BNDMR - National Data Bank for Rare Diseases (Banque Nationale de Données Maladies Rares)

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General

Identification

Detailed name	National Data Bank for Rare Diseases (Banque Nationale de Données Maladies Rares)
Sign or acronym	BNDMR
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Rare diseases
Health determinants	Addictions Climate Genetic Geography Healthcare system and access to health care services Iatrogenic Intoxication Lifestyle and behavior Medicine Nutrition Occupation Pollution Social and psychosocial factors
Keywords	Rare diseases, medical information, patient records, CEMARA

Scientific investigator(s) (Contact)

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Collaborations

Funding

Funding status	Public
Details	DGOS (Directorate General for Care Provision)

Governance of the database

Sponsor(s) or organisation(s) responsible	BNDMR
Organisation status	Public
Presence of scientific or steering committees	Yes

Additional contact

Main features

Type of database

Type of database	Health relevant administrative databases

Database objective

Main objective	This database aims to: ? Better document the patient and his/her disease ? Improve healthcare network organisation ? Make rare diseases visible and help regulatory reporting ? Better harness the potential of large national databases ? Improve research within the field

Inclusion criteria	Patients from voluntary reference and specialist centres for rare diseases.
Population type	
Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2003 (expansion of CEMARA [CEntres MAladies RAres (Rare Disease Centres)]
Size of the database	
Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	290,000 (37,000 new patients annually)
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration

Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption

Procedures

Data collection method	Innovative collection method by promoting data collection directly within the healthcare framework. National minimum data set for rare diseases ? MDS. BaMaRa: secure web application interoperable with the existing hospital information system that allows data on rare diseases (patient identification, activity, diagnosis, etc.) to be entered, monitored and exploited.
Classifications used	Rare diseases: suitable for various clinical situations and linked to Orphanet, OMIM, HPO, CIM10
Participant monitoring	No
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI, SNIIRAM

Promotion and access

Promotion

Link to the document	http://www.bndmr.fr/espace-documentaire/publications-scientifiques/

Access

Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only