citizen-contributed data will be a key basis for personalized health research, the next frontier is personalized education, which also relies on the aggregation of personal data that only individuals can combine.

MIDATA's initial customers are university hospitals and research organizations. MIDATA enables patient-reported outcome studies and citizen science projects in which citizens/patients collect relevant data via dedicated smartphone apps. Owing to the novel approach, these use cases have been and will be covered in the media, motivating further citizens to join MIDATA and develop their own interest groups and projects. Furthermore, for-profit third parties (start-up companies, retailers, insurers) can offer novel app based data services on the MIDATA platform.

2. The MIDATA Cooperative, its Values and its USP

The MIDATA cooperative has been founded in Zürich in 2015. Organized as a citizen-owned cooperative, it has four features that have been specifically designed for the democratization of personal data economy.

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[1] World Economic Forum. (2011). Personal Data: The Emergence of a New Asset Class (pp. 1–40).
[2] EU GDPR Press Release, http://europa.eu/rapid/press-release_IP-15-6321_en.htm
[3] The Boston Consulting Group. (2012). The Value of Our Digital Identity (pp. 1–65). Retrieved from http://www.libertyglobal.com/PDF/public-policy/The-Value-of-Our-Digital-Identity.pdf

(1) Individuals can open a MIDATA account without being a member. This ensures that effective inclusion of people in research projects. Account holders are encouraged to become members of the cooperative, thereby taking part in the governance.

(2) Account holders possess absolute control over their data, including anonymized data. Only they decide who can access their data and they can withdraw the data anytime.

(3) Members elect the members of the board and of the data ethics committee.

(4) Account holders cannot receive financial benefits for sharing data, nor can members obtain dividends. The value of personal data is not in the data set of an individual but in that of the collective. Individual financial incentives for data sharing are in conflict with ethics requirements in research. Our studies show that there is a large untapped potential in the population for altruistic data donation (including genome data) for research purposes. The citizen-owned non-profit cooperative ensures that the financial value of aggregated personal data is returned as a common good to society at large.

Since people across different countries have similar needs for services derived from controlled access to these data (e.g., healthcare), MIDATA cooperatives will be set-up in other countries in a joint effort to enable data access across cooperatives (e.g., for rare diseases research). This will result in a true democratization of the personal data ecosystem for the benefit of the society.

The MIDATA unique selling proposition lies in the full coverage of all of the following elements of its ecosystem:

• A secured IT Platform using cryptography and access control giving users full control over their data.
• A semantic model allowing, under user consent, to link and to reuse the data gathered from multiple sources through multiple projects, in particular patient reported outcomes, thus supporting in a novel way clinical research with real world data.
• A transparent and independent governance covering operations, project development and ethic oversight, allowing MIDATA to act as fiduciary between citizen and researchers or commercial partners.
• A clear technical and business separation of the nonprofit services covered by MIDATA and additional services running on the platform offered by for profit partners.
• A technological framework allowing MIDATA and its partners to develop user centred mobile apps within months.
• A sustainable and robust business model based on revenue stream from 6 pillars.

To our knowledge, no other platform on the market covers all those points, hence the interest manifested by larger research organizations over Europe.

3. Projects and International Partners

After three independent security checks the MIDATA platform has been operational since May 2016. The first completed project involved a patient reported outcome study in collaboration with Prof. Philipp Nett, a bariatric surgeon at the Bern University Hospital. Two other use cases involve collaborations between BFH, MIDATA and Prof. Thomas Pabst and Prof. Christoph Stettler from Bern University Hospital in the area of cancer and diabetes, respectively. The common denominator of all these uses cases is patient reported outcomes. Patients participate in the studies by downloading the corresponding app and consent to participating in the study through the app on the MIDATA platform.

The fourth use case is a collaboration between MIDATA, BFH and Professors Roland Martin and Andreas Lutterotti from the Neurology Clinic at the Zurich University Hospital (USZ). A smartphone app has been developed that allows continuous monitoring of patients with multiple sclerosis (MitrendS app). These initial projects include small numbers of patients (< 200). In March 2018, two large citizen projects will be initiated. In collaboration with Prof. Peter Schmid-Grendelmeier (USZ), BFH and MIDATA we are

starting a project addressing 100'000 participants on allergies and hay fever. In collaboration with Prof. Marcel Salathé (EPFL) MIDATA will be involved in another citizen science project on the connection between blood glucose levels, nutrition and gut microbiome involving several thousand participants.

In contrast to the regulatory frameworks and healthcare systems that can vary greatly from one country (or region) to another, the needs of patients and citizens regarding their health are similar globally. Thus MIDATA's transparent cooperative governance model and customized open source platform is also attractive for partner institutions (university hospitals and research centers) in other countries.

Our current partners are:
• Germany: Berlin Institute of Health and Charité: Letter of Intent signed
• Netherlands: Medical Delta (Leiden, Delft, Rotterdam), TNO: Letter of Intent signed
• UK: Oxford University Hospital Foundation Trust: Negotiations ongoing

An increased number of international users of the MIDATA platform will help reduce maintenance and development costs by sharing these costs across the national MIDATA instances from different countries. Furthermore, apps and use cases can be developed locally and propagated internationally.

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