

EURO-NMD Registry Hub

Registry Hub and FAIRification

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Registry Hub and FAIRification

- **Data entry:** options available to HCPs?
- **Registry Hub:** what is it all about?
- **FAIRification:** what are the steps involved?

To be explained with **one** example!

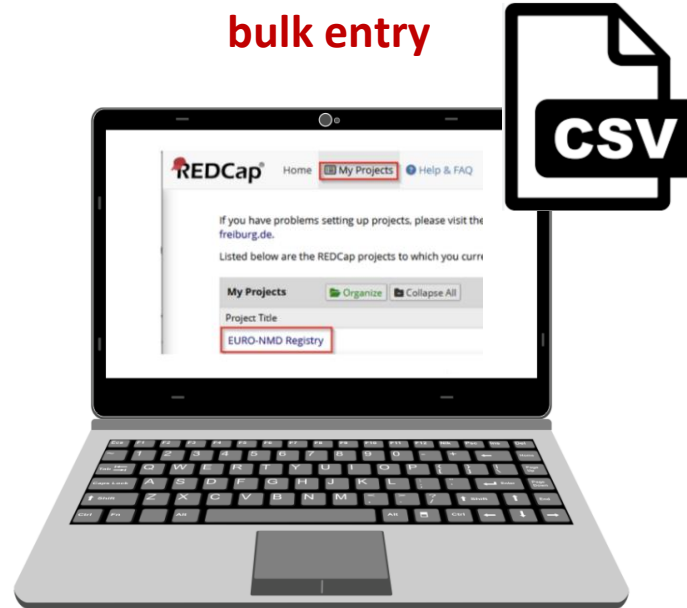
Data entry

Option 1:
Centralised
manual entry



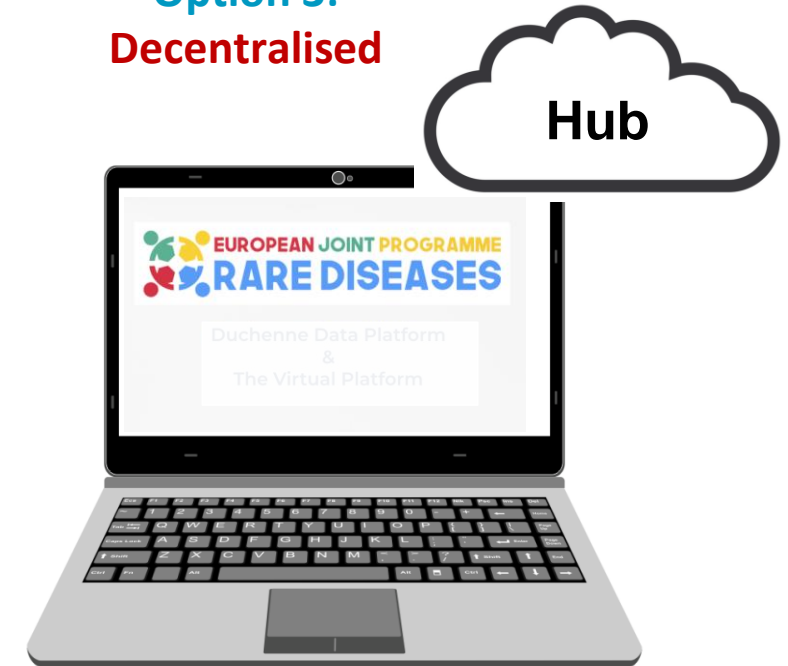
Direct entry
into the ERN Registry

Option 2:
Centralised
bulk entry



Extracted entries
from local systems into a
CSV file

Option 3:
Decentralised



Data 'visiting'
through own FAIRification &
connection to the **Hub**

Registry Hub and FAIRification Explained

Patient case

Patient: Lizanne

Age: 23 years-old

Gender: Female

Diagnosis: Duchenne Muscular Dystrophy

Her data stored in the Registry **Hub**
must be **FAIR**:

