Rare Diseases 360°
Collaborative Strategies to leave no-one behind

9th European Conference on Rare Diseases & Orphan Products
10-12 May 2018 Vienna

The digital patient

Take home remarks

Grounds

1

Sharing data is needed to **generate knowledge**

2

Data sharing is needed for **precision medicine**

3

We **have** to do it

Opportunities

We want to share data

But we want to share data understanding the consequences and the secondary use of data

GDPR as an opportunity. Europe is leading this change!

GDPR is not just a technical requirement. It's also about processes.

ERN

ERN is a big opportunity. It’s the opportunity European citizens have to create knowledge networks

Technology is critical for an European Data Space. Interoperability (GUID, semantic search, blockchain)

Change attention focus. From computer to conversation

Data donation

This topic is appearing in different discussions

We need to find new models to share data

Digital assets are different

Open data

01

Need to develop new **economy models** based on data

02

In the age of information **the new gold is the data**

03

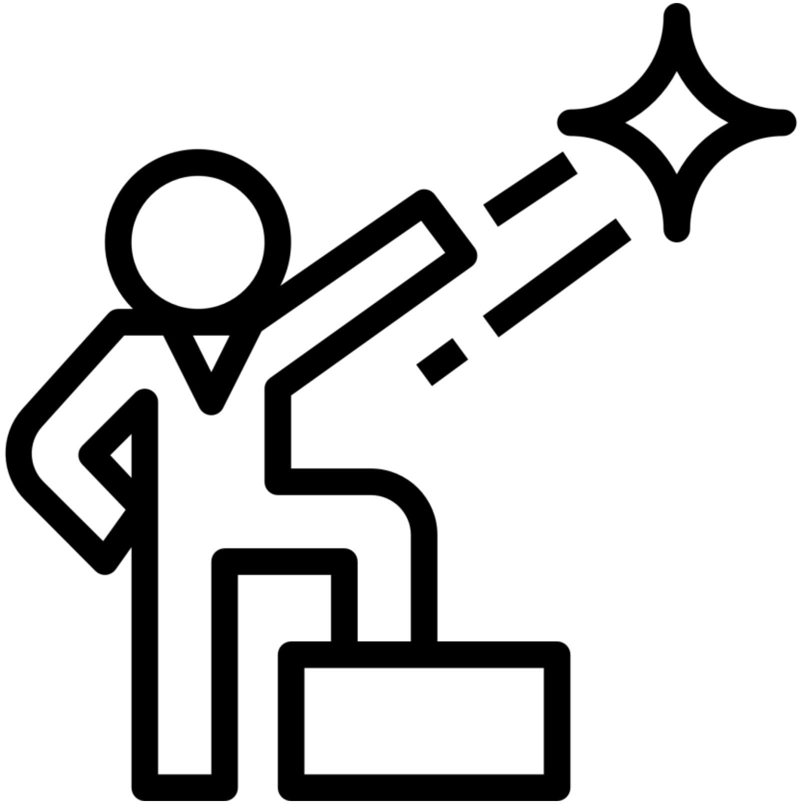
We need to table to **track** the contribution, the value and the ownership

Real examples of digital transformation

- Orphanet
- Existing ERN
- French national database for RD
- ePAG engagement

Patients leading the change

- Conversational interfaces to capture PROM
- Artificial intelligence for rare diseases
- Connecting our digital assets with ERN
- Telemetry
- How to make it real. EMA qualification



Risk

- Sharing data can have risks. Digital assets are different
- Risk management is very important
- Change management is critical

Thank you