RITA Ireland Vasculitis registry (formerly known as RKD registry and biobank)

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Data source | Human | Biobank | Disease registry

Administrative details

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Data source ID

1000000688

Data source acronym

RIV

Data holder

Trinity College Dublin

Data source type

Biobank

Disease registry

Main financial support

Funding from industry or contract research

Funds from patients organisations, charity and foundations

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

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

RIV registry and biobank

Contact details

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Data source regions and languages

Data source countries

Ireland

Data source languages

English

Data source regions

Connacht

Leinster

Munster

Ulster

Data source establishment

Data source established

01/05/2012

Data source time span

First collection: 01/07/2012

The date when data started to be collected or extracted.

Publications

Data source publications

ANCA-associated vasculitis in Ireland: a multi-centre national cohort study

The association between ambient UVB dose and ANCA-associated vasculitis relapse and onset

The Clinical Application of Urine Soluble CD163 in ANCA-Associated Vasculitis

Urinary Soluble CD163 in Active Renal Vasculitis

Data elements collected

The data source contains the following

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

Anti-glomerular basement membrane disease

Microscopic polyangiitis

Granulomatosis with polyangiitis

Eosinophilic granulomatosis with polyangiitis

Polyarteritis nodosa

Immune-mediated vasculitis

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

SNOMED CT

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

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?

Captured

Indication vocabulary

Not coded (Free text)

Medical devices

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

No

Administration of vaccines

Yes

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.

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

BMO

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?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

MedDRA

Orphanet Rare Disease Ontology (ORDO)

SNOMED CT

Medicinal product information

Not Captured

Medicinal product vocabulary

ATC

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

Country of origin

Education level

Ethnicity

Gender

Health area

Quantitative descriptors

Population Qualitative Data

Population age groups

Adult and elderly population (≥18 years)

Adults (18 to < 65 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

70% - inception cohort using hospital registration across 8 hospitals in Ireland

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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)

people who are registered only for private care are present but under-represented

Population

Population size

1027

Active population size

896

Median observation time

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

2.20

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

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).

RKD registry and biobank Protocol.pdf

English (1.05 MB - PDF)

View document

RIV registry and biobank

Biospecimen access

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

Yes

Biospecimen access conditions

MTA and data sharing agreement required

Cost recovery charge levied - amount variable depending on nature of engagement, and whether industry or academic

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Access to subject details

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

Yes

Description of data collection

Manual data entry at the time of clinical encounter, with data manager QC

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

Hospital encounters

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

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

Data source last refresh

15/07/2025

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 (other)

https://fairvasc-fdp.adaptcentre.ie/

Data source ETL specifications (link)

https://docs.google.com/spreadsheets/d/1m8jYdeWzoyrNDK-mT4pNLYW0rwuJz1qwJZkiWL_...

CDM name (other)

FAIRVASC ontology

Data source ETL frequency

6,00 months

Data source ETL specifications (link)

https://ontologies.adaptcentre.ie/fairvasc/