



rett   
database

# Patient registry

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# Patient registry

## Why?

- A registry is a collection of standardized information about a group of individuals, such as those living with the same disease
- With a rare disease registry, you bring together the entire community, which includes patients, caregivers, clinicians, researchers, and industry
- One of the main difficulties of learning more about rare diseases is the challenge of finding enough people eligible to participate in research studies. The more participants in a study, the more powerful the results.

Source <https://registries.ncats.nih.gov>

## What?

- Develop an open-source patient registry, with multi-language support that can be used by any rare disease community

## How can I help?

- Envisioning / Design Thinking
- Web front-end / back-end developer
- Azure infra setup / automation
- GitHub CI/CD
- DBA



*Groundbreaking initiative aimed at creating a **comprehensive and accessible database** for individuals affected by rare diseases.*

*This registry seeks to **bridge that gap** by bringing together patients, healthcare professionals, researchers, and advocates to collaborate and make a lasting impact on the lives of those living with rare diseases.*

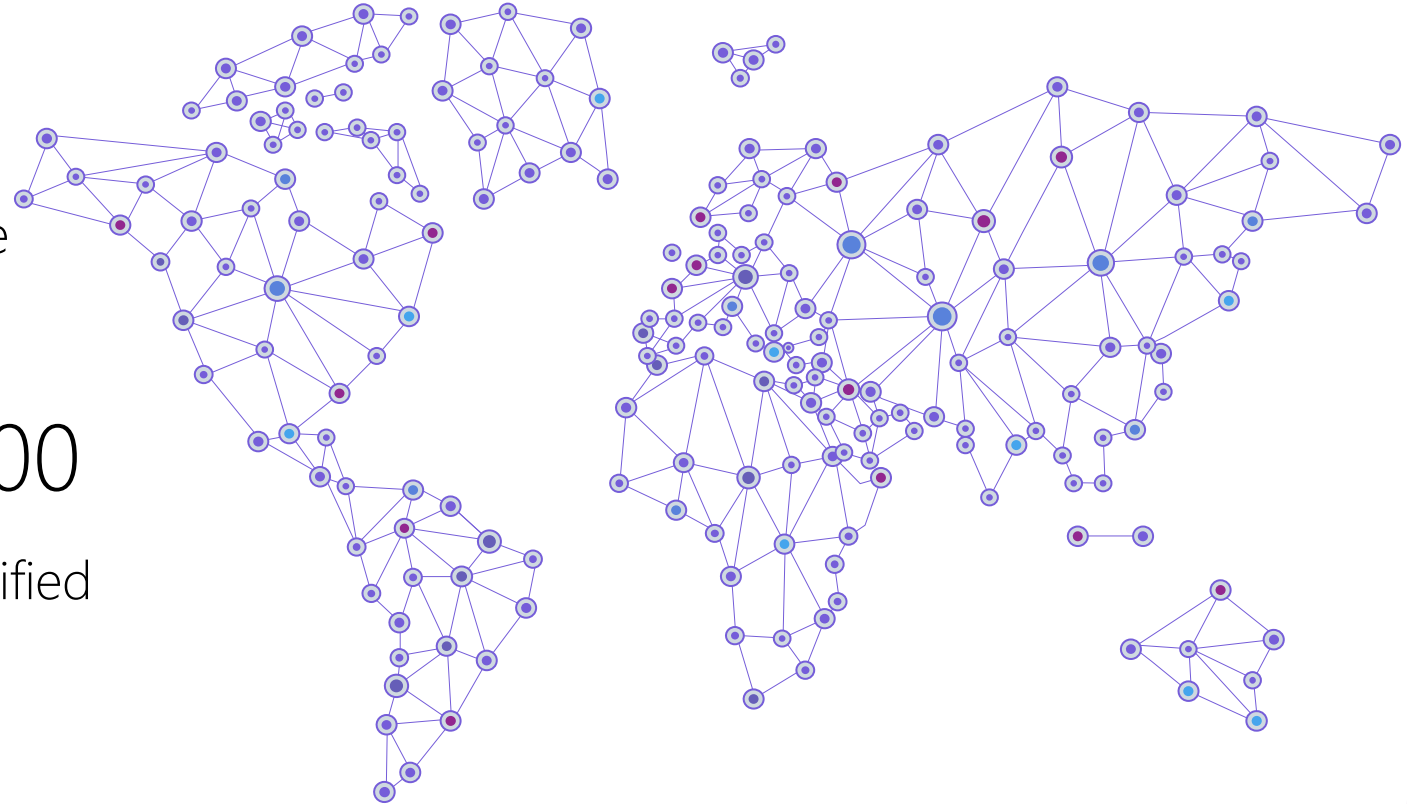
# Rare diseases: a global challenge

+ 300 million

People worldwide live with a rare disease

+ 7.000

Unique rare diseases identified



Together we can change puzzles into life changing solutions

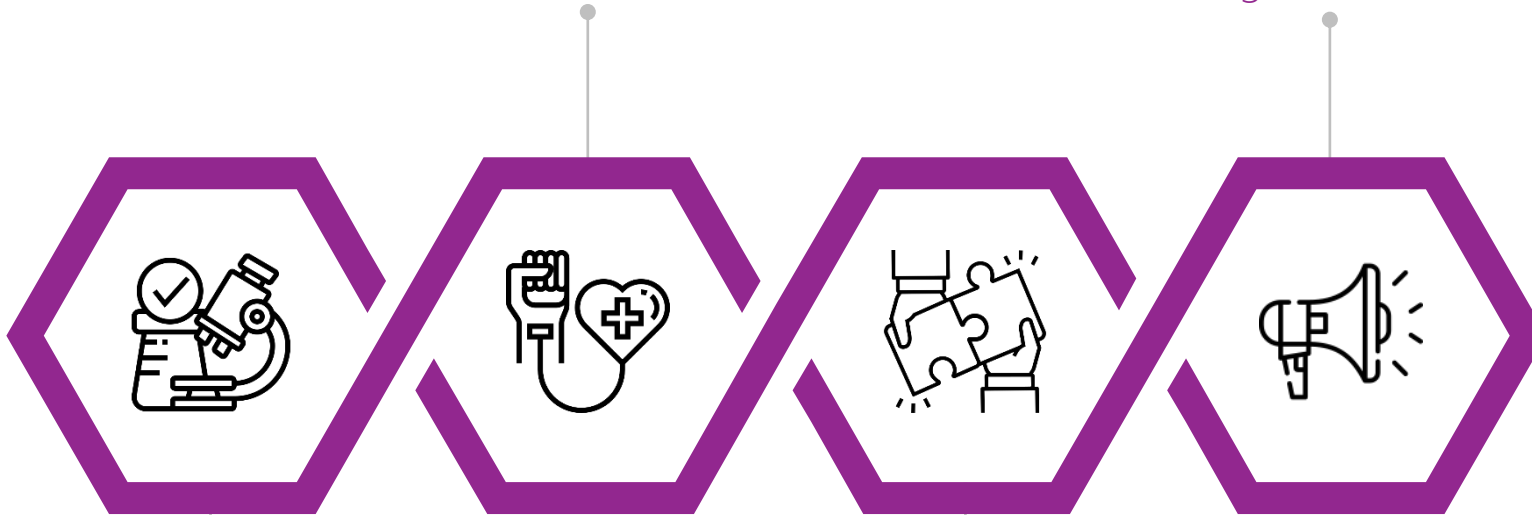
# Impact

Giving patients a platform to share experiences, access information, and find emotional support within a community of peers

## Empowering patients

Increasing awareness about rare diseases, their challenges, and the need for greater research funding and support

