

UKIVAS metadata

UKIVAS – Initial registry request data

Registry details	
Registry Name	UKIVas
Abbreviation	
Who can add data? (Please check as many that apply)	<input checked="" type="checkbox"/> Any clinician <input type="checkbox"/> Academic leads of registry <input type="checkbox"/> Research nurses <input type="checkbox"/> Other (free text):
IT platform(s) (Please check as many that apply)	<input checked="" type="checkbox"/> SQL database <input type="checkbox"/> Spreadsheet <input type="checkbox"/> Other (free text):
Remote access possible e.g. via VPN? (Please check one box)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No If Yes , please give details:
Is all data in digital format? (Please check one box)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No If No , please give details:
Is the data structured or unstructured?	<input checked="" type="checkbox"/> Structured (e.g. CSV, spreadsheet, database) <input type="checkbox"/> Unstructured (e.g. Word, PDF documents) <input type="checkbox"/> Mix of both Please give details:
Who is responsible for: (please provide name, email, position)	Data access: David Gray - david.gray@ndorms.ox.ac.uk Internal networks / firewalls: Servers: Joe Barrett - joe.barrett@ndorms.ox.ac.uk New services:
UML diagram(s)	<input type="checkbox"/> Available <input checked="" type="checkbox"/> Not available If available, please send via email to address above.

UKIVAS – ERDRI.dor metadata

Names
United Kingdom and Ireland Vasculitis Registry
General information

Acronym	UKIVAS
Medical area	Nephrology / Rheumatology
Type of Registry	Epidemiology, Clinical Registry, Pharmacological Research
Other type	
Description	The UKIVAS Registry is a collaboration between patients, clinicians and scientists to create the first comprehensive database of vasculitis patients in the UK and Ireland. Our long-term vision is that, through longitudinal data collection and data linkage, we will build a granular picture of the clinical course of vasculitis in the modern era, thereby enhancing the evidence base for diagnosis and treatment of patients with vasculitis.
Registry is member of Eurocat?	No
Website	https://ukivas.org
Sponsors	University of Oxford

Rare diseases	
Name of the disease	Orphan number
Anti-glomerular basement membrane disease	375
Anti-neutrophil cytoplasmic antibody-associated vasculitis	156152
Behçet disease	117
Cogan syndrome	1467
Cryoglobulinemic vasculitis	91138
Cutaneous small vessel vasculitis	889
Eosinophilic granulomatosis with polyangiitis	183
Giant cell arteritis	397
Granulomatosis with polyangiitis	900
Hypocomplementemic urticarial vasculitis	36412
IgG4-related aortitis	449400
Immune complex mediated vasculitis	156149
Immunoglobulin A vasculitis	761
Kawasaki disease	2331
Microscopic polyangiitis	727
Polyarteritis nodosa	767
Predominantly large-vessel vasculitis	156140
Predominantly medium-vessel vasculitis	156143
Primary angiitis of the central nervous system	140989
Takayasu arteritis	3287

Structure	
Inclusion and exclusion criteria	Primary vasculitis as above, all ages Able to give informed consent (or representative able to give informed consent)
Recruitment area	National
Name of the recruitment area	United Kingdom and Ireland

Recruitment	as of 01/02/2011 until 28/02/2022
Current number of cases	7500 at 20/11/2020
Data source	University hospital, Non university hospital
Other	
Number of Data Elements collected by the registry	1181
Technical solution (software) used	Bespoke web application
Data management	central
Link to the privacy policy	https://ukivas.ndorms.ox.ac.uk/privacy
Ethical review committee	NRES Committee London - South East
Availability for future collaborations/studies	Yes

Registry information	
Institution	University of Oxford
Facility	
Department	Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences
Street & number	Botnar Research Centre, Windmill Road
Postcode City	OX3 7LD Oxford
Country	United Kingdom of Great Britain and Northern Ireland

Responsible for the registry	
Contact person	Mr DM, FRCP, FRCPE Raashid Luqmani
Position	Professor of Rheumatology
E-Mail address	ukivas[AT]ndorms[DOT]ox[DOT]ac[DOT]uk
Phone number	+44 1865 737216/738106

European Patient IDentity (EUPID)	
EUPID short name of the registry	UKIVAS
EUPID extended name of the registry	United Kingdom and Ireland Vasculitis Registry

Biobanks		
Biobank name	Registry of biobanks	Biobank identifier
-	-	-

Additional components		
Name of the component	Component described in	Relationship component-registry
-	-	-

