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Designing Data Trusts

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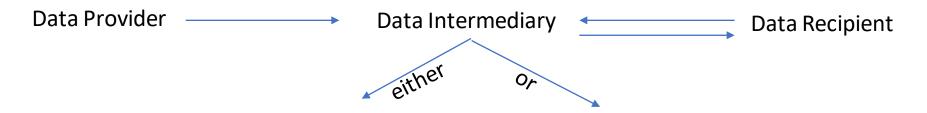
A purpose-based approach



From Data Intermediaries to Data Trusts







Functions as broker

=

brings data provider and data recipient together and enables them to share data (broker)

Functions as seller

=

shares data which he has received before to the data recipient

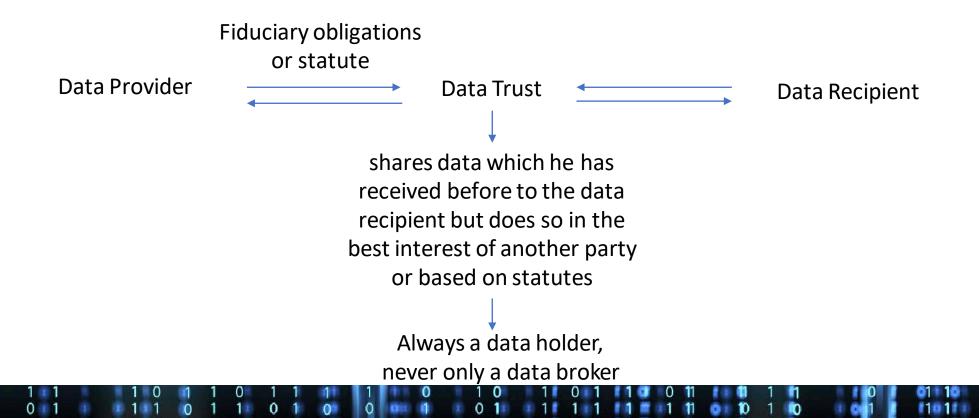


From Data Intermediaries to Data Trusts









Four basic forms of Data Trusts







	voluntary use	mandatory use
centralized data	optional	mandatory
storage	data host	data host
decentralized	optional	mandatory
data storage	data cache	data cache







What is required in the healthcare sector?

- Problem: Underutilization of data for research purposes results from legal uncertainty
- 1. Need: Legal certainty for sharing and evaluating large data sets in accordance with data protection legislation
- Solution: Data Clean Rooms
 - Data storage solutions that meet the highest it security standards, in which data can be merged and analyzed without the various data providers being able to access the data themselves.
 - Only the analysis results are output to all data providers









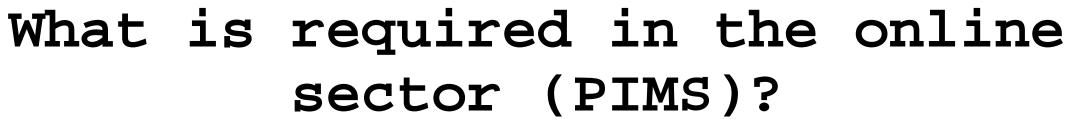




What is required in the healthcare sector?

- Problem: Underutilization of data for research purposes results from legal uncertainty
- 2. Need: Possibilities to improve the finding of data being already stored in a register
 - Solution: Coordinating Body which knows where a lready existing data can be found
- 3. Need: Possibilities to better "donate" data for research purposes
 - Solution: Improving the usability of electronic health records for this purpose









- Problem: Overuse of personal data is based on infomational, behavioural and competition problems as well as on enforcement deficit of data protection law
- Need: Better control over data use
- Solution: Personal Information Management Systems (PIMS)
 - already exist in the market but do not work because there is no benefit for the users
 - No benefit basically because the instructions of the PIMS are not mandatory





sector (PIMS)?





