GEVAS metadata

GEVAS – Initial registry request data

Registry details	
Registry Name	Gemeinsames Vaskulitis Register im deutschsprachigen Raum
Abbreviation	GeVas
Who can add data? (Please check as many that apply)	☐ Any clinician ☒ Academic leads of registry ☒ Research nurses ☐ Other (free text): access to registry only after training and a formal request
IT platform(s) (Please check as many that apply)	☒ SQL database ☐ Spreadsheet ☐ Other (free text):
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:
Who is responsible for: (please provide name, email, position)	Data access: Dr. Margit Kaufmann, margit.kaufmann@uniklinik-freiburg.de, Datamanagement team leader Internal networks / firewalls: Adrian Tassoni, adrian.tassoni@uniklinik-freiburg.de, IT team leader Servers: Adrian Tassoni, adrian.tassoni@uniklinik-freiburg.de, IT team leader New services: Adrian Tassoni, adrian.tassoni@uniklinik-freiburg.de, IT team leader
UML diagram(s)	☐ Available ☒ Not available If available, please send via email to address above.

GEVAS – ERDRI.dor metadata

Registry name
Joint Vasculitis Registry in German-speaking Countries [Gemeinsames Vaskulitis Register im deutschsprachigen Raum]

General information	
Acronym	GeVas
Medical area	Rheumatology
Type of Registry	Clinical Registry
Other type	
Description	The objective of GeVas is to record all patients, who have been recently diagnosed with systemic or single-organ vasculitides according to the Chapel Hill Consensus Conference (CHCC) nomenclature and definitions, or who have changed their treatment due to a relapse, in a prospective, web-based, clinician-driven, transregional, multicenter registry, and to document long-term disease outcomes in a standardized and systematic manner.
Registry is member of Eurocat?	No
Website	
Sponsors	

Rare diseases	
Name of the disease	Orphanumber
Anti-neutrophil cytoplasmic antibody-associated vasculitis	156152
Giant cell arteritis	397
Immune complex mediated vasculitis	156149
Immunoglobulin A vasculitis	761
Predominantly large-vessel vasculitis	156140
Predominantly medium-vessel vasculitis	156143
Predominantly small-vessel vasculitis	156146

Structure	
Inclusion and exclusion criteria	
Recruitment area	International
Name of the recruitment area	Germany, Austria, Switzerland
Recruitment	as of 05/06/2019
Current number of cases	169 at 31/10/2020
Data source	University hospital, Non university hospital, Physician
Other	
Data management	central
Link to the privacy policy	

Ethical review committee	Ethics committee of the University of Lübeck
Availability for future collaborations/studies	

Registry information

Institution	University of Lübeck, Germany (UKSH)
Facility	
Department	Department of Rheumatology and Clinical Immunology
Street & number	Ratzeburger Allee 160
Postcode City	23538 Lübeck
Country	Germany

Responsible for the registry

Contact person	Mr Professor Peter Lamprecht
Position	
E-Mail address	peter[DOT]lamprecht[AT]uksh[DOT]de
Phone number	+4945150045201

Biobanks

Biobank name	Registry of biobanks	Biobank identifier
-	-	-

Additional components

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