

# Duchenne Data Platform and GDPR



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D U C H E N N E

A 360° DOCUMENTARY

# Why we need a platform

- Currently, there is a severe underutilisation of patient-derived and patient-provided data.
- Data are collected and kept in silo's.
- Modern technologies, including personal wearable sensors, health apps and federated learning over large numbers of distributed data sets fully enable the dovetailing of classical research data with data from patients and healthy citizens.

## Why we need a platform

- The role patient participation, expert annotation and crowd sourcing, collective hypothesis-analysis and citizen science in general can play in the acceleration of the development, testing and adoption of new interventions is frequently ignored
- Educated patients and their family members feel a dire need for much more effective (re)use of their data, as well as their own time and skills in knowledge discovery and the fast-track translation of knowledge derived from studies into health practice.

## Why we need a platform

- Data of DMD patients are collected in silo's
- Huge variety of data collected
- Some include PROs others are not
- Network of DMD registries exist.
- Currently no data sharing other than through queries on a specific question (from industry)
- Lack of 'Natural History of PROMs'
- Patients don't benefit (enough) from their own data as they are scattered
- Patients should benefit more from the total of data collected in registries

# GDPR

- ‘The GDPR addresses data portability under **Article 20**, stating that the data subject has the right to receive their data in an appropriate format without hindrance and for data to be transferred between data controllers where technically feasible.’

# Duchenne Data Platform and GDPR

- Patients can ask for their personal data (for example in Json file/format) from different sources
- Patients can upload and download their own information (store data in their own locker)
- Patients can decide with whom they are willing to share their data (i.e. for which projects their data can be used)

