Haematological Malignancy Research Network

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Data source **Human** **Cancer registry**

Administrative details

Administrative details

Data source ID

1000000256

Data source acronym

HMRN

Data holder

Epidemiology and Cancer Statistics Group, University of York (ECSG UoY)

Data source type

Cancer registry

Main financial support

Funds from patients organisations, charity and foundations

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – GP, community pharmacist level

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

Haematological Malignancy Research Network

Contact details

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Main

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Data source regions and languages

Data source countries

United Kingdom

Data source languages

English

Data source regions

East Riding of Yorkshire

Kingston upon Hull

North Yorkshire

York

Data source establishment

Data source established

01/09/2004

Data source time span

First collection: 01/09/2004

The date when data started to be collected or extracted.

Publications

Data source publications

The Haematological Malignancy Research Network (HMRN): a new information strategy for population based epidemiology and health service research

Cohort Profile: The Haematological Malignancy Research Network (HMRN): a UK population-based patient cohort

Cohort Profile Update: The Haematological Malignancy Research Network (HMRN) UK population-based cohorts

Full list of publications

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

Lymphoma

Leukaemia

Plasma cell myeloma

Haematological malignancy

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)?

No

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

ICD-10

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)?

Captured

Procedures vocabulary

OPCS

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?

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

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.

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

Other

Diagnosis / medical event vocabulary, other

ICD-O-3

Medicinal product information

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Deprivation index

Ethnicity

Health area

Living in rural area

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

All

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

Our population-based patient cohort comprises all patients diagnosed with a haematological malignancy or related precursor condition within the study region.

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

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

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)?

No

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?

No