Polish metadata

Polish – Initial registry request data

Registry details	
Registry Name	
Abbreviation	POLVAS
Who can add data? (Please check as many that apply)	☒ Any clinician ☐ Academic leads of registry ☐ Research nurses ☐ Other (free text):
IT platform(s) (Please check as many that apply)	☒ SQL database ☐ Spreadsheet ☒ Other (free text): MySQL
Remote access possible e.g. via VPN? (Please check one box)	☒ Yes ☐ No If Y**es**, please give details: Vasculistis registry (POLVAS) is a web application. The programming language used in the application is Python 2.7 and JavaScript for the correct display of pages. The server should be supported by Linux. To allow flexible selection of data subgroups depending on various criteria, a relational database based on SQL was chosen. In further work, due to the limitations of the server provided (QNAP), the use of MySQL was forced. For proper operation of the application you need an http application server supporting applications based on python language running on the server. For better data flow control, one of the popular http server applications (apache, nginx) can be used as an intermediary application for http exchange and responsible for security (https, access logs). Access to the application is via a web browser that supports HTML5 and JavaScript. The application works correctly on browsers: Firefox (version 43), Chrome (version 49), Internet Explorer (version 11). Vasculitis is a web application based on the http protocol that allows operation both in the internal network and on the Internet. This document presents an example installation and configuration of the vasculitis application, however, the configuration should be implemented with the approval of people administering the given server due to possible security policy or the specificity of the given server.
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: data are exportes to excel, CSV or

Who is responsible for: (please provide name, email, position)	Data access: Krzysztof Wójck MD PhD, krzysztof.wojcik@uj.edu.pl, assitant Professor Internal networks / firewalls: M.Eng. Wojciech Majka, w.majka@cm-uj.krakow.pl, Head of IT unit Servers: New services:
UML diagram(s)	☐ Available ☐ Not available If available, please send via email to address above.

Polish – ERDRI.dor metadata

Registry name
Polish Vasculitis Registry

General information	
Acronym	POLVAS
Medical area	Rheumathology
Type of Registry	Epidemiology, Clinical Registry
Other type	
Description	The POLVAS registry is designed for research purposes and includes retrospective and prospective databases. The retrospective part concentrates on epidemiology, clinical picture, as well as treatment safety and efficacy in the current routine care of vasculitis patients. The major aims of the prospective part include studies on pathogenesis, diagnostic, and disease activity markers in serum, treatment efficacy and safety, long‚Äëterm disease outcome including clinical and social consequences.
Registry is member of Eurocat?	No
Website	ERN RITA
Sponsors	https://2katwew.cm-uj.krakow.pl/polvas/

Rare diseases	
Name of the disease	Orphanumber
Anti-glomerular basement membrane disease	375
Anti-neutrophil cytoplasmic antibody-associated vasculitis	156152
Cryoglobulinemic vasculitis	91138
Eosinophilic granulomatosis with polyangiitis	183

Giant cell arteritis	397
Granulomatosis with polyangiitis	900
Immunoglobulin A vasculitis	761
Microscopic polyangiitis	727
Polyarteritis nodosa	767
Takayasu arteritis	3287

Structure

Inclusion and exclusion criteria	
Recruitment area	National
Name of the recruitment area	Poland
Recruitment	as of 04/01/2016
Current number of cases	1250 at 08/01/2021
Data source	University hospital, Non university hospital
Other	
Data management	central and decentral
Link to the privacy policy	
Ethical review committee	Yes
Availability for future collaborations/studies	Yes

Registry information

Institution	Jagiellonian University Medical College
Facility	
Department	Allergy, Autoimmunity and Hypercoagulabilyty
Street & number	≈öwiƒôtej Anny 12
Postcode City	31-008 Krak√≥w
Country	Poland

Responsible for the registry

Contact person	Mr Professor Jacek Musia≈Ç
Position	
E-Mail address	jacek[DOT]musial[AT]uj[DOT]edu[DOT]pl
Phone number	+48 12 4305266

Biobanks

Biobank name	Registry of biobanks	Biobank identifier
POLVAS biobank	-	POLVAS_bio_bank

Additional components

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