Links and references

Publications

- The original MyData white paper in Finnish (Ministry of Transport and Communications) http://www.lvm.fi/julkaisu/4420389/my-data-johdatus-ihmiskeskeiseen-henkilotiedon-hyodyntamiseen
- World Economic Forum report: http://www.wefo-rum.org/projects/rethinking-personal-data

Technical specifications and related communities

- User Managed Access (UMA) 1.0 Core Protocol (Kantara) https://kantarainitiative.org/confluence/display/uma/UMA+1.0+Core+Protocol
- UMA Working Group (Kantara) https://kantarainitiative.org/confluence/display/uma/Home
- Consent & Information Sharing Work Group (Kantara) https://kantarainitiative.org/confluence/display/infosharing
- Open Notice http://opennotice.org/
- MyData Architecture – technical specification (DHR): https://hiit.github.io/mydata-stack/

Other communities

- Personal Data and Privacy Working Group (Open Knowledge): http://personal-data.okfn.org/
- MyData Working Group in Finland (Open Knowledge Finland): http://fi.okfn.org/wg/my-data/

Related projects and initiatives

- Digital Health Revolution (DHR project): http://www.digitalhealthrevolution.fi
- Revolution of Knowledge Work project (Re:Know project): http://www.reknow.fi
- Midata initiative (UK): https://www.gov.uk/government/publications/midata-voluntary-programme-review
- Personal Clouds: http://personal-clouds.org/

Word from the Finnish Ministry of Transport and Communications

This paper is an English summary that elaborates on a Finnish study commissioned by the Ministry and published in September 2014 on the concept and phenomenon of MyData and its technical, legal, and business implications. The paper is intended to launch a discussion on the potential and impact of a model for handling personal data in a new way.

The paper provides an overview of the theme and a basis for networking and further work by all parties interested in MyData. Due to the novelty of the concept of MyData, there are a number of issues, such as interests and rights of various parties, that need to be discussed and technical problems that need to be solved.

The paper is intended to encourage those interested in MyData to launch further studies and experiments for testing various MyData models, their feasibility, and dissemination.

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MyData

– A Nordic Model for human-centered personal data management and processing

Ministry of Transport and Communications

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Kai Kuikkaniemi
Harri Honko

This white paper presents a framework, principles, and a model for a human-centric approach to the managing and processing of personal information. The approach – defined as MyData – is based on the right of individuals to access the data collected about them. The core idea is that individuals should be in control of their own data. The MyData approach aims at strengthening digital human rights while opening new opportunities for businesses to develop innovative personal data based services built on mutual trust.

PHOTO: MEG STEWART (CC BY 2.0)

MyData Principles

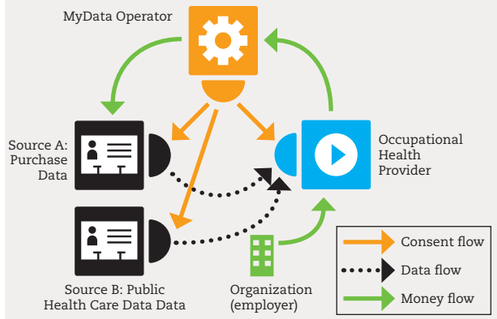
1. **Human centric control and privacy:** Individuals are empowered actors, not passive targets, in the management of their personal lives both online and offline – they have the right and practical means to manage their data and privacy.
2. **Usable data:** It is essential that personal data is technically easy to access and use – it is accessible in machine readable open formats via secure, standardized APIs (Application Programming Interfaces). MyData is a way to convert data from closed silos into an important, reusable resource. It can be used to create new services which help individuals to manage their lives. The providers of these services can create new business models and economic growth to the society.
3. **Open business environment:** Shared MyData infrastructure enables decentralized management of personal data, improves interoperability, makes it easier for companies to comply with tightening data protection regulations, and allows individuals to change service providers without proprietary data lock-ins.

Contributors: Antti Eskola, Juuso Parkkinen, Mark Lizar, Molly Schwartz, Myles Byrne, Samuel Rinnetmäki and Tuukka Lehtiniemi

9 – Give me some examples!

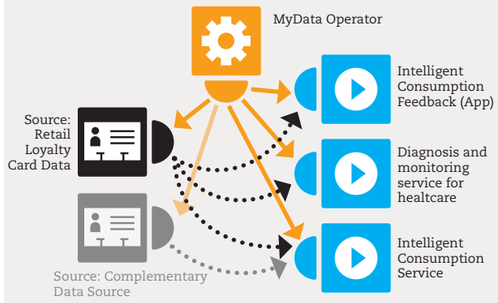
MyData is a high-level approach for organizing personal data in human centric way. MyData principles are applicable to all areas of life. The same personal data can be used in different sectors. Some data types are specific to sectors, such as clinical health data, but the primary objective for the MyData infrastructure is to enable the flow of data between sectors. MyData can be applied to organizing healthcare data management, to developing new kinds of mobility services, to supporting individuals with their personal finances, to informing consumption decisions, and to creating new kind of research databases.

In this last chapter we describe three use case scenarios for MyData in more detail. The schematic illustrations show how the personal data, authorizations / consents, and money flow between different actors.



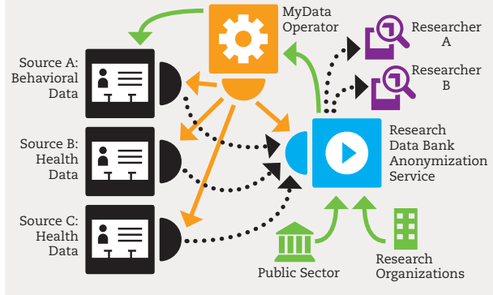
Example 1: MyData and Occupational health

Modern health care requires data. Clinical data usually consist of various test results and diagnosis. Occupational health care providers change when individuals change jobs. There is no convenient way to organize data logistics between different occupation health care providers. Furthermore, getting more data about individuals would significantly help personalize and optimize health and wellbeing services and provide alternative means for diagnosis. For example, an individual's profile data, consumption data, and activity tracking data could be used for healthcare services. The MyData infrastructure can provide standardized methods for managing data logistics between different professional and public health organizations and sources of behavioral data in robust ways across organizations.



Example 2: MyData and Loyalty card data

Loyalty card data can reveal the individual's consumption history, which can be used to provide health recommendations, to recommend changes in shopping behavior, and to optimize personal spending. Providing individuals with access comprehensive consumption feedback through their loyalty card data may have beneficial society-wide effects. Smarter consumers have the power to influence change production patterns. Fragmented datasets from a single loyalty cards provide limited insights into consumption behaviors, but the MyData infrastructure creates the mechanism to integrate data from multiple sources for more meaningful results.



Example 3: MyData and research data banks

The development of computational sciences has produced flexible tools that can be used to combine and analyze multiple data sources. Integrating data from multiple sources may increase risks of privacy invasion. According to recent research, over 60% of individuals have expressed their willingness to donate their personal data for research purposes. The MyData infrastructure can provide a common framework for different kinds of research data banks to easily acquire consumers' consent to collect their data. Research data banks could then provide access to their data without violating individual privacy rights, but still maintain the capability to cross-reference data.