Findable

Accessible

Interoperable

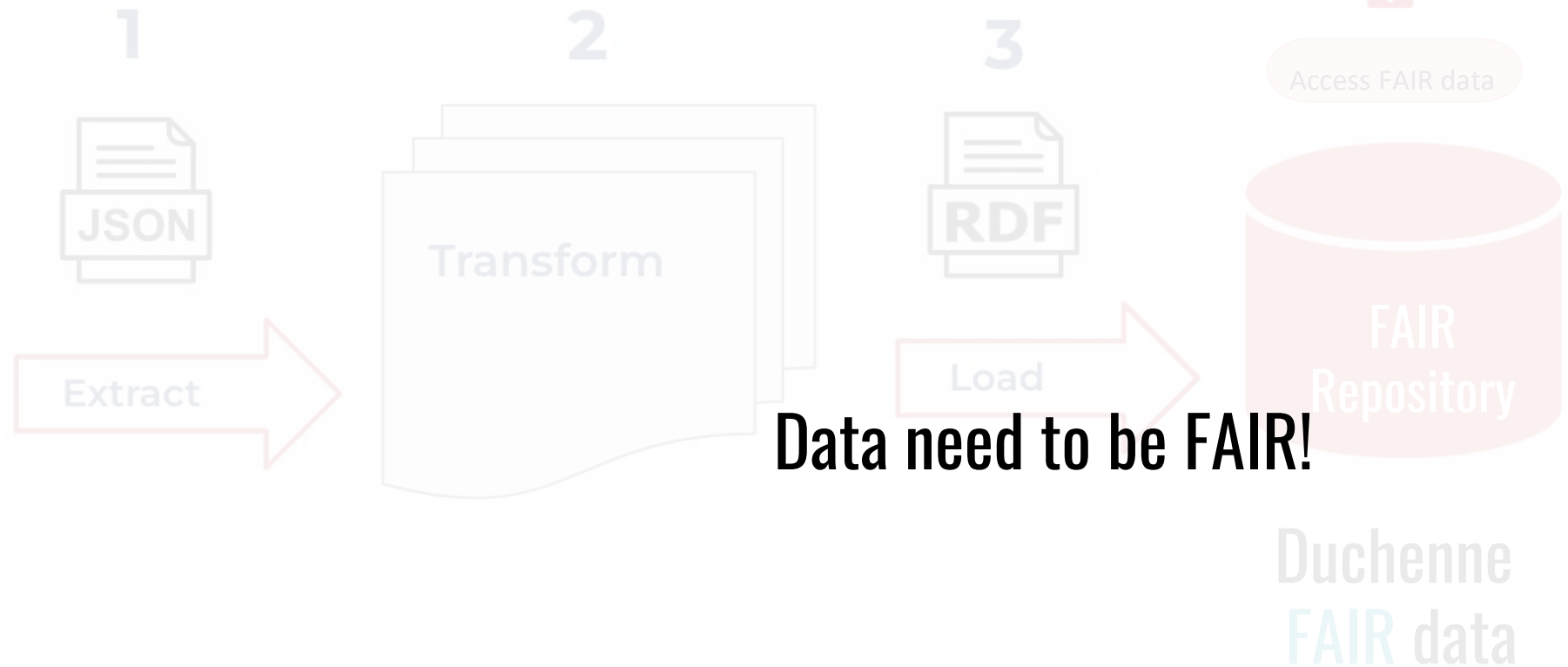
Reusable





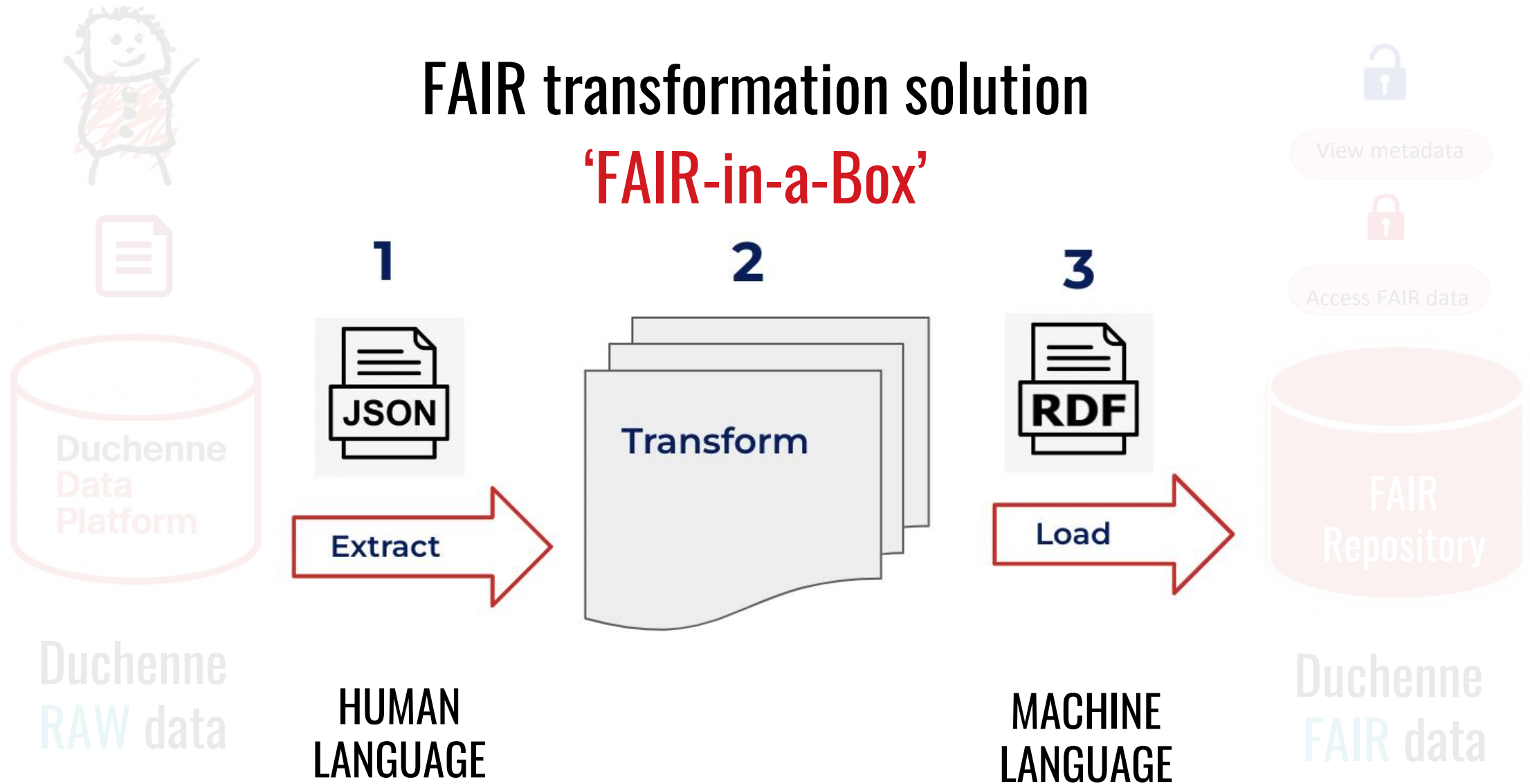
Duchenne
RAW data

Lizanne is registered in **DDP**
Her **consented** health data can now be
used for research



