



European Rare Blood  
Disorders Platform

# How ENROL Supports Clinical Research

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# What we learned from the 1<sup>st</sup> webinar

**Main objective:** The challenge of fragmentation of data in rare haematological disorders and how ENROL is addressing it at the EU level

## Addressed questions

- Data fragmentation in rare hematological disorders
- The EU context on patients' registries and ENROL Registry
- What does FAIR (Findable, accessible, interoperable and re-usable) mean
- ENROL strategy for patients' registries in RHD

# Learning objectives of the 2<sup>nd</sup> webinar

**Main objectives:** Why Registry facilitate research & How registries ENROL support patient-centric research

## Addressed questions

- How do patients find out about the research their data has been used for?
- What are some real life examples of how registries have helped patients by improving knowledge about diseases?
- How can registries improve access to treatment where there is none?
- Can registries help identify new symptoms? Side effects of drugs? Safety issues?
- What is real world evidence and how does this help patients?
- How can registries help collect QoL which is very relevant for patients?



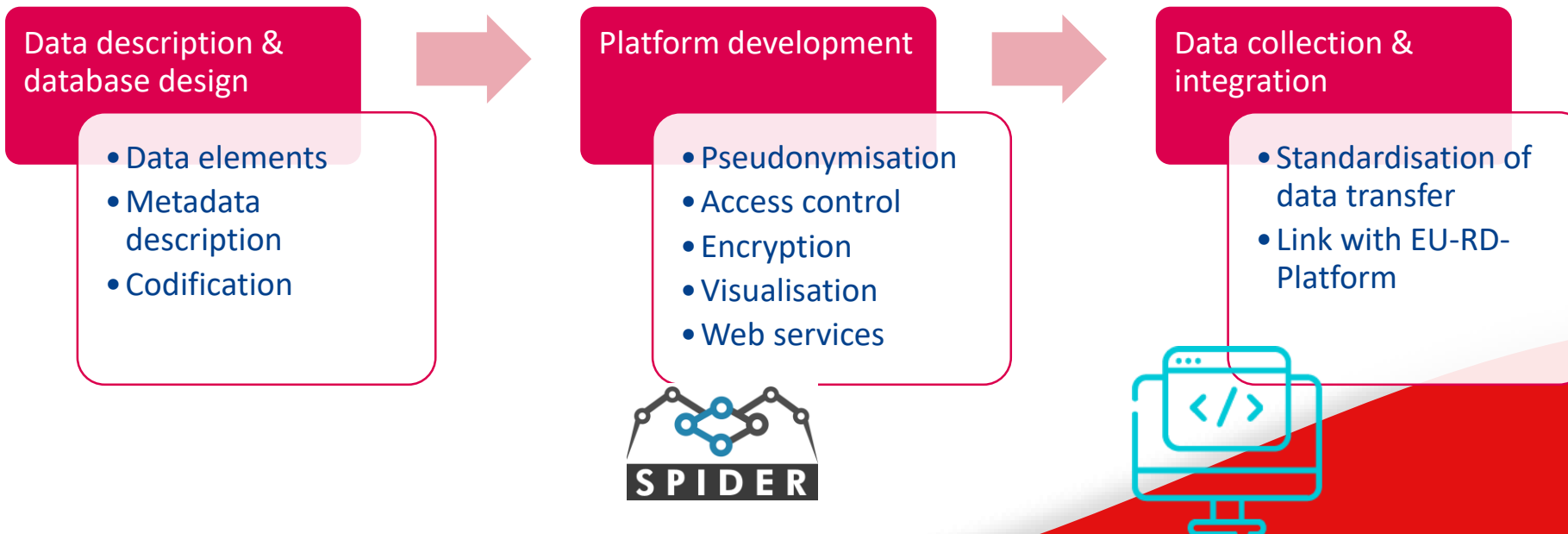
How registry facilitate research?



## ENROL Platform

Interoperable centralized web-based platform

It enables entering and integration of certified patient data from available sources



## ENROL

Maps common data across existing registries in Europe: disease, age, country, symptoms treatment...

- Facilitating to monitor a disease across Europe
- Helping research and policy' development for rare haematological diseases.

## ENROL

- Gather data that in Europe would have been fragmented in one central platform.
- Enrol makes data understandable, accessible and reusable by researcher and policy makers and guarantying patients' privacy.



How do patients find out about the research their data has been used for?



# Title

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx



What are some real life examples of how registries have helped patients by improving knowledge about diseases?

**Title**

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx



How can registries improve access to treatment where there is none?

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx

**Title**







Can registries help identify new symptoms? Side effects of drugs? Safety issues?

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx

# Title



What is real world evidence and how does this help patients?

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx

**Title**



How can registries help collect QoL which is very relevant for patients?

# Learning objectives of the 2<sup>nd</sup> webinar

**xxxx:** How registries (and ENROL) support patient-centric research

**xxxx**

- Xxx
- Xxxx
- xxxx



# Thank You



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