- Solution: Regulation on the system level FIRST
 - Obligation to comply with the instructions of PIMS
 - Interoperability standards
- Second: Regulation of the details
 - Enabling broad consent towards PIMS
 - Enabling the enforcement of data subjects' rights
 - Measures to minimize risks e.g. to the right to informational self-determination
 - Competition policy solutions

DGA-E and § 26 TTDSG

provide for only such
measures

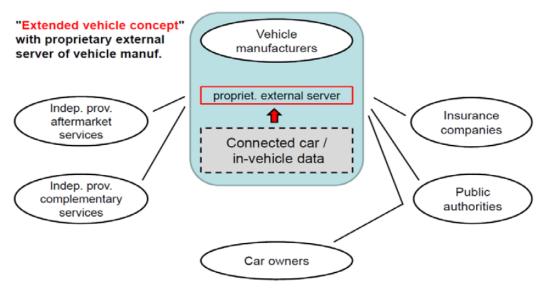






Mobility sector: Data in connected cars

Current governance concept of vehicle manufacturers (VM):



- all data directly transmitted to proprietary server of VMs
- VMs have exclusive control of
 - access to in-vehicle data and
 - technical access to the car (closed system / no interoperability)
 - => gatekeeper position
- allows VMs to control all secondary markets and foreclose independent service providers and leverage market power to these markets
- negative effects on competition, innovation, consumer choice
- => Independent service providers and consumer associations demand a regulatory solution for these problems (policy discussion since 2016)

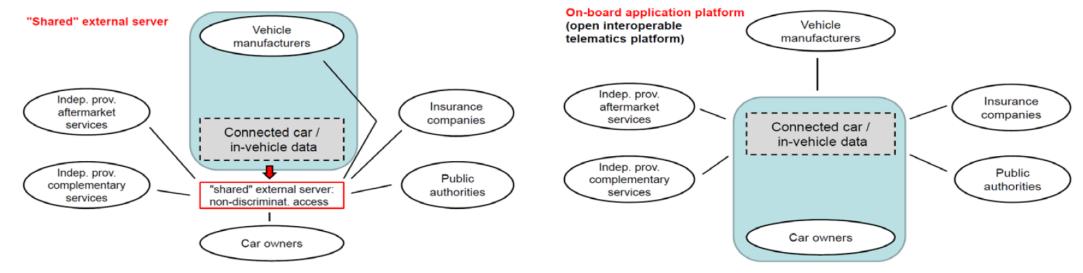


Mobility sector: Data in connected cars





Alternative solutions for access to data and the car:



- "shared server" operated by neutral entity (data trustee solution)
- open interoperable telematics platforms: data stored in the car, and car user has direct control over whom to give access to data and the car
- => both solutions would eliminate gatekeeper position of VM
- TRL study 2017: both solutions superior to "extended vehicle" concept, and also the security problems can be solved









Mobility sector: Data in connected cars

EU Commission acknowledged the problems of "extended vehicle" concept, announced solution but so far no policy proposal

Policy options for solving gatekeeper problem:

(necessary: solutions for data access, interoperability, and security)

- 1) Strict regulatory FRAND solution for access to in-vehicle data and the car (interoperability, security), e.g. via Type Approval Regulation for motor vehicles
- 2) On-board application platform: needs far-reaching standardisation regarding telematics platform and security => car owners can give access!
- 3) Data trustee solution: (as obligatory data host)
 - legislator establishes a data trustee which has the task of granting access to the in-vehicle data according to certain objectives and principles
 - data access for firms, public institutions (public interest), research
 - plus: regulatory solution for interoperability and security
 - mobility data of connected cars as "infrastructure" for innovation ...







Different purposes of data trusts

Better and easier data sharing

Necessary in the healthcare sector

Solution: Optional Data Hosts as Data Clean Rooms Avoiding de facto "data exclusivity"

Necessary in the mobility sector

Solution: Mandatory Data Hosts

More control over data processing

Necessary in the online sector

Solution: Mandatory Data Hosts/mandatory Data Cache as PIMS











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