Interoperability at national & European level

The French model

Elisa Salamanca – French National RD Databank

BNDMR
Banque Nationale de Données Maladies Rares

bndmr.fr

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

FAIR principles

Findable

Accessible

Interoperable

Reusable

- How the French model implements interoperability in health information systems?

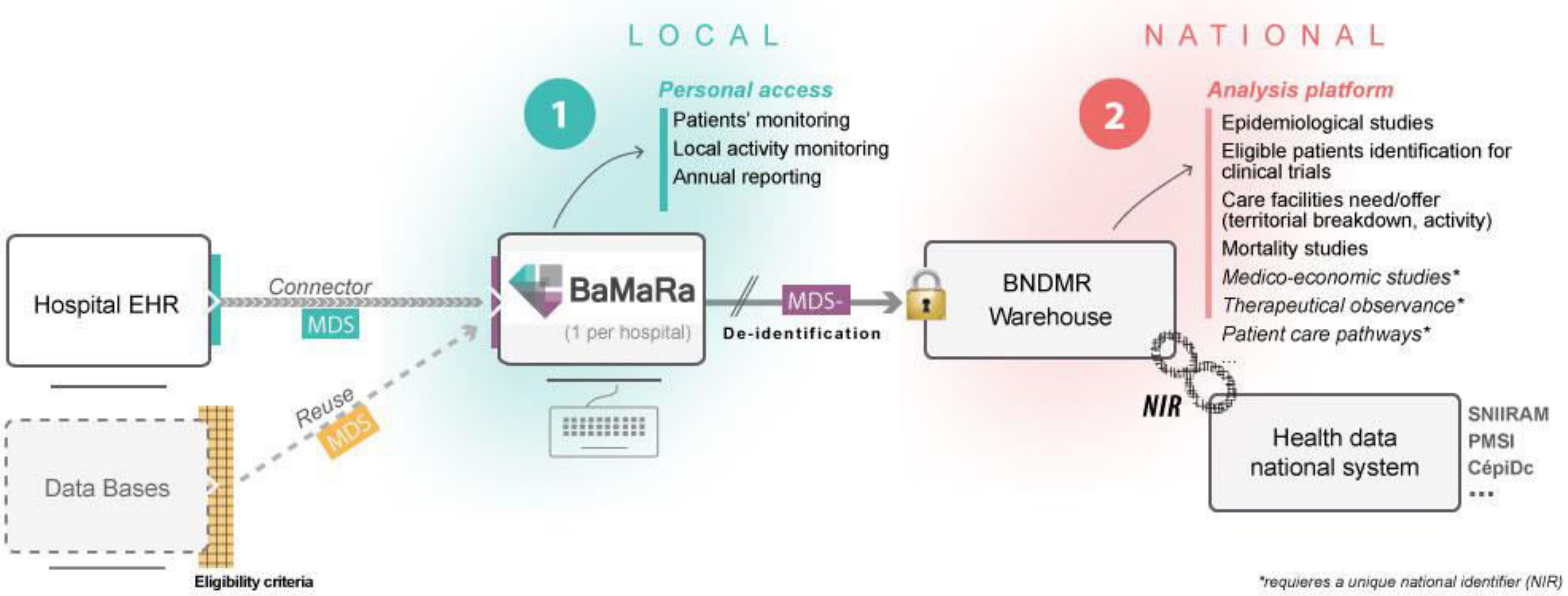
Aims pursued by the BNDMR data warehouse

- To gather information about the patient and his/her disease
- To improve healthcare planning and organization
- To make visible the rare disease activity in EHR and improve reporting and assessment on rare diseases
- To ensure linkage 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

The French model

BNDMR
Banque Nationale de Données Maladies Rares
bndmr.fr

A National data bank for rare diseases (BNDMR) and a national information system dedicated to the centres of expertise (BaMaRa)



