Irish metadata

Irish – Initial registry request data

Registry details	
Registry Name	Rare Kidney Disease Registry & Biobank
Abbreviation	RKD
Who can add data? (Please check as many that apply)	☐ Any clinician ☒ Academic leads of registry ☒ Research nurses ☒ Other (free text): Specified clinicians, medical students, research nurses who sign a data privacy agreement
IT platform(s) (Please check as many that apply)	☐ SQL database ☐ Spreadsheet ☒ Other (free text): REDCap hosted in Trinity College Dublin network
Remote access possible e.g. via VPN? (Please check one box)	☒ Yes ☐ No If Yes, please give details: web-based system, https, SSL encryption
Is all data in digital format? (Please check one box)	☒ Yes ☐ No If **No**, please give details:
Is the data structured or unstructured?	☒ Structured (e.g. CSV, spreadsheet, database) ☐ Unstructured (e.g. Word, PDF documents) ☐ Mix of both Please give details: Structured in REDCap (using ontologies, dropdowns, radio buttons, no freetext). Data can be exported based on 'instruments'.
Who is responsible for: (please provide name, email, position)	Data access: Prof Lucy Hederman, ADAPT centre. hederman@scss.tcd.ie Internal networks / firewalls: TCHPC, TCD - point of contact: Jess Braun, BRAUNJE@tcd.ie Servers: TCHPC, TCD - point of contact: Jess Braun, BRAUNJE@tcd.ie New services: TCHPC, TCD - point of contact: Jess Braun, BRAUNJE@tcd.ie
UML diagram(s)	☒ Available ☐ Not available If available, please send via email to address above.

Irish – ERDRI.dor metadata

Registry Name
Rare Kidney Disease registry

General information	
Acronym	RKD
Medical area	Nephrology/Rheumatology
Type of Registry	Epidemiology, Clinical Registry, Basic Research, Patient Registry
Other type	
Description	Created in 2012, the VINE registry covers the whole of Ireland and recruits patients with systemic vasculitis. The longitudinal clinical data are linked to multiple biological sample types obtained at various stages of the disease.
Registry is member of Eurocat?	No
Registry is member of:	ERN RITA
Website	https://www.tcd.ie/medicine/thkc/research/rare.php
Sponsors	Trinity College Dublin

Rare diseases	
Name of the disease	Orphanumber
Anti-glomerular basement membrane disease	375
Eosinophilic granulomatosis with polyangiitis	183
Granulomatosis with polyangiitis	900
Immunoglobulin A vasculitis	761
Microscopic polyangiitis	727
Predominantly medium-vessel vasculitis	156143
Predominantly small-vessel vasculitis	156146
Secondary vasculitis	445197
Vasculitis	52759

Structure	
Inclusion and exclusion criteria	Inclusion criteria 1. Diagnosis of one of the following forms of systemic vasculitis: (i) Small vessel vasculitis (ANCA associated): a. Microscopic polyangiitis (including renal limited vasculitis) b. Granulomatosis with polyangiitis (Wegener) c. Eosinophilic granulomatosis with polyangiitis (Churg Strauss) d. ANCA vasculitis unclassified (ii) Small vessel vasculitis (Immune complex) a. anti-GBM disease b. Cryoglobulinemic vasculitis c. IgA vasculitis (Henoch-Schonlein) (iii) Medium vessel vasculitis: a. Classical PAN b. Kawasaki disease (iv) Large vessel vasculitis: a. Giant cell

	arteritis b. Takayasu's arteritis (v) Variable vessel vasculitis: a. Behcet's disease b. Cogan's syndrome (vi) Single organ vasculitis: a. Isolated aortitis b. Primary cerebral angiitis
Recruitment area	National
Name of the recruitment area	Republic of Ireland
Recruitment	as of 01/03/2012
Current number of cases	820 at 15/09/2020
Data source	University hospital, Non university hospital
Other	
Data management	central and decentral
Link to the privacy policy	https://www.tcd.ie/medicine/thkc/assets/pdf/RKD%20PIL-v4-280413.pdf
Ethical review committee	St James/Tallaght Hospital
Availability for future collaborations/studies	Yes

Registry information

Institution	Trinity College Dublin
Facility	Trinity Translational Medicine Institute
Department	Trinity Health Kidney Centre
Street & number	St James Hospital
Postcode City	D08 W9RT Dublin
Country	Ireland

Responsible for the registry

Contact person	Mr MBBCh PhD Mark Little
Position	Professor of Nephrology
E-Mail address	mlittle[AT]tcd[DOT]ie
Phone number	+35318964810

Biobanks

Biobank name	Registry of biobanks	Biobank identifier
Rare Kidney Disease Biobank	RD-CONNECT	178115
Rare Kidney Disease Biobank	MERIL	15476

Additional components

Name of the component	Component described in	Relationship component-registry
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