

Enhancing Access to Health Data: Exploring the Global Data Trustee Landscape

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Objectives:

Secondary use of health data, from clinical information to data from wearables, offers enormous research potential but is limited by legal and technical constraints¹. The data trustee concept, especially state-organized, is being discussed as a promising solution for overcoming access barriers.²
A definition of a data trustee was recently given by Specht-Riemenschneider et al.:

»A data trustee is 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«³

As the concept is rather young in research, detailed studies on their practical applicability and their design are still rare, despite existing data trustees. In the course of the project GUIDERS (Business and financing models of state-organized data trustees for health data), funded by the German federal ministry of education and research⁴, this study aims to bridge this gap by providing a better overview on the global data trustee landscape.

Methods:

To identify relevant organizations, a systematic literature review (SLR) on data trustees was conducted in January and February 2024, using the Scopus and SpringerLink databases based on selected search terms (Tbl. 1).

Tbl. 1: Search terms used for SLR in Scopus and SpringerLink

„data access body“	„data trustee“
„data custody“	„health data use“
„data facilitator“	„datenmittler“
„data fiduciary“	„datentreuhand“
„data intermediary“	„datentreuhänder“
„data stewardship“ AND „healthcare“	„treuhänderische Verwaltung“ AND „daten“

The review followed the PRISMA guidelines in a 4-eyes review process and focused on English and German publications since 2013. Supplementary desk research was conducted to further analyze organization's data trustee characteristics (e. g. organizational form, permission for secondary data usage).

