



# GUIDERS – Business and financing models of state-organized data trustees for health data

## Background

### Utilizing Health Big Data in research

»Sharing data for better care«: Data from clinics, health insurance companies and other sources can be used for solutions for better patient care, personalized medicine and managing diseases. This requires access to structured and bundled data instead of the current practice of data silos for individual sources. This could make health data available for secondary use in research. One model for accessing and using this data for research purposes is the data trust model as an intermediary third party.

### Further developing data trustees as an opportunity for health research

State models of data trustees are already common practice in various European countries. Developments such as the European Health Data Space (EHDS) at EU level or the Health Data Utilization Act (GDNG) in Germany are

shifting the focus to the underlying issues relating to data in the healthcare sector. Both legislative projects are intended to define a framework for the use of health data, in which matters of access and data use are directly linked to fiduciary management. Various national and European research activities have considered economic aspects only to a limited extent. In order to advance the implementation of a state data trustee model for health data, the role of business and financing models must be analyzed in more detail.

## Project description

### Business and financing models for data trustees

The GUIDERS project explores approaches for the development of viable business and financing models for state-organized data trustees, especially with regard to health data.

The research focuses on the following questions: How could the business models of state health data trustees be structured? Which funding and revenue generation options are possible for public health data trustees?

## Range of services

### Evaluation of best practices and recommended course of action

Using systematic literature review and desk research, the researchers at Fraunhofer IMW identify and analyze existing international state data trustees, their business models and best practices. They then conduct semi-structured expert interviews focusing on business and financing models. Based on the results, archetypes of business models can be developed and evaluated for their practicability with a further interview study. The socio-economic expertise and broad domain knowledge in the field of digital health form the basis for the development.

## Clients



Bundesministerium  
für Bildung  
und Forschung



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## Project page



<https://s.fhg.de/guiders-en>

## Project duration

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