

From the French national rare disease registry to ERNs registries: an innovating project of data reuse

Julia Rougier (1), Marion Duboc (1), Céline Angin (1), Arnaud Sandrin (1), Anne-Sophie Jannot (1)
¹Banque Nationale de Données Maladies Rares – BNDMR (AP-HP), Paris (France)

Projects involved : the European Joint Action JARDIN and the PNMR4



JARDIN




36 months



Started in
Feb 24

Joint Action to Integrate ERNs into National Healthcare Systems
 Launched by the European Commission and funded by the EU4Health programme and the Member States

The **General Directorate of Health Care Provider (DGOS)** is co-leading *Data Management Work package (WP8)* and the BNDMR team is leading subgroup 8.4 (Agile implementation of WP8 deliverables) and subtask 8.4.1



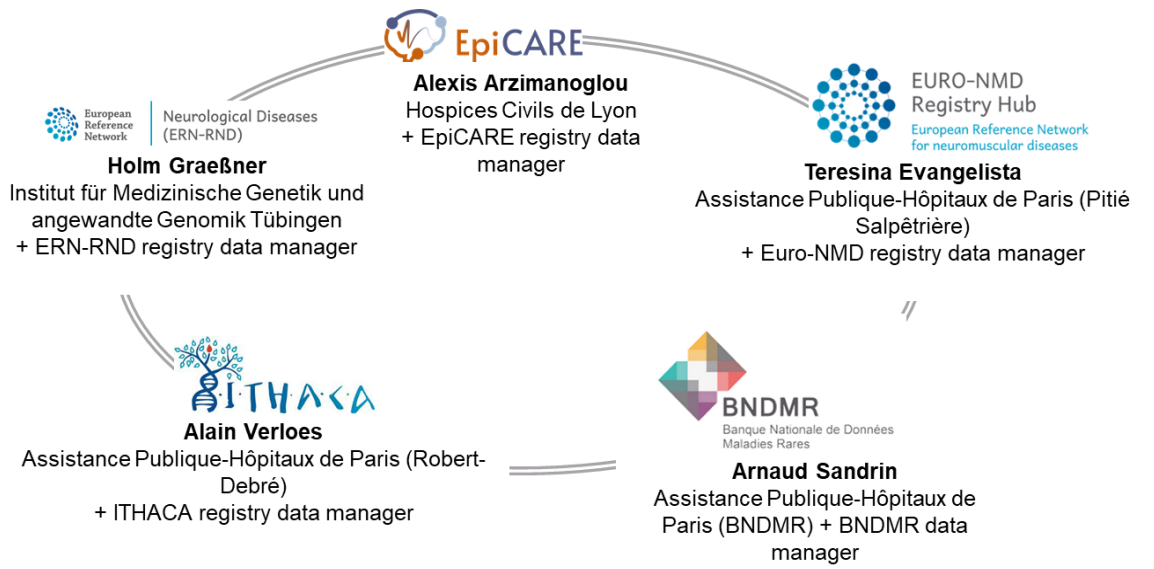
The 4th French National Plan for Rare Diseases (PNMR4)




Led by the General Directorate of Health Care Provider (DGOS)

Subtask 8.4.1 : Reuse data from national registries into ERNs registries

- 4 pilots ERNs:**
- ERN-RND
 - ITHACA
 - EURO- NMD
 - EpiCARE




Some actions focus on Europe



Sharing health data with Europe in connection with the joint action on integrating ERNs into national health systems JARDIN

Reusing data from national registries into ERNs registries - Overview



EHR

Electronic Health Records

Data entries in BaMaRa :

French Minimal Data Set (SDM)

+ Specific data by disease, where applicable



Data transformation in BaMaRa:



Pseudonymisation of patient data with **SPIDER**, European tool required in the Set of Common Data Elements (CDE)

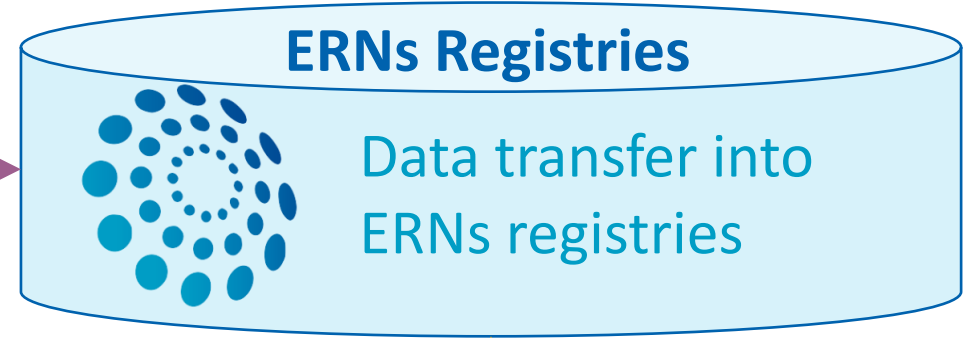


Checking regulatory aspects : patient consent, agreements...



Mapping between French Minimal Data Set (SDM) and Common Data Elements (CDE) including translation

https://eu-rd-platform.jrc.ec.europa.eu/set-of-common-data-elements_en



In others European Union's countries:
Others systems