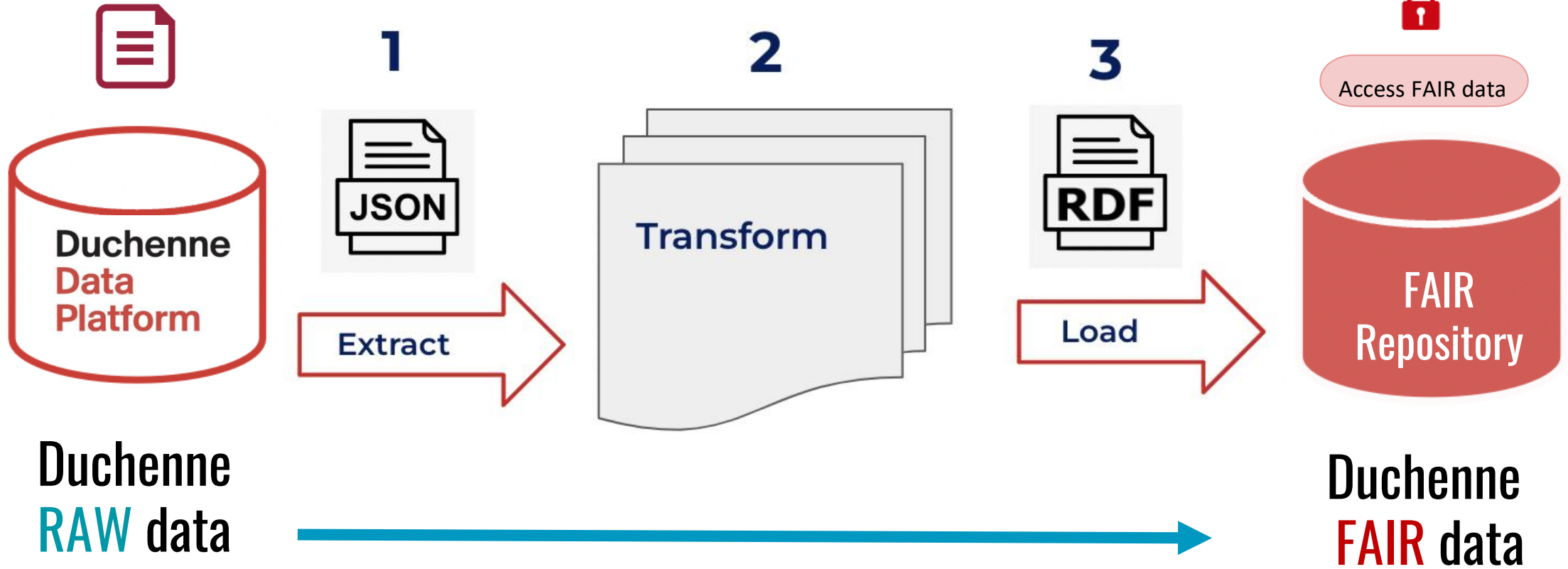
FAIR transformation solution

'FAIR-in-a-Box'



