

# 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

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### **Main financial support**

European public funding

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### **Care setting**

Hospital inpatient care

Hospital outpatient care

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### **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

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### **Data source website**

<https://www.ospedalebambinogesu.it/>

## Contact details

Diana Ferro [diana.ferro@opbg.net](mailto:diana.ferro@opbg.net)

Main

[diana.ferro@opbg.net](mailto:diana.ferro@opbg.net)

## Data source regions and languages

### **Data source countries**

Italy

Poland

Romania

Ukraine

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### **Data source languages**

Italian

## Data source establishment

### **Data source established**

15/06/2023

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### **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

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## **Disease details**

Brain tumour operation

Brain cancer metastatic

Glioma

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## **Disease details (other)**

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

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## **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

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## **Pregnancy and/or neonates**

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

Yes

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## **Hospital admission and/or discharge**

Yes

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## **ICU admission**

Is information on intensive care unit admission available?

Yes

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## **Cause of death**

Captured

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## **Cause of death vocabulary**

ICD-9-CM

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## **Prescriptions of medicines**

Captured

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## **Dispensing of medicines**

Captured

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## **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

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## **Contraception**

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

No

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## **Indication for use**

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

Captured

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## **Indication vocabulary**

ICD-9-CM

SNOMED

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## Medical devices

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

Yes

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## Administration of vaccines

Yes

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## Procedures

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

Captured

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## Procedures vocabulary

ICD-9-CM

SNOMED

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## 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

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## Clinical measurements

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

Yes

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## Genetic data

Are data related to genotyping, genome sequencing available?

Captured

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## Genetic data vocabulary

Other

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## 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

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## Biomarker data vocabulary

Other

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## Patient-reported outcomes

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

No

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## Patient-generated data

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

No

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## 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

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## Unique identifier for persons

Are patients uniquely identified in the data source?

No

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## **Diagnostic codes**

Captured

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## **Diagnosis / medical event vocabulary**

ICD-9-CM

SNOMED

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## **Medicinal product information**

Captured

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## **Medicinal product information collected**

Active ingredient(s)

Dose

Formulation

Route of administration

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## **Medicinal product vocabulary**

ATC

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## **Quality of life measurements**

Captured

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## **Quality of life measurements vocabulary**

Not coded (Free text)

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## **Lifestyle factors**

Not Captured

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## **Sociodemographic information**

Captured

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## **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)

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### **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

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## 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 ( $\geq 18$ 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

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**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

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## **Biospecimen access conditions**

OPBG Biobank

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## **Access to subject details**

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

Yes

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## **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

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

End of treatment

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## **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

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### Informed consent for use of data for research

Required for all studies

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### Possibility of data validation

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

Yes

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### Data source preservation

Are records preserved in the data source indefinitely?

Yes

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### Approval for publication

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

Yes

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### 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

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### CDM website

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

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### Data source ETL CDM version

5.4

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### Data source ETL status

Planned

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### Data source ETL specifications (link)

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