IQVIA CTcue NL Network

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Administrative details

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Data source ID

1111179

Data source acronym

CTcue NL

Data holder

IQVIA NL, Real-World-Evidence

Data source type

Emergency care discharge records

Hospital discharge records Hospital inpatient records Hospital outpatient visit records Pharmacy dispensing records Primary care medical records Registration with healthcare system

Main financial support

Funding by own institution Funding from industry or contract research National, regional, or municipal 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

Contact details

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Main

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Data source regions and languages

Data source countries

Netherlands

Data source languages

Dutch

Data source regions

Drenthe

Flevoland

Fryslân

Gelderland

Groningen

Limburg

Noord-Brabant

Noord-Holland

Overijssel

Utrecht

Zeeland

Zuid-Holland

Data source establishment

Data source established

01/01/2000

Data source time span

First collection: 01/01/2000

The date when data started to be collected or extracted.

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.

No

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

Not coded (Free text)

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

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)].

Yes

Contraception

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

Yes

Indication for use

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

Captured

Indication vocabulary

ICD-10 ICD-9 Other

Indication vocabulary, other

Diagnosis referential will depend on the hospital, could be mapped project per project, Ongoing harmonization work (started from 2022)

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)?

Captured

Procedures vocabulary

Other

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?

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.

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?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

ICD-9

Not coded (Free text)

Other

SNOMED CT

Diagnosis / medical event vocabulary, other

DHD

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dosage regime

Dose

Route of administration

Strength

Medicinal product vocabulary

Other

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Other

Sociodemographic information

Captured

Sociodemographic information collected

Age Pharmaceutical copayment Sex

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) Children (2 to < 12 years) Adolescents (12 to < 18 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)

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

30 out of 80 hospitals: 37,5%

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)

population managed outside of hospital

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

Pseudonymized patient records collected from each hospital's main data sources. Contains data for public hospitals, university hospitals, and local (Dutch) hospital networks

Event triggering registration

Event triggering registration of a person in the data source

Birth
Disease diagnosis
Other
Practice registration
Start of treatment

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

First patient visit to hospital

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

Death Emigration End of treatment Loss to follow up Other Practice deregistration

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

Any other hospital exit event

Event triggering creation of a record in the data source

Any other hospital event

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

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

Yes

Data source, other

Hospital EMR systems

Linkage strategy

Deterministic

Linkage variable

patient_id

Linkage completeness

100% completeness. All events are linked to the patient.

Data management specifications that apply for the data source

Informed consent for use of data for research

Not Required

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

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

CTcue Datamodel

Data source ETL CDM version

The CTcue Datamodel is a privacy-by-design on-premise clinical Data warehouse used mostly via the accompanying CTcue search application

Data source ETL status

Completed