Personal access

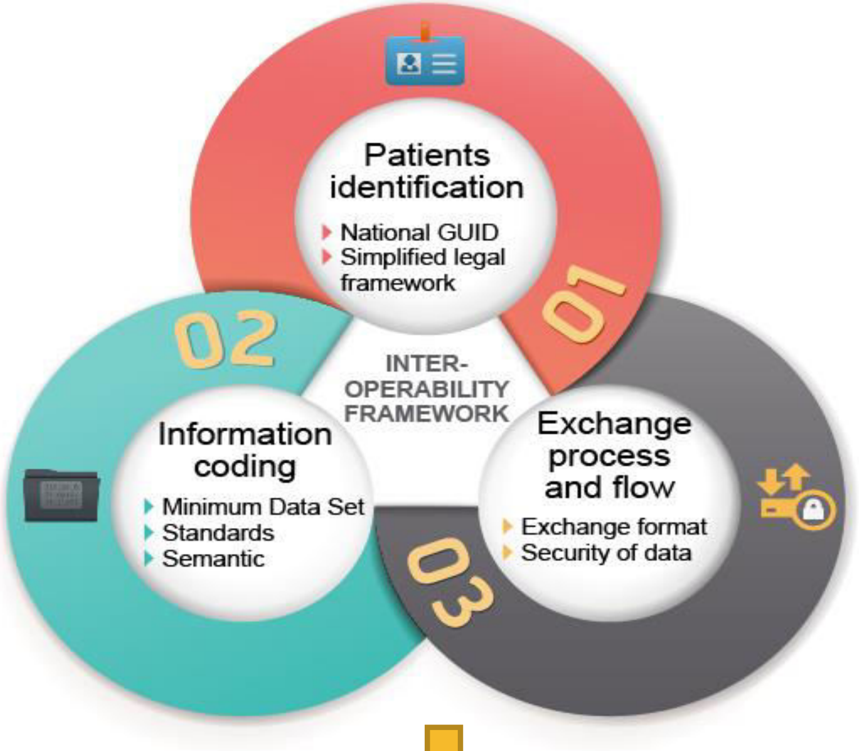
- Patients' monitoring
- Local activity monitoring
- Annual reporting

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**
- ...

**requieres a unique national identifier (NIR)*

National interoperability framework for RD



INTER-OPERABILITY FRAMEWORK

01 Patients identification

- National GUID
- Simplified legal framework

02 Information coding

- Minimum Data Set
- Standards
- Semantic

03 Exchange process and flow

- Exchange format
- Security of data

3 Pillars for interoperability with hospitals information systems

Patient identification

How?

- A national identifier has to be:
  - (A) Anonymous
  - (S) Sustainable
  - (U) Unique

Why?

- To enable de-identified data sharing (i.e. Patient records exchange)
- To reduce the number of duplicates (two IDs for a single patient) and potential collisions (same ID for two different patients) to get more precise patient counting for statistical and epidemiologic purposes
- To enable patients following overtime and systems/databases

Information coding

How?

- Information coding has to be standardized
  - **List of items :** Common data set / data elements (CDE)
  - **List of values :** Catalogues + Nomenclatures

Why?

- To homogenize data collection
- To make every system able to understand each other
- To ease the implementation in EHR

Information coding in the French model

- Minimum data set (MDS) => about 60 items

- Nomenclatures in use:
  - Diagnosis = **Orphanet** (diseases and subtypes)
  - Phenotypes = **HPO**, **ICD-10**, **Orphanet** (groups of diseases)
  - Genes = **HGNC**

- At EU level, several initiatives such as the EUCERD's MDS, EPIRARE's CDS, JRC's Set of Common Data Elements… inspired by the French MDS

Exchange process

How?

- **International standard formats for data sharing:**
  - HL7, CDA-R2…
- **Data encoding** and highly **secure data transfers**
  - TLS, SSL…

Why?

- To make system able to read and integrate the information
- Sensitive data => protections are mandatory

Why we need European interoperability?

- For a better care across borders:
  - in order to exchange patients records (anonymously or not)
- For statistical purposes
- For research
  - Benefit from bigger cohorts
  - Re-use of collected data
- For clinical trials