Making Health Data Trustees Sustainable

An Overview of Potential Business and Financing Models

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RWD120

Objectives

The data trustee concept facilitates the secondary use of health data for both scientific and business purposes, thus, reducing barriers to access health data.[1] A data trustee can be described as a

"[…] natural or legal person or a partnership that mediates access to data provided or held by data trustees in accordance with contractually agreed or legally prescribed data governance regulations in the interest of third parties"[2]

Kilz et al. (2024) show that data trustees are predominantly active in the global north, with few cases outside of Europe and the USA. The majority is focusing on health data.[3] While research focuses on the legal, technological and organizational design of data trustees, the business model perspective has received limited attention so far.

In the course of the project GUIDERS (funded by BMFTR) we aim to answer the research question (RQ): *„What are potential business and financing models for health data trustees?"* by identifying existing business models and developing archetypes for health data trustees.

Methods

We conducted a qualitative interview study with 11 European and non-European data trustees from November 2023 until August 2024 and received one written response. All participants were at least management level. We evaluated the findings from the transcribed and anonymized interviews using qualitative content analysis[4] and deductive coding based on the Business Model Canvas by Osterwalder and Pigneur[5] to subsequently develop business and financing model archetypes with experts in a workshop (see an overview of data and data providers in Tbl.1 and Fig. 1.).

Belgium (2)	Health (1) Human and veterinary health (1)
Canada (2)	Health, social, demographics, education, environment (1) Health, social assistance, education, environment, immigration, labor (1)
Finland (1)	Social and health
France (1)	Health
Germany (4)	Finance (1) Health (2) Mobility (1)
Italy (1)	Health and health related
UK (1)	Health, socioeconomic, justice, administrative, environment, work

Tbl. 1: Overview of the data made available for secondary use by the interviewees