## Raising awareness



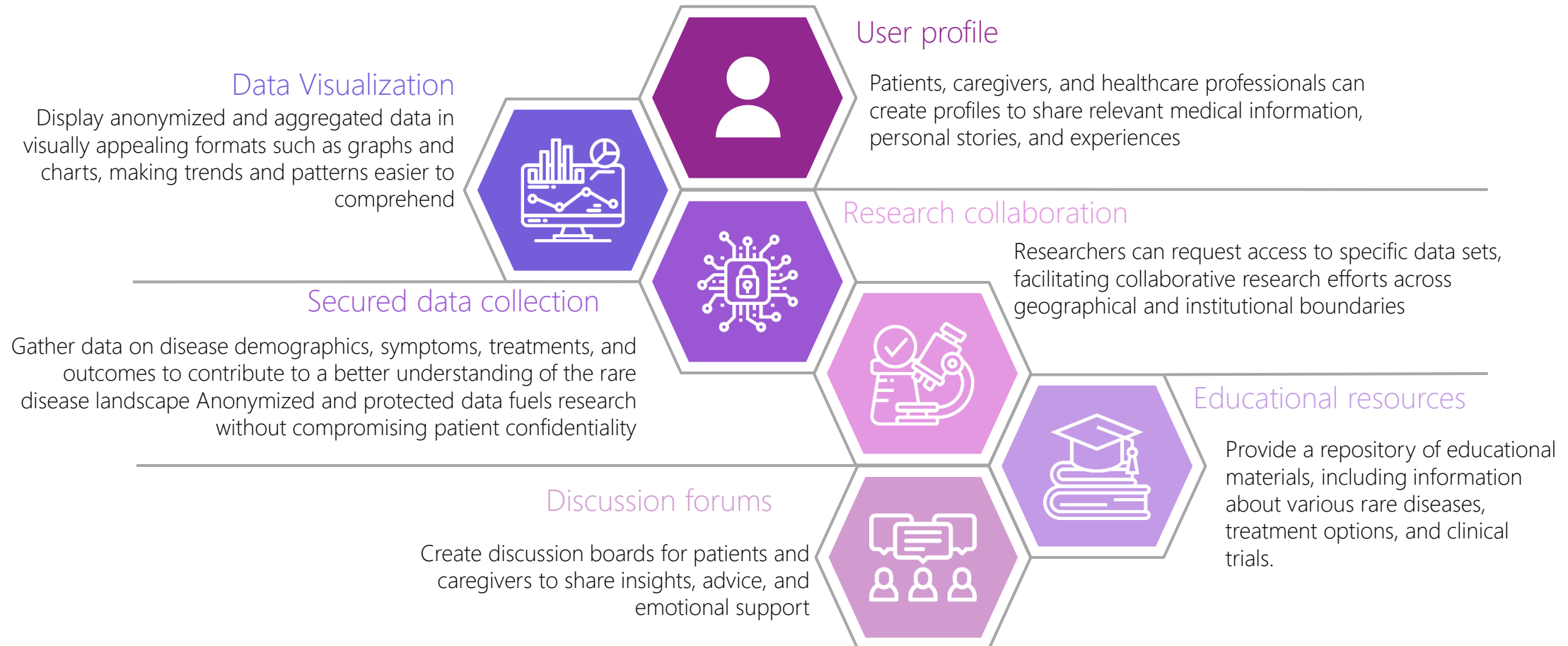
## Advancing research

Accelerating the pace of rare disease research by providing researchers with a comprehensive and diverse data pool

## Foster collaboration

Facilitating collaboration among patients, healthcare professionals, researchers, and advocacy groups to drive innovation in rare disease research and care

# Features and functionality



# Benefits



Patient-centric registry with structured data stored using industry standards

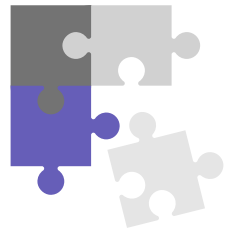
Security and privacy in the core using state of art technologies

Enable patients to manage their medical history



Foster the patient community (forums, discussion, messaging)

Raise rare disease awareness



Data sharing policies

Longitudinal data for Natural History studies



Unlock research potential with rich patient data

Attract pharmaceutical partnerships, enhancing patient access to clinical trials and therapies

rettX

database



Take the database survey now

## Rett Syndrome Europe Database Survey

