

CARMEN - AUTOIMMUNE CYTOPENIA REGISTRY IN MIDI-PYRENEÉS REGION

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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

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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
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Collaborations

Participation in projects, networks and consortia	Yes
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Details	MaRIH
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Funding

Funding status	Mixed
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Details	Toulouse university hospital, French Society of internal medicine, CSL Behring, Novartis
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Governance of the database

Sponsor(s) or organisation(s) responsible	Toulouse university hospital
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Organisation status	Public
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Sponsor(s) or organisation(s) responsible	INSERM - Institut National de la Santé et de la Recherche Médicale
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Organisation status	Public
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Presence of scientific or steering committees	Yes
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Additional contact

Main features

Type of database

Type of database	Morbidity registers
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Additional information regarding sample selection.	Investigators prospectively include all newly diagnosed adult patients for ITP of AIHA
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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"> - aged 18 or over - outvisit or hospitalisation for ITP or AIHA diagnosis - no oppsition to participate - followed in the Midi-Pyrénées region
Population type	
Age	<ul style="list-style-type: none"> 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	<p>D69 - Purpura and other haemorrhagic conditions</p> <p>D59 - Acquired haemolytic anaemia</p>
Gender	<ul style="list-style-type: none"> 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 Research Assistant and medicine doctor specialized 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 for all operational information.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only