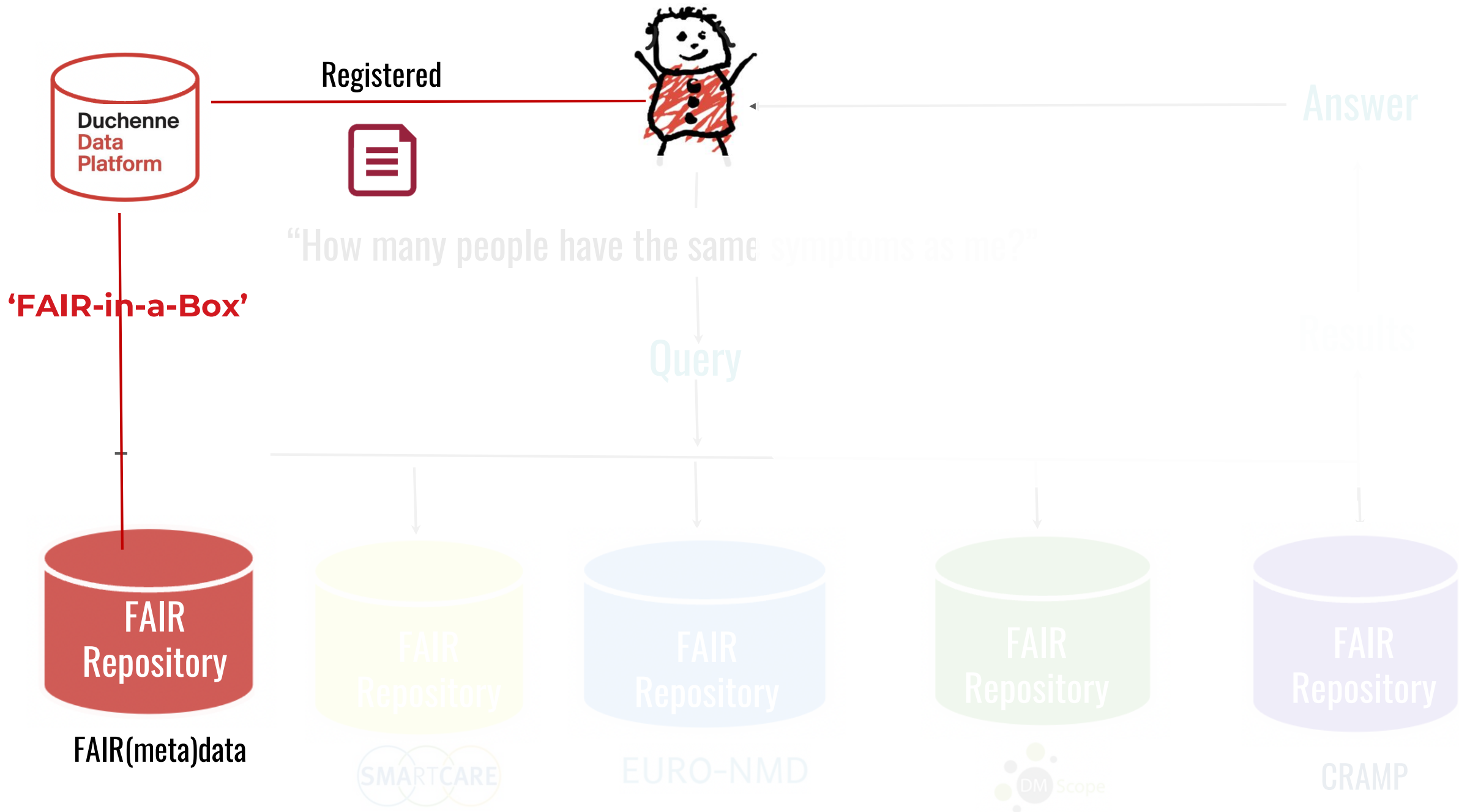


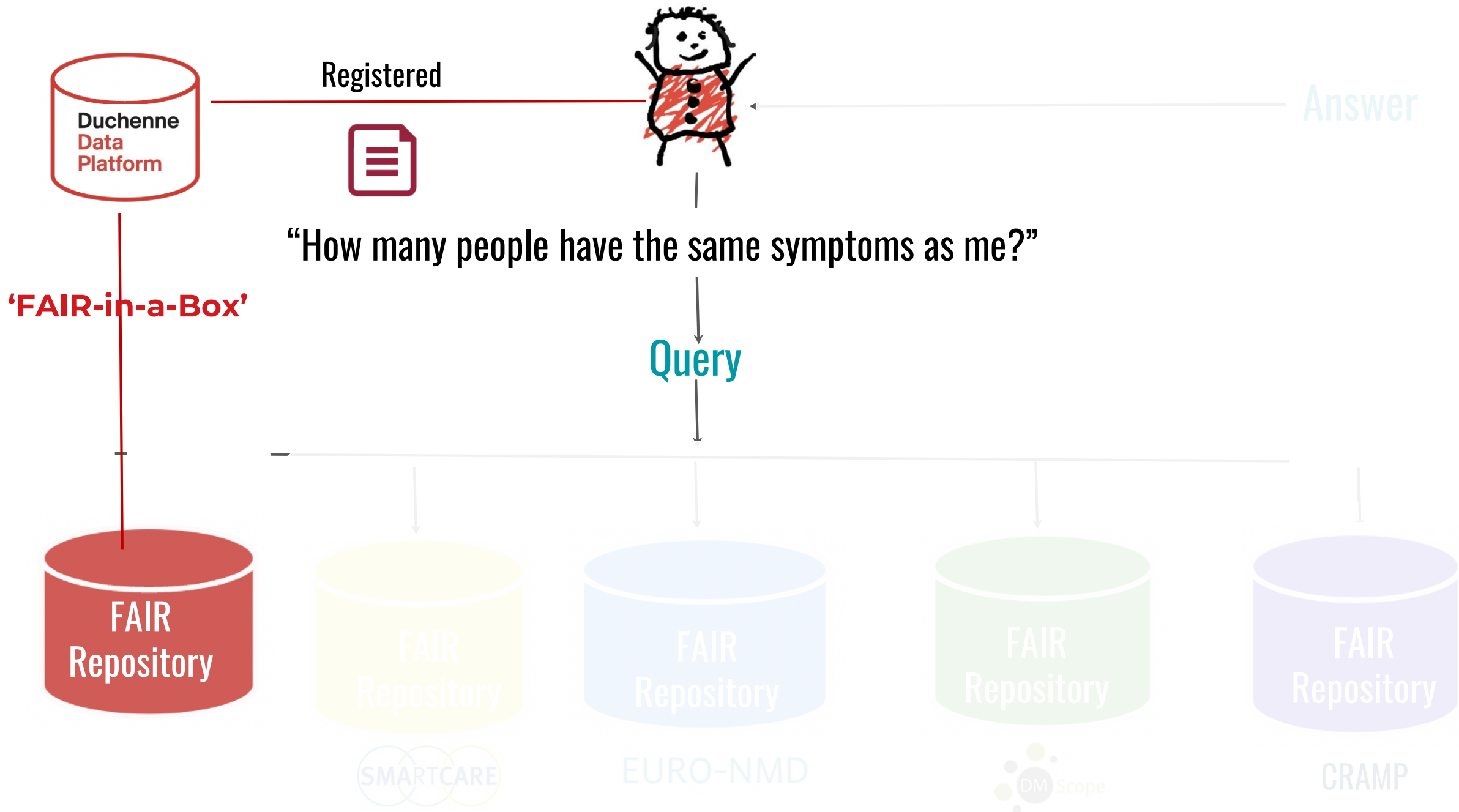
FAIRification of a patient-led registry

