Czech – Initial registry request data

Registry details			
Registry Name	Czech Registry of ANCA-associated vasculitides		
Abbreviation	(none used)		
Who can add data?	Any clinician		
	Academic leads of registry		
(Please check as many that	Research nurses		
apply)	U Other (free text):		
IT platform(s)	SQL database		
	Spreadsheet		
(Please check as many that	1 - 		
apply)			
Remote access possible	Yes No		
e.g. via VPN?	If Yes, please give details:		
(Please check one box)			
Is all data in digital			
format?	If No , please give details:		
(Please check one box)	M.C. 11 CCV 11 11 11		
Is the data structured or unstructured?	Structured (e.g. CSV, spreadsheet, database)		
unstructureu:	Unstructured (e.g. Word, PDF documents) Mix of both		
	Please give details:		
	rease give details.		
Who is responsible for:	Data access:		
-	Prof.Vladimir Tesař/ Zdenka Hruskova (MDs)// Jiří Dvořák (IT		
(please provide name,			
email, position)	Internal networks / firewalls:		
	General University Hospital in Prague		
	Servers:		
	General University Hospital in Prague		
	New services:		
TIME I	Jiří Dvořák		
UML diagram(s)	Available Not available		
	If available, please send via email to address above.		

CZECH – ERDRI.dor metadata

Registry name	
Czech Registry of ANCA-associated vasculitis	
General information	

Acronym	NA
Medical	nephrology, rheumatology
area	
Type of	Epidemiology, Clinical Registry
Registry	
Other type	
Description	The registry recruits patients with ANCA-associated vasculitis including
	longitudinal clinical and laboratory data
Registry is	
member of	
Eurocat?	
Website	
Sponsors	

Rare diseases	
Name of the disease	Orphanumber
Eosinophilic granulomatosis with polyangiitis	183
Granulomatosis with polyangiitis	900
Microscopic polyangiitis	727

Structure	
Inclusion and exclusion criteria	
Recruitment area	National
Name of the recruitment area	Czech Republic
Recruitment	
Current number of cases	1050 at 01/09/2020
Data source	University hospital, Non university hospital
Other	
Data management	NA
Link to the privacy policy	NA
Ethical review committee	NA
Availability for future	NA
collaborations/studies	

Registry information	
Institution	General University Hospital in Prague
Facility	
Department	Department of Nephrology
Street & number	U nemocnice 2
Postcode City	128 08 Praha
Country	Czech Republic

Responsible for the registry	
Contact person	Mr Vladimir Tesar MD, PhD
Position	Head of department
E-Mail address	vladimir[DOT]tesar[AT]vfn[DOT]cz
Phone number	+420 224962664

Biobanks		
Biobank name	Registry of biobanks	Biobank identifier
-	-	-

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