European Commission

THE EUROPEAN PLATFORM ON RARE DISEASES REGISTRATION (EU RD PLATFORM)

A disease is a

RARE DISEASE

if it affects **fewer than** 5 in 10 000 people

>30 million
PEOPLE IN EU are affected

>6 000
DIFFERENT KNOWN RARE DISEASES
(e.g. Cystic fibrosis, Huntington's disease)

Rare diseases data are scattered **across Europe** in

>600
DIFFERENT REGISTRIES

REGISTRY

INFORMATION FRAGMENTED AND NOT SHARED

PATIENTS OFTEN SUFFER ALONE WITH LITTLE HOPE OF CURE

The European Platform on Rare Diseases Registration

Connects registry data

Supports research to improve diagnosis and treatment

Joint Research Centre

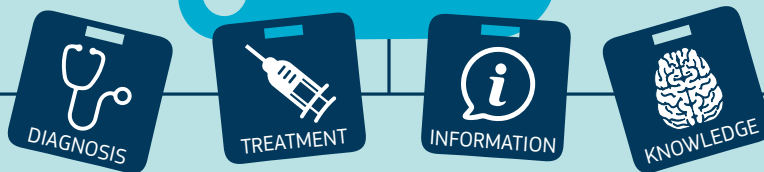# The European Platform on Rare Diseases Registration
makes rare disease patients' data both **searchable** and **findable** at EU level

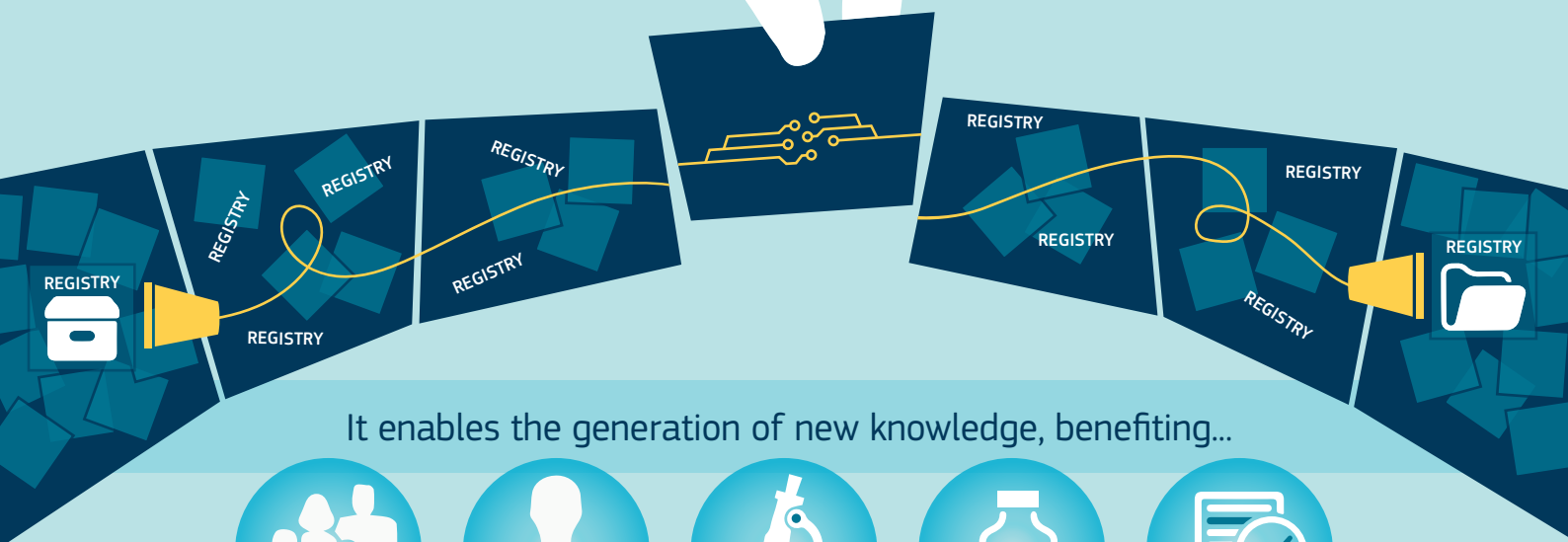## The Platform includes the European Rare Disease Registry Infrastructure

European Directory of Registries
gives an overview of all the participating registries

Central metadata repository

Data protection tool
makes sure patients' data is held under a pseudonym, protecting their privacy

DIAGNOSIS

TREATMENT

INFORMATION

KNOWLEDGE

The Platform sets EU standards for data collection and data sharing and provides training sessions for registry staff

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It enables the generation of new knowledge, benefiting...

Patients and their families

Healthcare providers

Researchers

Pharmaceutical industry

Policymakers

For more information:
https://eu-rd-platform.jrc.ec.europa.eu