

# INvestigating SIgnificant Health Trends in Growth Hormone Treatments Registry

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Data source

Human

Disease registry

## Administrative details

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#### Data source ID

1000000148

#### Data source acronym

INSIGHTS-GHT

#### Data holder

[GWT-TUD GmbH - Gesellschaft für Wissens- und Technologietransfer](#)

#### Data source type

Disease registry

#### Main financial support

Funding from industry or contract research

## Care setting

Hospital outpatient care

Secondary care – specialist level (ambulatory)

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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

[INSIGHTS-GHT](#)

## Contact details

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## Data source regions and languages

### Data source countries

Germany

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### Data source languages

German

# Data source establishment

## Data source established

01/02/2022

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## Data source time span

**First collection:** 15/02/2022

The date when data started to be collected or extracted.

# Publications

## Data source publications

[Investigating significant health trends in growth hormone treatments registry: rationale, aims and design of a nationwide prospective registry \(study protocol\)](#)

[First 100 patients receiving long-acting growth hormone therapy: real-world evaluation from INSIGHTS-GHT registry](#)

## Data elements collected

## The data source contains the following information

### 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

Blood growth hormone decreased

Growth hormone deficiency

Prader-Willi syndrome

Turner's syndrome

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### **Disease details (other)**

SHOX Deficiency

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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-10

MedDRA

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## **Prescriptions of medicines**

Captured

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## **Prescriptions vocabulary**

ATC

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## **Dispensing of medicines**

Not 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-10

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## **Medical devices**

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

No

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## Administration of vaccines

No

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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-10

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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?

Not Captured

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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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## **Biomarker vocabulary, other**

No specific vocabulary. Free text language is used, e.g. IGF-I, IGFBP-3

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## **Patient-reported outcomes**

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

Yes

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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.

Yes

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## **Unique identifier for persons**

Are patients uniquely identified in the data source?

Yes

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## **Diagnostic codes**

Captured

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## **Diagnosis / medical event vocabulary**

ICD-10

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## **Medicinal product information**

Not Captured

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### **Quality of life measurements**

Captured

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### **Quality of life measurements vocabulary**

other

SF-12

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### **Quality of life measurements, other**

KIDSCREEN-27

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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

Ethnicity

Gender

Pharmaceutical copayment

## Quantitative descriptors

## Population Qualitative Data



## **Population age groups**

All

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adult and elderly population ( $\geq 18$  years)

Adults (18 to < 65 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly ( $\geq 65$  years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

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## **Estimated percentage of the population covered by the data source in the catchment area**

Information not available as several conditions are covered, with the common denominator that all require treatment with growth hormone.

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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 not receiving specialist care. INSIGHTS-GHT investigators are experts in growth hormone treatment, mostly endocrinologists. Patients without written informed consent and those not available for long-term follow-up are also not documented.

## **Population**

**Population size**

2100

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**Active population size**

2050

## Median observation time

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

2.50

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

2.00

## Data flows and management

### Access and validation

**Governance details**

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

[Publication in BMC Orphanet Journal of Rare Diseases on Rationale, design and methods](#)

## **Biospecimen access**

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

No

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## **Access to subject details**

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

No

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## **Description of data collection**

The web-based registry collects long-term data on growth hormone treatment in routine clinical care, from consecutive patients newly initiated or receiving maintenance growth hormone treatment. It meets high quality standards through several measures (planned minimum centre contribution, automated plausibility checks of data at entry, statistical checks, queries, monitoring with source data verification in at least 20% of participating centres).

# Event triggering registration

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

Start of treatment

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

Death

Loss to follow up

Practice deregistration

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## **Event triggering creation of a record in the data source**

Withdrawal of patient consent

# 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?

Yes

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## Linkage description, possible linkage

The data source may potentially be linked with additional data sources, such as for comparisons with other registries or with post-authorisation safety studies; however, the specific methods for such linkage are yet to be defined.

# Data management specifications that apply for the data source

## Data source refresh

Every 6 months

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## Informed consent for use of data for research

Other

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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?

No

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## Data source preservation length (years)

10 years

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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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### **Informed consent, other**

If pseudonymized data is used for purposes not originally covered in the patient information, ethics committees might require obtaining new informed consent from patients for these new purposes.

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### **Data source last refresh**

01/10/2025

## **Common Data Model (CDM) mapping**

### **CDM mapping**

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

No