

## French metadata

### French – Initial registry request data

Registry details	
Registry Name	French Vasculitis Suty Group Registry
Abbreviation	FVSG Registry
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 checked="" type="checkbox"/> Other (free text): CRA
IT platform(s) (Please check as many that apply)	<input checked="" type="checkbox"/> SQL database <input type="checkbox"/> Spreadsheet <input checked="" type="checkbox"/> Other (free text): eCRF CleanWEB
Remote access possible e.g. via VPN? (Please check one box)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No If <b>Yes</b> , please give details: https
Is all data in digital format? (Please check one box)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No If <b>No</b> , 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: MariaDB
Who is responsible for: (please provide name, email, position)	Data access: Dr Xavier Puéchal xavier.puechal@aphp.fr (Responsible of the registry) Fabrice GOURMELON; fabrice.gourmelon@aphp.fr ; (datamanager responsible of login credentials) Internal networks / firewalls: Open to external access (DMZ) Servers: https://cleanweb-production2.aphp.fr/Ctms-aphp2/portal/login New services:
UML diagram(s)	<input type="checkbox"/> Available <input checked="" type="checkbox"/> Not available  If available, please send via email to address above.

## French – ERDRI.dor metadata

<b>Registry name</b>
French Vasculitis Study Group Registry

<b>General information</b>	
Acronym	FVSG Registry
Medical area	Vasculitis
Type of Registry	Epidemiology, Clinical Registry, Basic Research, Patient Registry, Healthcare planning
Other type	
Description	The French Vasculitis Study Group is a multidisciplinary network grouping together in France expert physicians taking care of patients suffering from vasculitis and leading research protocols on these vasculitides for 40 years. The FVSG has created and maintains a database gathering 4000 cases of vasculitis, distributed mainly on French territory, so as to be able to favour research studies. This network has designed numerous therapeutic trials, some of which led to change standard of care.
Registry is member of Eurocat?	No
Registry is member of:	<a href="#">ERN RITA</a>
Website	<a href="https://www.vascularites.org">https://www.vascularites.org</a>
Sponsors	Assistance Publique - Hôpitaux de Paris, Cochin Hospital

<b>Rare diseases</b>	
Name of the disease	Orphanumber
Anti-glomerular basement membrane disease	375
Anti-neutrophil cytoplasmic antibody-associated vasculitis	156152
Behçet disease	117
Buerger disease	36258
Cogan syndrome	1467
Cryoglobulinemic vasculitis	91138
Cutaneous polyarteritis nodosa	439729
Cutaneous small vessel vasculitis	889
Drug-induced vasculitis	251325
Eosinophilic granulomatosis with polyangiitis	183
Giant cell arteritis	397
Granulomatosis with polyangiitis	900
Hereditary pediatric Behçet-like disease	476102
Hypocomplementemic urticarial vasculitis	36412
Immune complex mediated vasculitis	156149
Immunoglobulin A vasculitis	761
Kawasaki disease	2331

Microscopic polyangiitis	727
Polyarteritis nodosa	767
Postinfectious vasculitis	48435
Predominantly large-vessel vasculitis	156140
Predominantly medium-vessel vasculitis	156143
Primary angiitis of the central nervous system	140989
Primary polyarteritis nodosa	439737
Rare pediatric vasculitis	280369
Relapsing polychondritis	728
Secondary polyarteritis nodosa	439746
Single-organ polyarteritis nodosa	439755
Susac syndrome	838
Takayasu arteritis	3287

<b>Structure</b>	
Inclusion and exclusion criteria	From 1975, all patients from France with incident vasculitis fulfilling the international classification criteria (ACR, EULAR) were recruited to participate in the FVSG Registry. All clinical, biological, pathological data were included in the e-CRF at diagnosis and at each yearly evaluation.
Recruitment area	National
Name of the recruitment area	France
Recruitment	as of 01/01/1975
Current number of cases	4303 at 11/01/2021
Data source	University hospital, Non university hospital, Physician
Other	
Data management	central
Link to the privacy policy	<a href="https://www.tentelemed.com/hebergement-securise/?lang=en">https://www.tentelemed.com/hebergement-securise/?lang=en</a>
Ethical review committee	CNIL and CCTIRS (French Regulatory and Ethical Committee) approval on August 31, 2015 and Septembre 29, 2016
Availability for future collaborations/studies	availability in the context of vasculitis of international cooperations

<b>Registry information</b>	
Institution	National Referral Center for Rare Systemic Auto-immune Diseases
Facility	Cochin Hospital
Department	Internal Medicine
Street & number	27 rue du faubourg Saint Jacques
Postcode City	75014 Paris
Country	France

**Responsible for the registry**

Contact person	Mr MD, PhD Xavier Puechal
Position	Physician
E-Mail address	xavier[DOT]puechal[AT]aphp[DOT]fr;
Phone number	33158412971

<b>Biobanks</b>		
Biobank name	Registry of biobanks	Biobank identifier
-	-	-

<b>Additional components</b>		
Name of the component	Component described in	Relationship component-registry
-	-	-