Ospedale Bambino Gesù Pediatric Oncology Health Data database

First published: 01/02/2024

Last updated: 17/10/2024

Data source   Human   Biobank   Hospital inpatient records

Hospital outpatient visit records   Specialist ambulatory care records

Administrative details

Administrative details

Data source ID

1111157

Data source acronym

OBG-POHD

Data holder

Bambino Gesù Children's Hospital (Ospedale Pediatrico Bambino Gesù, OPBG)

Data source type

Biobank

Hospital inpatient records

Hospital outpatient visit records

Specialist ambulatory care records

Main financial support

European public funding

Care setting

Hospital inpatient care

Hospital outpatient care

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

https://www.ospedalebambinogesu.it/

Contact details

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Data source regions and languages

Data source countries

Italy

Poland

Romania

Ukraine

Data source languages

Italian

Data source establishment

Data source established

15/06/2023

Data source time span

First collection: 01/01/2018

The date when data started to be collected or extracted.

Last collection: 29/02/2024

If data collection in the data source has ceased, the date new records last entered the data source.

Publications

Data source publications

Second series by the Italian Association of Pediatric Hematology and Oncology of children and adolescents with intracranial ependymoma: an integrated molecular and clinical characterization with a long-term follow-up

Infant High-Grade Gliomas Comprise Multiple Subgroups Characterized by Novel Targetable Gene Fusions and Favorable Outcomes Cancer Discov. 2020 Jul;10(7):942-963

The Multidimensional Assessment for Pediatric Patients in Radiotherapy (M.A.P.-RT) Tool for Customized Treatment Preparation: RADAR Project

Droplet digital PCR-based detection of circulating tumor DNA from pediatric high grade and diffuse midline glioma patients

Data elements collected

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details

Brain tumour operation

Brain cancer metastatic

Glioma

Disease details (other)

Methylation profile; centralized review of pathology samples and diagnostic imaging; treatment plan (radiotherapy/proton-therapy)

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

ICD-9-CM

Prescriptions of medicines

Captured

Dispensing of medicines

Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Captured

Indication vocabulary

ICD-9-CM

SNOMED

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

Yes

Administration of vaccines

Yes

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

ICD-9-CM

SNOMED

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

Yes

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

Other

Biomarker data

Does the data source capture biomarker information? The term "biomarker" refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Captured

Biomarker data vocabulary

Other

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

No

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-9-CM

SNOMED

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Dose

Formulation

Route of administration

Medicinal product vocabulary

ATC

Quality of life measurements

Captured

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Adolescents (12 to < 18 years)

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Patients are not selected by socioeconomic status as the Italian Health System provides universal health coverage

Family linkage

Family linkage available in the data source permanently or can be created on an ad hoc basis

Ad hoc

Population

Population size

2957

Active population size

2957

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	898	898
Infants and toddlers (28 days – 23 months)	11	11
Adolescents (12 to < 18 years)	1034	1034
Adult and elderly population (≥18 years)	2059	2059

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

4.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

4.00

Data flows and management

Access and validation

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

Yes

Biospecimen access conditions

OPBG Biobank

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

Yes

Description of data collection

Data are collected and updated daily. Data are then processed and moved to a Research Layer in accordance with IRB protocols.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Event triggering de-registration of a person in the data source

End of treatment

Event triggering creation of a record in the data source

New patient with Brain Cancer

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Required for all studies

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Data source last refresh

26/02/2024

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

Yes

CDM Mappings

CDM name

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.4

Data source ETL status

Planned

Data source ETL specifications (link)

https://ohdsi.github.io/CommonDataModel/cdm54.html