COPARIME 5000 - Cohort of 5,000 Patients at Risk of Melanoma

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General	
Identification	
Detailed name	Cohort of 5,000 Patients at Risk of Melanoma
Sign or acronym	COPARIME 5000
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL : 11/04/2011
General Aspects	
Medical area	Cancer research General practice
Keywords	malignancies, immune deficiencies, autoimmune diseases, users, Health episodes, prevention, health system
Scientific investigator(s) (Contact)	
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Organization	UNIVERSITE DE
Collaborations	
Participation in projects, networks and consortia	Yes
Funding	
Funding status	Public
Details	INCA

Governance of the database	
Sponsor(s) or organisation(s) responsible	CHU Nantes
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Cohort study
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Prospective Inclusion cut-off date: 01/07/2011
Database objective	
Main objective	General objective: to estimate the risk of developing de novo melanoma for at-risk patients according to the SAMScore (Self Administrated Melanoma risk score). Secondary objective: - To describe patient epidemiological and clinical characteristics - To develop a biobank in order to facilitate studies on these diseases and to investigate the physiopathogenic, haemato-immunological and genetic mechanisms of the same To establish and validate national treatment guidelines according to potential patient sub-groups.
Inclusion criteria	Patients having 18 years old or more and at elevated risk of melanoma.
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population

Gender	Male Woman
Geography area	Departmental
French regions covered by the database	Pays de la Loire
Detail of the geography area	Departments of Loire Atlantique and Vendée
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	04/2011
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	8000
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Self-administered questionnaire: input from a paper questionnaire Clinical examinations: direct input Biological analysis: handwritten
Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)

Links to administrative sources	Yes
Linked administrative sources (detail)	CRAM, other health insurance databases, pathology register
Promotion and access	
Promotion	
Link to the document	<u>http://www.em-</u> <u>consulte.com/article/743618/article/cohorte-de-</u> patients-a-risque-de-melanome-coparime-
Link to the document	<u>http://www.cclinouest.com/JOSE/Page_2011/nguyen</u> _ <u>jose_2011.pdf</u>
Link to the document	http://tinyurl.com/Pubmed-COPARIME
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams. Contractual access conditions: project submission to the scientific council To be decided if data may be used by industrial teams.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only