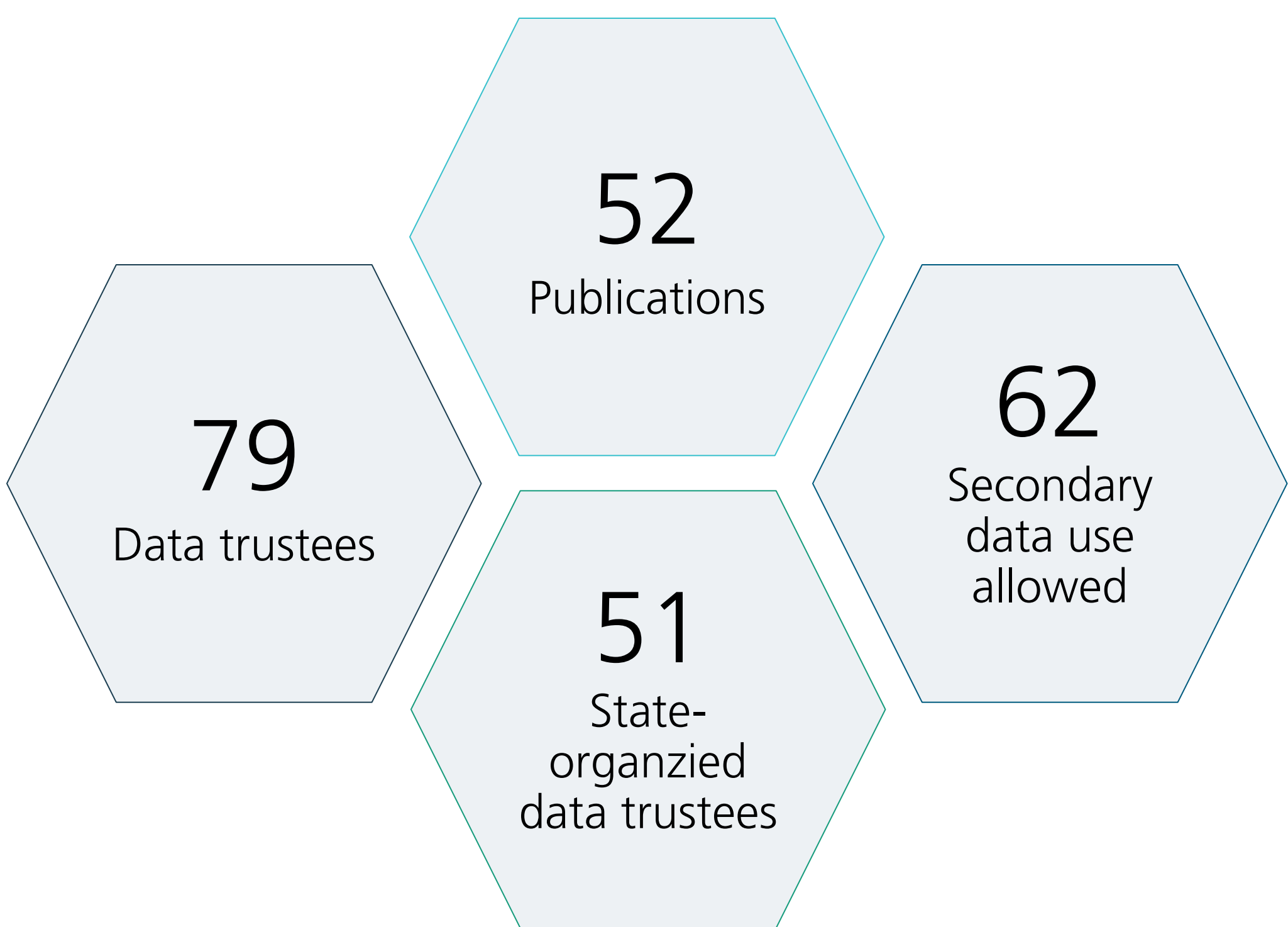


Fig. 1: Key results from SLR on state-organized data trustees

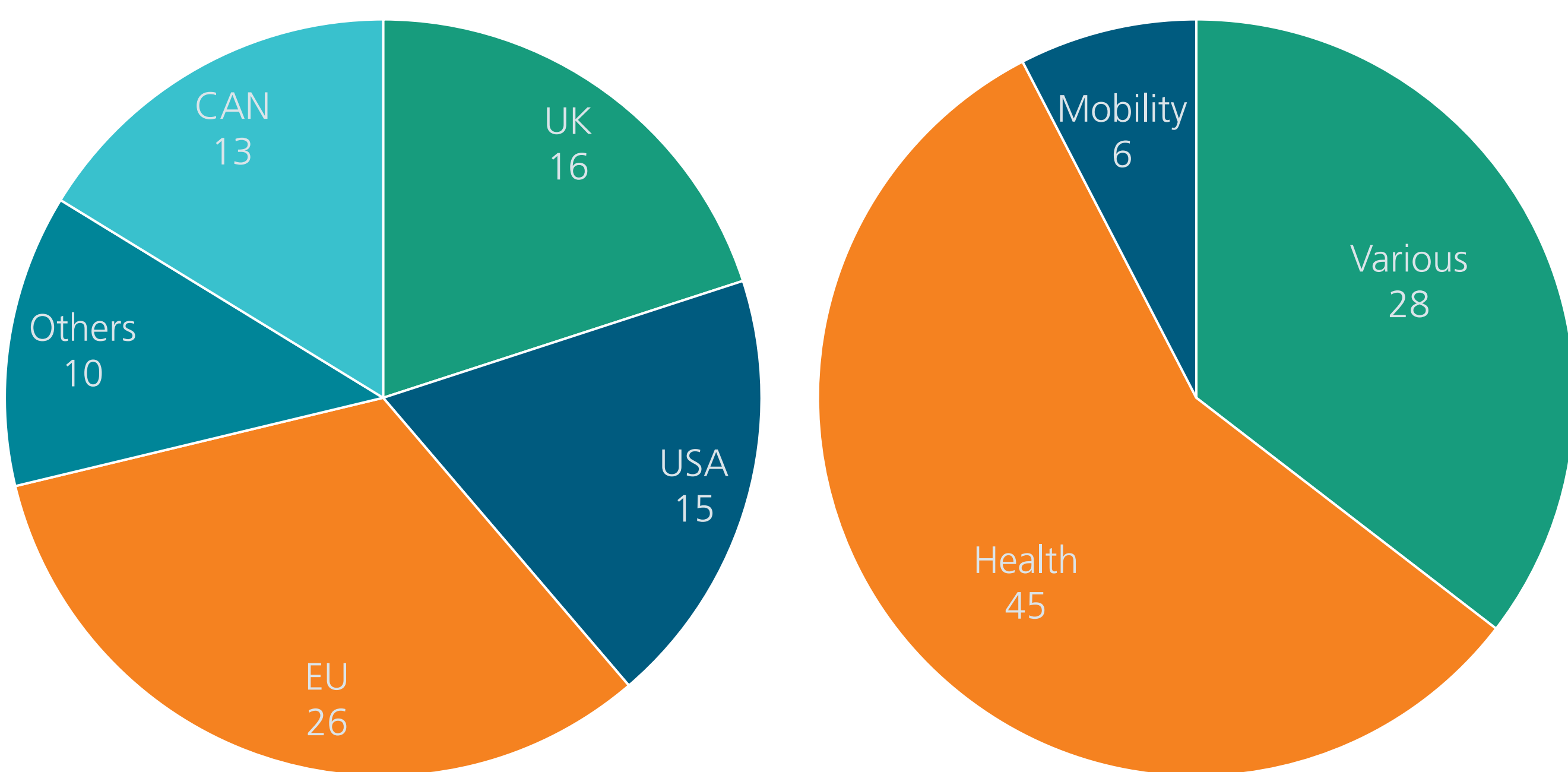


Fig. 2: Nominal distribution of regions concerned with data trustees according to SLR and data types, identified data trustees were concerned with (double nomination possible)

Results:

From 52 publications, mentioning organizations in data trustee context, we extracted 89 organizations. By supplementary desk research, we identified 79 as data trustees according to the rather broad definition of Specht-Riemenschneider et al.¹, 51 were state-organized (including funding, e. g. by the EU). The majority of those (67) enabled secondary data use (Fig. 1).

The geographical distribution (doubling possible) showed 26 data trustees in the EU (12 in Germany), 16 in the UK, 15 in the US, 13 in Canada, and individual organizations in Korea, Japan, Singapore and Ethiopia. The vast majority of organizations (> 55) was handling health data (45 exclusively), while six were handling mobility data and 28 others (finance, business, cities and socio-economic data) (Fig. 2).

Conclusion:

In research, data trustees are predominantly concentrated in the global North with few cases outside Europe and the USA and some cross-country initiatives. The collected use cases show an overall strong focus on healthcare, implying a high potential and applicability of health data trustees, and provide a basis for further research. Especially the European focus on healthcare can be explained by on-going legislation (European Health Data Space).⁵
Due to the actuality of data trustees to be established in a variety in European countries an urgent need for business model and financing concepts may arise soon. This work can be used as a basis for the development of business model archetypes, which is part of the research project GUIDERS.

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4 GUIDERS - Business and financing models of state-organized data trustees for health data; <https://www.imw.fraunhofer.de/en/research/corp-development/digital-health/projects/guiders-.html>; accessed 18.10.2024
5 Proposal for a Regulation of the European Parliament and of the Council on the European Health Data Space. 2022