A disease is a **RARE DISEASE** if it affects fewer than 5 in 10 000 people.

>6000 DIFFERENT KNOWN RARE DISEASES (e.g. Cystic fibrosis, Huntington's disease)

>600 DIFFERENT REGISTRIES

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

**>30 million** PEOPLE IN EU are affected

**>6000**

**>30 million**

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

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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.

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

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