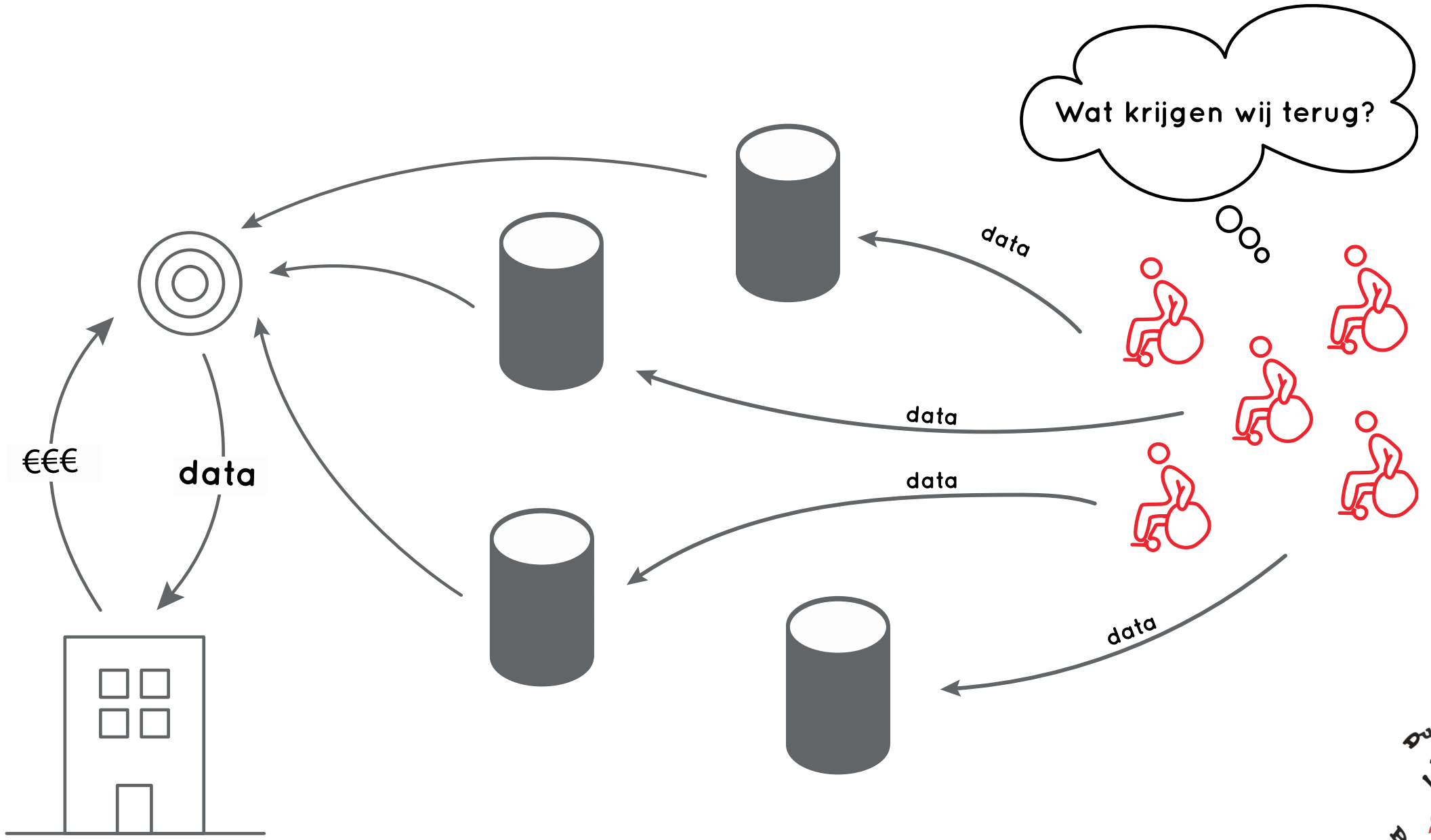
# The importance of data

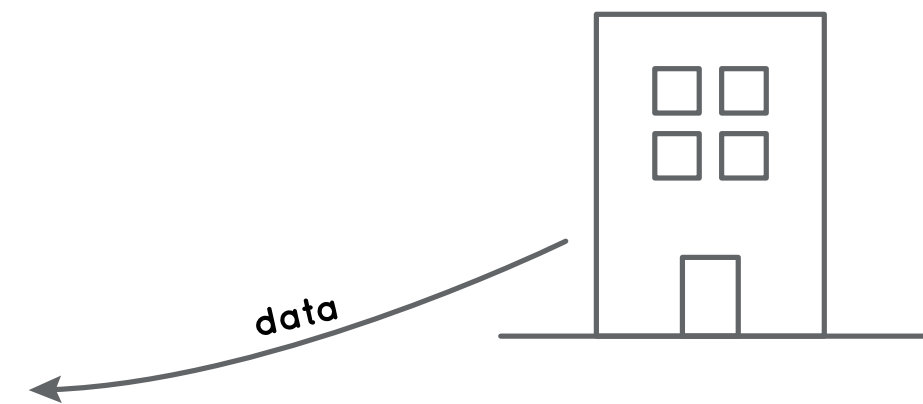
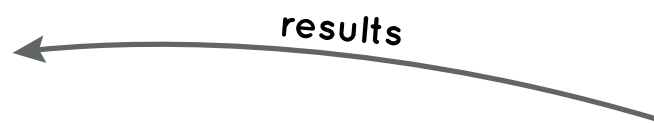
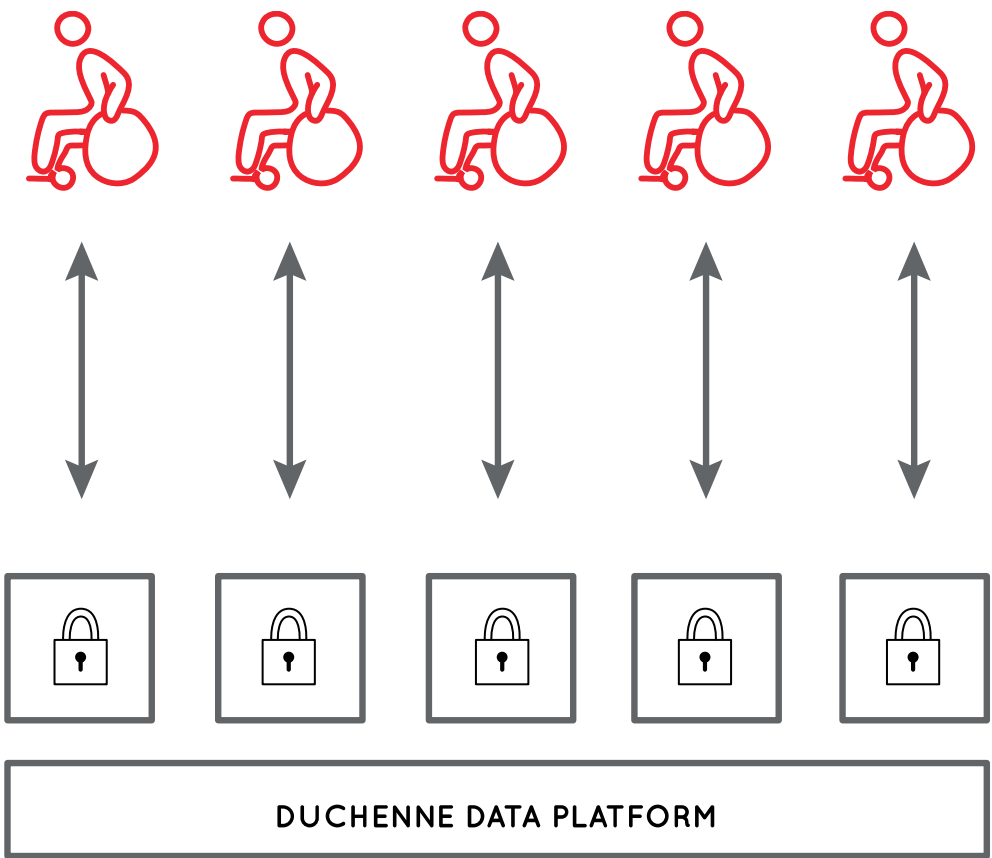
- Data relevant for patients are relevant for drug development
- We need answers to relevant questions, asked by for example regulators, not based on opinions but on collective data
- Data in silo cannot do for patients what collective data can do



# Data platform

- Gives patients the power and control over the use of their own data.
- Gives patients the option to 'get their data together'. See it as 'storing in a locker'
- Patient data can be used for questions relevant to the patient community whether it is development of new drugs, new technologies or about daily life.
- Will facilitate the adoption of emerging technologies regarding data collection and enable their optimal application in health research care and drugdevelopment





# In the Netherlands

## Collaboration with

- Dutch Dystrophinopathy Database (DDD) – LUMC (works together with Parelinoer Institute)
- Duchenne Center Netherlands