The BNDMR project relies on several tools

A **Minimal Data Set for rare diseases** to harmonise data collection at the national level: identification of the patient, medical activities, diagnosis, etc.

A **National Rare Diseases Identifier (IdMR)** to guarantee anonymity and interoperability with other registries on rare diseases.

The **BaMaRa app**, which can be accessed online (autonomous mode) or interconnected with the hospital's EHR (connected mode), to facilitate rare diseases data inputs by the medical staff.

Different **international standards** and nomenclatures to specify the diagnosis and other descriptors such as phenotypes (Orphanet, HPO, ICD-10) or genes (HGNC).

Aims pursued by the BNDMR data warehouse:

▸ To gather information about the patient and his/her disease

▸ To improve healthcare planning and organisation

▸ To make visible the rare disease activity in EHR and improve reporting and assessment on rare diseases

▸ To ensure linkage with with other national major databases (i.e. hospital database (PMSI) or French National Health Insurance system database (SNIIRAM))

▸ To facilitate research in the field of rare diseases

Find more information on: **bndmr.fr**

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ASSISTANCE HÔPITAUX
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BNDMR
Banque Nationale de Données Maladies Rares
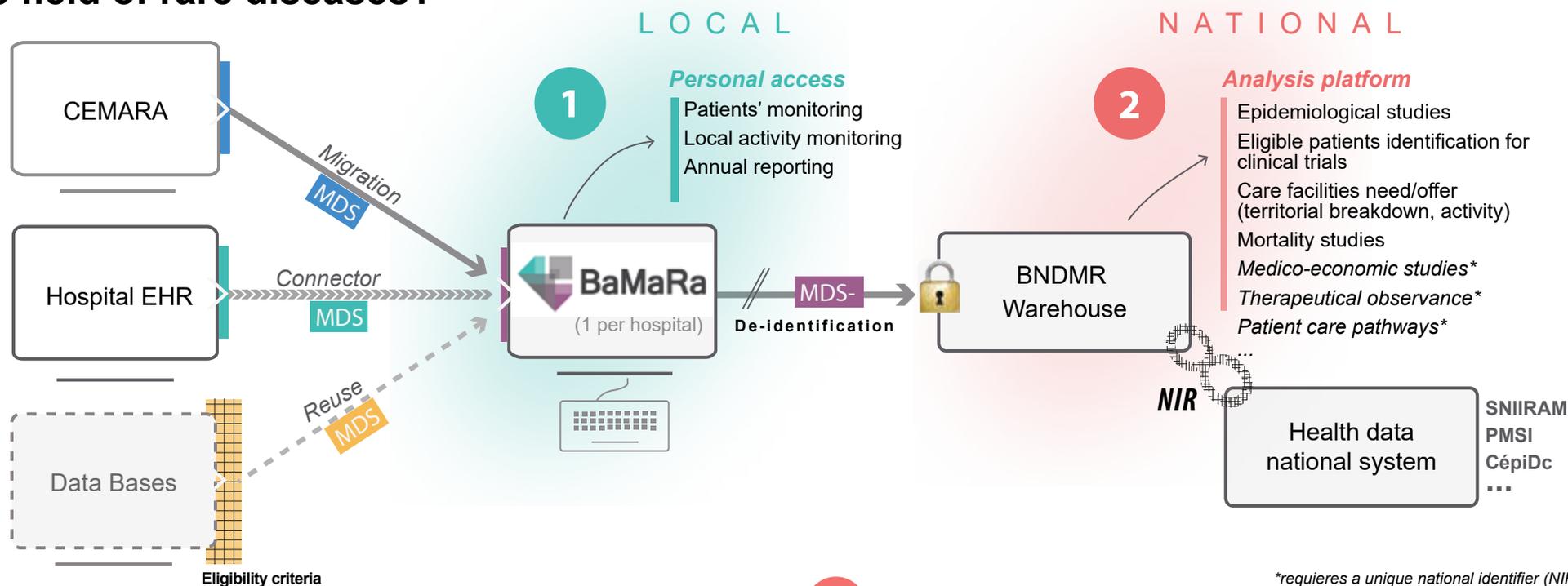
The French National Registry for Rare Diseases

La Banque Nationale de Données Maladies Rares (BNDMR)

The French National Registry for Rare Diseases is a national tool for **epidemiology** and **public health** purposes in the field of rare diseases (RD).

In line with the objectives defined by the 2nd French National Plan for Rare Diseases, the BNDMR team develops a secure national information system which gathers anonymized clinical data of patients affected by rare diseases in its BNDMR data warehouse.

How does the BNDMR promote a unique information system for clinical data collection in the field of rare diseases?

LOCAL

NATIONAL

1 Personal access
- Patients' monitoring
- Local activity monitoring
- Annual reporting

2 Analysis platform
- Epidemiological studies
- Eligible patients identification for clinical trials
- Care facilities need/offer (territorial breakdown, activity)
- Mortality studies
- *Medico-economic studies**
- *Therapeutical observance**
- *Patient care pathways**
- ...

CEMARA

Migration — MDS

Hospital EHR

Connector — MDS

Data Bases

Reuse — MDS

Eligibility criteria

BaMaRa (1 per hospital)

MDS- — De-identification

BNDMR Warehouse

NIR

Health data national system — SNIIRAM, PMSI, CépiDc, ...

*requieres a unique national identifier (NIR)

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1 At the local level: data collection through BaMaRa

Data is collected through BaMaRa by the medical staff during the consultation at the expert centres on rare diseases. The Minimal Data Set collection is mandatory and the information collected at that stage are not anonymised yet.

BaMaRa, as a tool of clinical management, enables the medical staff to access information about their recorded activities and the data collected in the centres of expertise they practise in. Besides, BaMaRa is a tool which facilitates activity and assessment reporting on rare diseases both at the local and national level.

BaMaRa is an app provided by the Assistance Publique - Hôpitaux de Paris (AP-HP) through partnership agreements with care facilities hosting expert centres on rare diseases.

2 At the national level: data analysis through BNDMR warehouse

In line with the objective of conducting multi-centric research studies at the national level, the BNDMR warehouse has been set up to gather data collected through BaMaRa. Those data are systematically de-identified before the integration in the warehouse.

In the near future, there is hope to combine data issued from BNDMR warehouse, electronic health records and patient-reported outcomes to provides new possibilities for research and innovation.

Gathering data from different countries is the only way to achieve a sufficient sample size for epidemiological and/or clinical research into rare diseases. However, this requires access, interoperability, sustainability and quality control, objectives which are thoroughly pursued through the BNDMR model, according to the FAIR principles.