TREAT NL/BE registry (TREatment of Atopic eczema, the Netherlands and Belgium)

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Data source | Human | Disease registry

Administrative details

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PURI

https://redirect.ema.europa.eu/resource/1000000108

Data source ID

1000000108

Data source acronym

TREAT NL/BE registry

Data holder

Amsterdam UMC

Data source type

Disease registry

Main financial support

Funding by own institution

Funding from industry or contract research

National, regional, or municipal public funding

Care setting

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

TREAT Registry Taskforce website

Contact details

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Data source regions and languages

Data source countries

Belgium

Netherlands

Data source languages

English

Data source establishment

Data source established

14/08/2018

Data source time span

First collection: 20/11/2017

The date when data started to be collected or extracted.

Publications

Data source publications

Real-world reported adverse events related to systemic immunomodulating therapy in patients with atopic dermatitis: Results from the TREAT NL (TREatment of ATopic eczema, the Netherlands) registry

Mapping exercise and status update of eight established registries within the TREatment of ATopic eczema Registry Taskforce

The clinical relevance of dupilumab serum concentration in patients with atopic dermatitis: a two-center prospective cohort study

Comparison of real-world treatment outcomes of systemic immunomodulating therapy in atopic dermatitis patients with dark and light skin types

Work ability and quality of working life in atopic dermatitis patients treated with dupilumab

The Selection Process for a Web-Based Application to Measure Patient-Reported Outcomes Following the Example of the TREAT NL Registry

Effectiveness of dupilumab treatment in 95 patients with atopic dermatitis: daily practice data

Paternal and maternal use of dupilumab in patients with atopic dermatitis: a case series

Response to: “Comment on ‘Long-term effectiveness and safety of treatment with dupilumab in patients with atopic dermatitis: Results of the TREAT NL (TREatment of ATopic eczema, the Netherlands) registry’”

TREatment of ATopic eczema (TREAT) Registry Taskforce: protocol for a European safety study of dupilumab and other systemic therapies in patients with atopic eczema

Long-term effectiveness and safety of treatment with dupilumab in patients with atopic dermatitis: Results of the TREAT NL (TREatment of ATopic eczema, the Netherlands) registry

Studies

List of studies that have been conducted using the data source

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

Dermatitis atopic

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)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

MedDRA

Prescriptions of medicines

Captured

Prescriptions vocabulary

not coded

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?

No

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

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

other

Quality of life measurements, other

DLQI, QWLQ

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Ethnicity

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

All

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

95%

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 can choose to refrain from participating in the registry.

Population

Population size

430

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?

No

Description of data collection

In the TREAT NL/BE (TREatment of ATopic eczema, The Netherlands and Belgium) registry, long-term observational data is collected from patients with moderate-to-severe atopic eczema, both children and adults, who start treatment with systemic therapies (e.g., dupilumab, ciclosporin, methotrexate) and phototherapies (e.g., UVB) in daily practice.

At the moment, participating centers include Amsterdam UMC, Huid Medisch Centrum, Centrum Oosterwal, Leids Universitair Medisch Centrum, Medisch Centrum Leeuwarden, Dijklander Ziekenhuis, Onze Lieve Vrouwe Gasthuis, Erasmus MC, Rijnstate Ziekenhuis, Flevoziekenhuis and Universitair Ziekenhuis Gent.

With this registry, we aim to investigate the (cost-)effectiveness and safety of these treatments for atopic eczema on the long term. The TREAT NL registry was established in 2017 and is part of the TREAT Registry Taskforce, an international network of registries within Europe that collect the same data using a core dataset, to ensure uniformity in data collection.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

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

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?

No

Data source preservation length (years)

15 years

Approval for publication

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

Yes

Common Data Model (CDM) mapping

CDM mapping

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

No