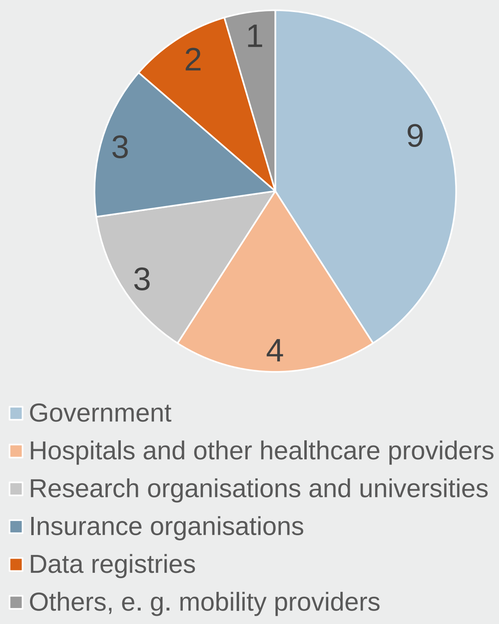

Fig. 1: Distribution of data providers

Results

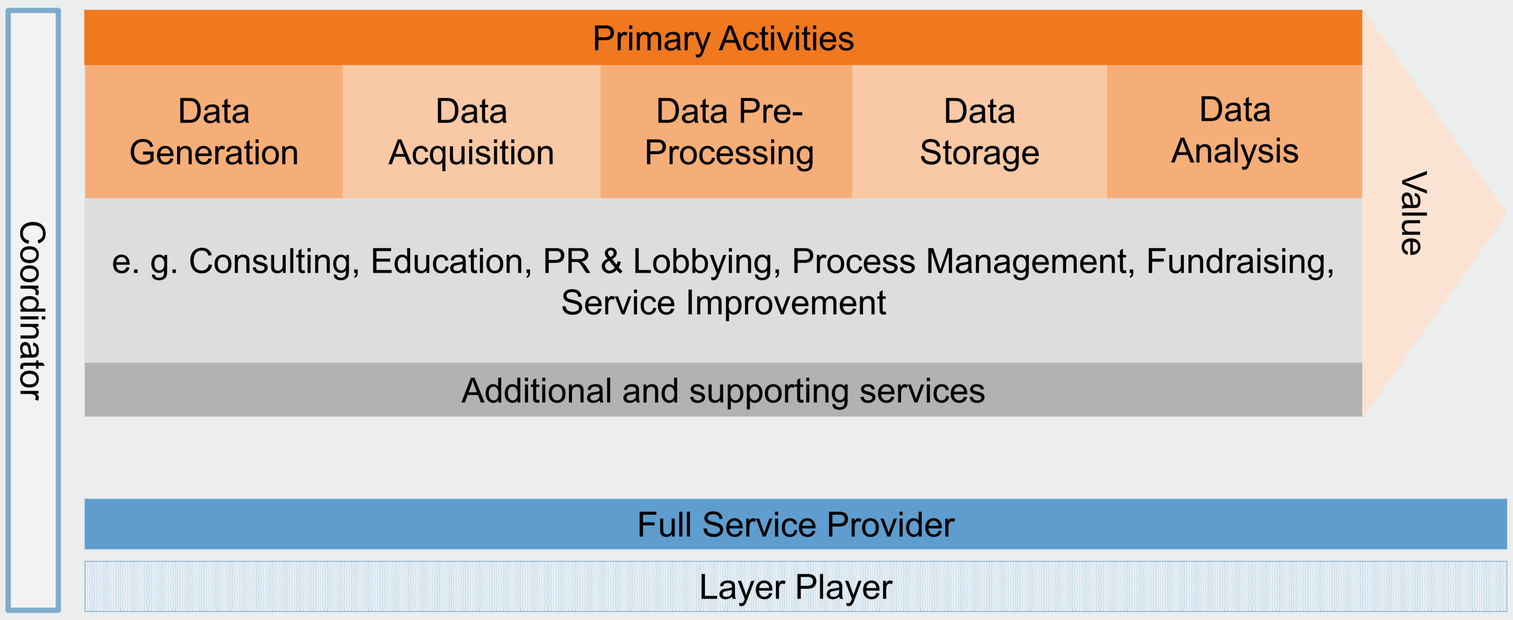

Fig. 2: The three developed business model archetypes along the data trustee value chain based on Faroukhi et al. (2020)

Based on the interview results and an expert workshop, we developed a value chain for (health) data trustees based on Faroukhi et al. (2020)[6] and derived three archetypes of potential business models (see Fig. 2): a "*Full Service Provider*", covering the entire data value chain, a "*Layer Player*", providing specific services of the data value chain and a "*Coordinator*", focusing solely on intermediary activities.

We find the main value proposition of state-organized data trustees are provision of data, enabling research and innovation, support of societal, environmental and industrial goals, trust, independence, consulting for data users, enabling data usage and education. The trustees showed different levels of service provision. Some trustees provided services such as paid-for consulting and research services, while others focused on core tasks according to the data value chain (data generation, data acquisition, data processing, data storage, data analysis). This is attributed to the wide range of interviewees.

The study revealed a broad variety of financing of health data trustees. Interviewees described predominantly "pay-per-use" financing models, supported by additional state financing while none of the interviewed organizations was able to recover costs without public funding.

Conclusion

Our study shows that there is not yet one established business model for state-organized (health) data trustees. Some data trustees perform services beyond the scope of the common data trustee definition such as paid-for consulting and research services, seemingly to create revenue for their general operations and to be less reliant on public funding. Furthermore, this study shows, that there is currently no data trustee that is financed solely by fees in a sustainable manner, but always requires support from public funding. The value chain and archetypes will provide players with options to ensure the financial sustainability of a data trustee. This work can be used as a basis for the development of a scoring model to evaluate the archetypes and to develop a flowchart as a guide to the relevant business and financing model, which is part of the research project GUIDERS.

Sources

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Funded by the European Union NextGenerationEU

Bundesministerium für Forschung, Technologie und Raumfahrt

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