German Atopic Dermatitis Registry TREATgermany

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Data source | Human | Disease registry | Primary care medical records

Administrative details

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Data source ID

49775

Data source acronym

TREATgermany-AD Registry

Data holder

TU Dresden, Department of Medicine

Data source type

Disease registry

Primary care medical records

Main financial support

Funding from industry or contract research

Care setting

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

Secondary care – specialist level (ambulatory)

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.treatgermany.org

Contact details

Jochen Schmitt treatgermany@ukdd.de

Main

treatgermany@ukdd.de

Sigrid Mueller sigrid.mueller@ukdd.de

Alternate

sigrid.mueller@ukdd.de

Data source regions and languages

Data source countries

Germany

Data source languages

German

Data source establishment

Data source established

15/06/2016

Data source time span

First collection: 23/06/2016

The date when data started to be collected or extracted.

Publications

Data source publications

Atopic dermatitis displays stable and dynamic skin transcriptome signatures

Elevated NK-cell transcriptional signature and dysbalance of resting and activated NK cells in atopic dermatitis

Implementation of dupilumab in routine care of atopic eczema: results from the German national registry TREATgermany

Perception of the coronavirus pandemic by patients with atopic dermatitis – Results from the TREATgermany registry

Status report on the atopic dermatitis registry TREATgermany

Obesity is linked to disease severity in moderate to severe atopic dermatitis- Data from the prospective observational TREATgermany registry

The importance of registries in clinical practice: Insights from the national atopic dermatitis registry TREATgermany

Treatment of Moderate-to-severe Atopic Dermatitis with Upadacitinib: Results from an Interim Analysis of the TREATgermany Registry

Studies

List of studies that have been conducted using the data source

Survey on the collection of data on adverse events related to medicinal products through registries

A pan-European registry-based observational study of abrocitinib and conventional systemic therapies in moderate and severe atopic dermatitis (Dream to TREAT AD)

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

Disease details (other)

Patients with moderate to severe atopic dermatitis. EASI, oSCORAD, IGA, PGA, DLQI, POEM, NRS (Pruritus, Sleep disorder, Pain), RECAP, CES-D, FSS, Adverse Events

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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.

No

Pregnancy and/or neonates

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

No

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Not Captured

Dispensing of medicines

Not 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?

Not Captured

Medical devices

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

No

Administration of vaccines

No

Procedures

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

Not Captured

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.

No

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?

Not Captured

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.

Not Captured

Patient-reported outcomes

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

Yes

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

Not Captured

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dosage regime

Dose

Medicinal product vocabulary

Not coded (Free text)

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

other

Quality of life measurements, other

DLQI

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Education level

Gender

Marital status

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

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

<0.1%

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)

Nation-wide

Population

Population size

2846

Active population size

1655

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	469	309
Infants and toddlers (28 days – 23 months)	55	30
Children (2 to < 12 years)	274	203
Adolescents (12 to < 18 years)	140	76
Adult and elderly population (≥18 years)	2377	1346
Adults (18 to < 65 years)	2239	1269
Adults (18 to < 46 years)	1531	850
Adults (46 to < 65 years)	708	419
Elderly (≥ 65 years)	138	77
Adults (65 to < 75 years)	104	64

Age group	Population size	Active population size
Adults (75 to < 85 years)	31	12
Adults (85 years and over)	3	1

Median observation time

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

1.00

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

1.50

Data flows and management

Access and validation

Biospecimen access

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

No

Access to subject details

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

Yes

Description of data collection

Data is recorded in an electronic database by physicians and patients during the visits

Event triggering registration

Event triggering registration of a person in the data source

Other

Event triggering registration of a person in the data source, other

oSCORAD>20 OR current systemic treatment OR past systemic treatment (last 24 month)

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

Death

Loss to follow up

Event triggering creation of a record in the data source

If defined inclusion criteria are met by the patient and informed consent is provided, further records are generated during subsequent patient visits at the recruiting sites (prospective observational study). Participation is voluntary.

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

Yearly

Informed consent for use of data for research

Required for general use

Possibility of data validation

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

No

Data source preservation

Are records preserved in the data source indefinitely?

No

Data source preservation length (years)

10 years

Approval for publication

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

Yes

Data source last refresh

30/12/2024

Common Data Model (CDM) mapping

CDM mapping

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

No