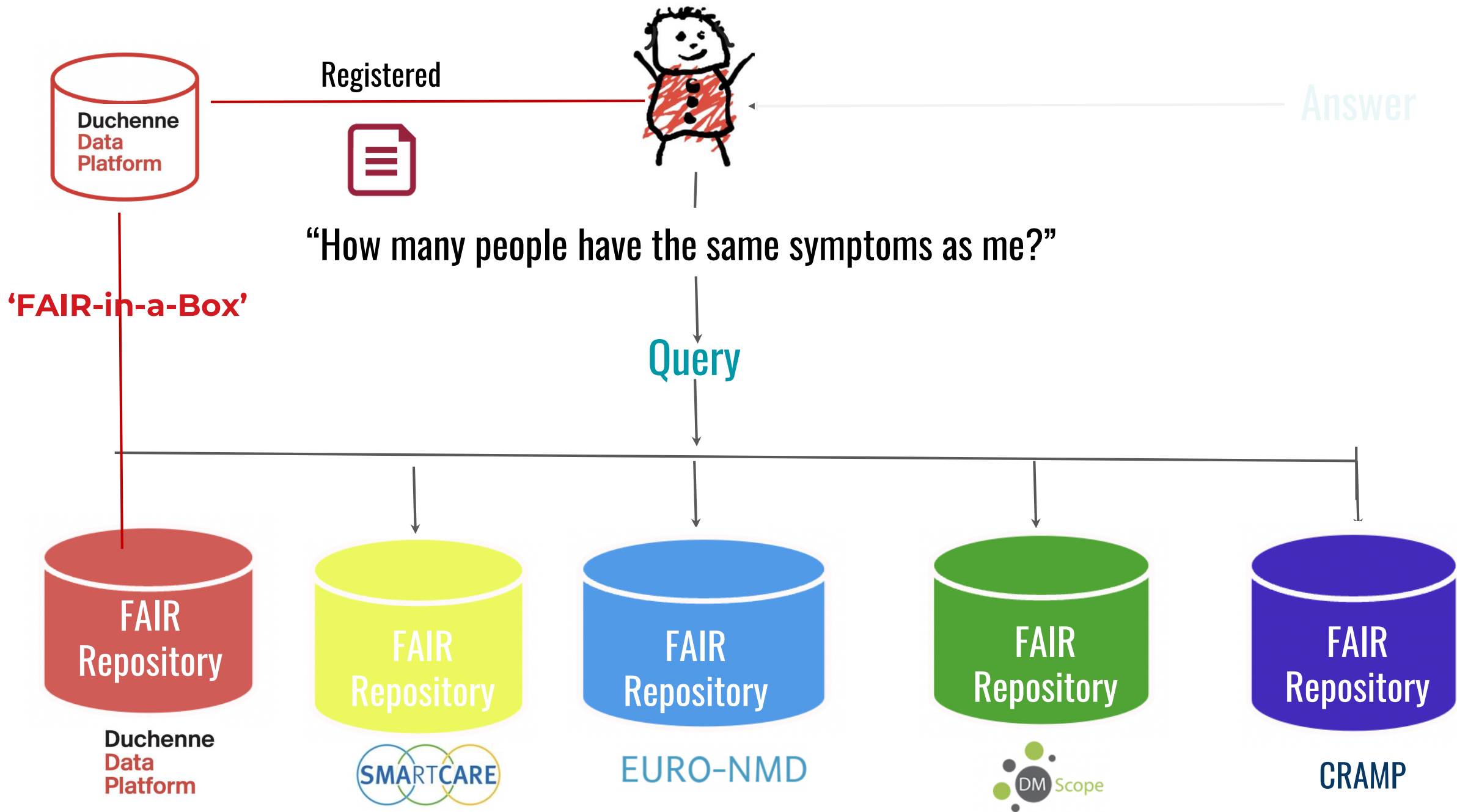


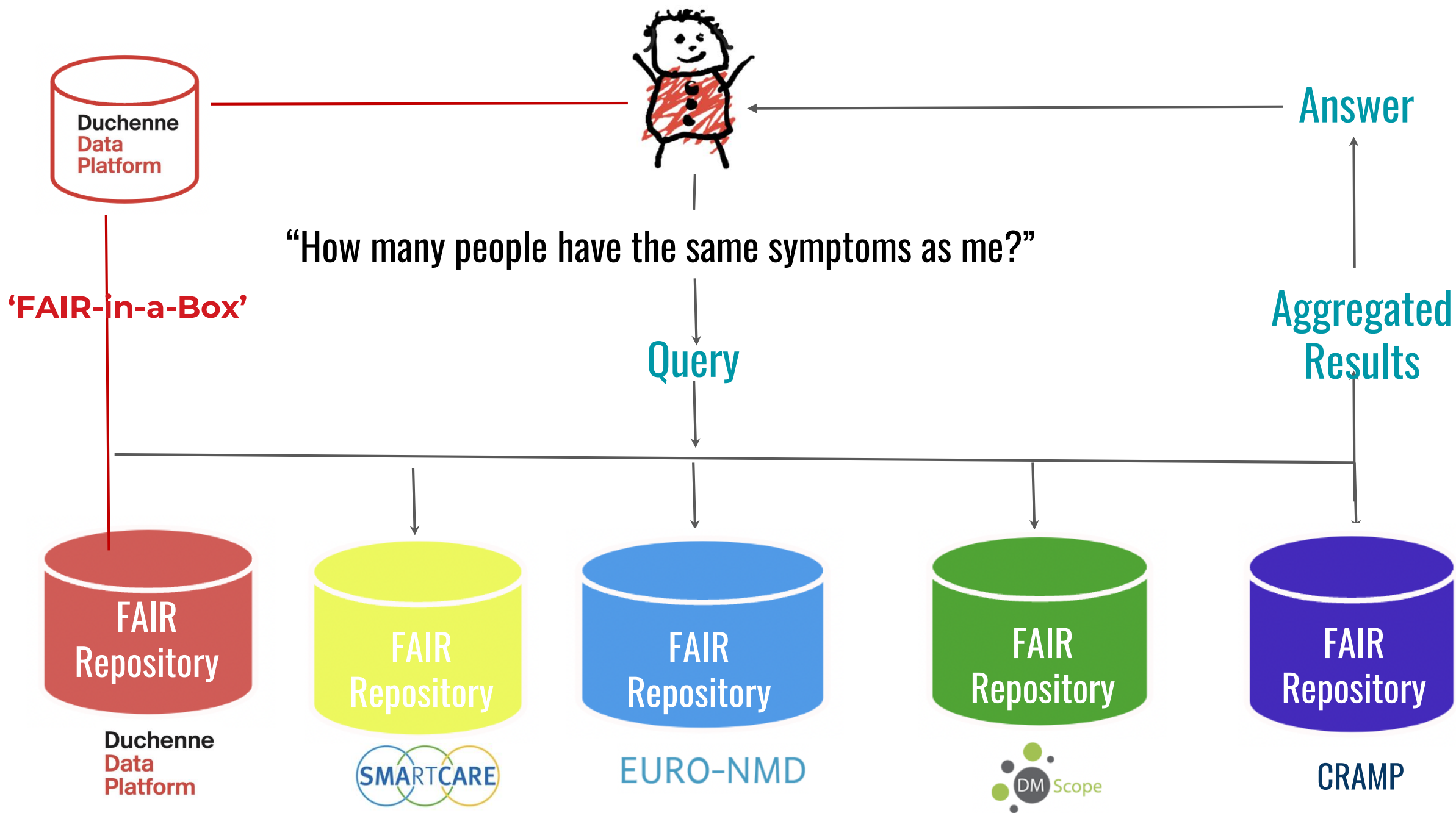
How can FAIR data in the ERN Registry Hub make a difference to Lizanne?

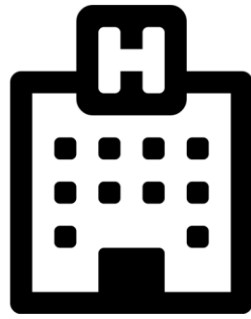












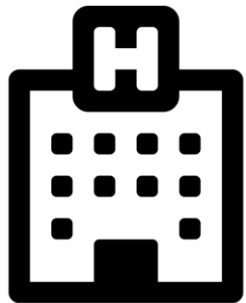
Same process for HCPs

“Which neuromuscular registries have patients recorded with Myotonic Dystrophies?”

