

# CARMEN - AUTOIMMUNE CYTOPENIA REGISTRY IN MIDI-PYRENEÉS REGION

Head :Moulis Guillaume, UMR INSERM-Université de Toulouse 1027, équipe 6  
Adoue Daniel

Last update : 11/10/2017 | Version : 1 | ID : 5294

General	
Identification	
Detailed name	AUTOIMMUNE CYTOPENIA REGISTRY IN MIDI-PYRENEÉS REGION
Sign or acronym	CARMEN
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL no. 2012-438; CCTIRS no. 12.067
General Aspects	
Medical area	Hematology Immunology
Pathology (details)	immune thrombocytopenia, autoimmune hemolytic anemia
Health determinants	Iatrogenic Medicine
Keywords	immune thrombocytopenia, autoimmune hemolytic anemia, registry, epidemiology, pharmacoepidemiology
Scientific investigator(s) (Contact)	
Name of the director	Moulis
Surname	Guillaume
Address	Faculté de Médecine, 37 allées Jules Guesde 31000 Toulouse
Phone	+ 33 (0)5 61 77 96 78
Email	moulis.g@chu-toulouse.fr

Unit	UMR INSERM-Université de Toulouse 1027, équipe 6
Organization	INSERM - Institut National de la Santé et de la Recherche
Name of the director	Adoue
Surname	Daniel
Email	adoue.d@chu-toulouse.fr
Collaborations	
Participation in projects, networks and consortia	Yes
Details	MaRIH
Funding	
Funding status	Mixed
Details	Toulouse university hospital, French Society of internal medicine, CSL Behring, Novartis
Governance of the database	
Sponsor(s) or organisation(s) responsible	Toulouse university hospital
Organisation status	Public
Sponsor(s) or organisation(s) responsible	INSERM - Institut National de la Santé et de la Recherche Médicale
Organisation status	Public
Presence of scientific or steering committees	Yes
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Investigators prospectively include all newly diagnosed adult patients for ITP of AIHA
Database objective	

Main objective	To describe the epidemiology of immune thrombocytopenic purpura (ITP) and of autoimmune hemolytic anemia (AIHA) , real-life exposure to treatments and their risk-benefit ratio.
Inclusion criteria	<ul style="list-style-type: none"> <li>- aged 18 or over</li> <li>- outvisit or hospitalisation for ITP or AIHA diagnosis</li> <li>- no opposition to participate</li> <li>- followed in the Midi-Pyrénées region</li> </ul>
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Pathology	D69 - Purpura and other haemorrhagic conditions  D59 - Acquired haemolytic anaemia
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Languedoc-Roussillon Midi-Pyrénées
Detail of the geography area	Midi-Pyrénées (Occitanie West)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2013
Date of last collection (YYYY or MM/YYYY)	2023
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	298 at december 31,2016

Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire
Paraclinical data (detail)	At diagnosis and during follow up if any event occurs
Biological data (detail)	At diagnosis and during follow up
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Procedures	
Data collection method	Follow-up forms will be completed by the investigating physician upon each patient consultation or hospitalisation at the investigating centre
Quality procedure(s) used	Check of data by medical record review by Reserch Assistant and medicine doctor specilized in autoimmune cytopenia if necessary
Participant monitoring	Yes
Monitoring procedures	Monitoring by contact with the referring doctor
Details on monitoring of participants	10 years
Links to administrative sources	Yes
Linked administrative sources (detail)	SNIIR-AM for completeness assessment

## Promotion and access

### Promotion

Link to the document [published\\_article.pdf](#)

Description Study protocol

Link to the document [Moulis\\_et\\_al-2017-American\\_Journal\\_of\\_Hematology.pdf](#)

Description Epidemiology of ITP

### Access

Terms of data access (charter for data provision, format of data, availability delay) Consult person in charge. [registre.carmen@chu-toulouse.fr](mailto:registre.carmen@chu-toulouse.fr) for all operational information.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only