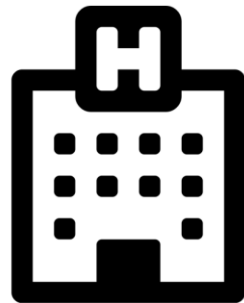
Query

Answer

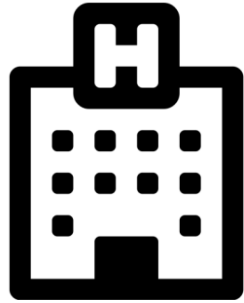
Aggregated Results



Country 1



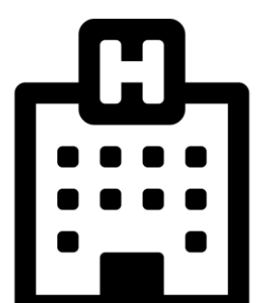
Country 2



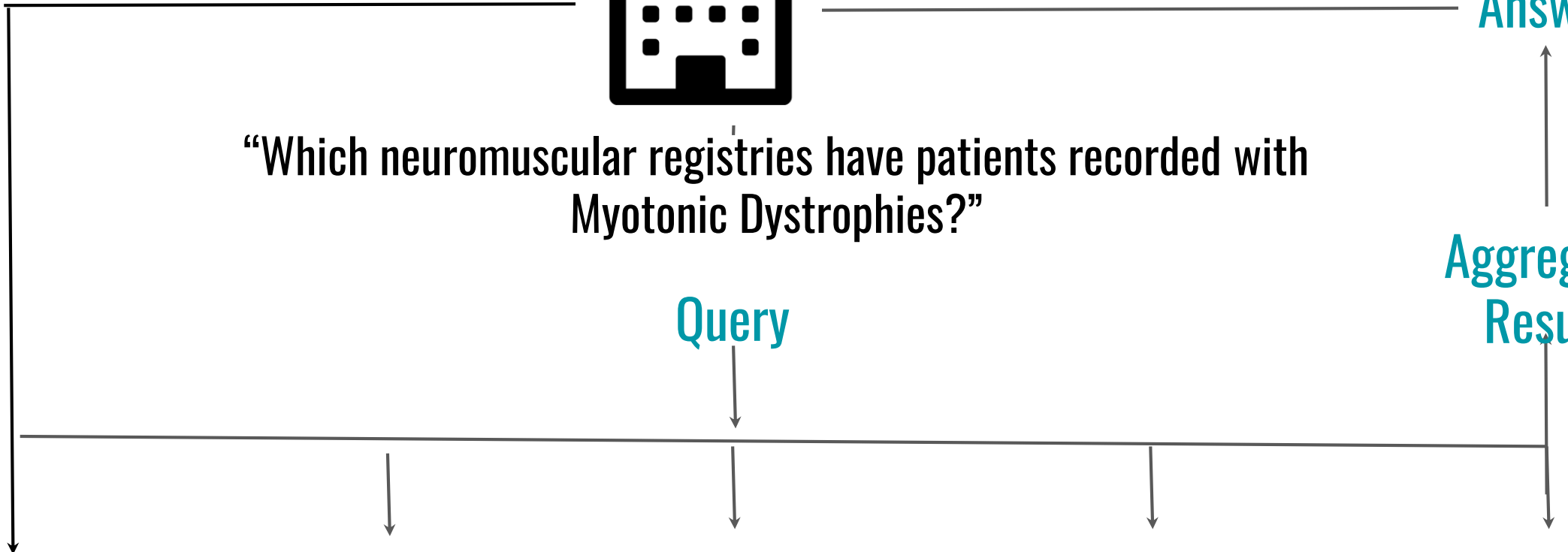
Country 3



Country 4



Country 5



Meet the real Lizanne!

Aspiring screenwriter, digital television production professional and a young woman living with Duchenne Muscular Dystrophy

“I want to find others in the same boat as me.” Lizanne Schreur



How can EURO-NMD Registry Hub find patients “in the same boat as Lizanne’s?”

- Registry FAIR by design
- Provides entry points to other NMD registries that follow the FAIR principles
- Federated querying infrastructure in place
- Enable GDPR-compliant information exchange
- Combine Lizanne’s consented health data, with anonymous data from “patients in the same boat as her” while protecting their privacy.
- Receive up-to-date and instant results automatically
- Saves time and valuable resources

Wish to find out more?

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