

GENEPSO - Prospective Breast and Ovarian Genetic Study: genetic predisposition to breast and ovarian cancer: a prospective study of BRCA mutation carriers

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General	
Identification	
Detailed name	Prospective Breast and Ovarian Genetic Study: genetic predisposition to breast and ovarian cancer: a prospective study of BRCA mutation carriers
Sign or acronym	GENEPSO
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL, CPP
General Aspects	
Medical area	Cancer research
Health determinants	Genetic
Keywords	BRCA gene mutation, standardised collection, prospective follow-up, Health events, death
Scientific investigator(s) (Contact)	
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Organization	Centre René
Collaborations	
Participation in projects, networks and consortia	Yes
Funding	
Funding status	Mixed
Details	Ligue contre le Cancer, FDF
Governance of the database	
Sponsor(s) or organisation(s) responsible	Centre René HUGUENIN
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
Database objective	
Main objective	General objective: to form a cohort of BRCA gene mutation carriers for standardised data collection and to establish a prospective follow-up over 10 years. Treatment for families can be improved by resolving certain questions (projects with associated INSERM teams): 1) what is the risk of

developing breast and/or ovarian cancer for gene mutation carriers during their lifetime? 2) are cancer risks modified by environmental factors (in particular medical radiation), hormonal factors (endogenous or exogenous), or other genetic factors? 3) should the same parameters be used to evaluate the prognosis of sporadic cancer? 4) what is the psychological and social impact for people with a known predisposition to breast and/or ovarian cancer?

Inclusion criteria	Adult subjects with no mental disability who are BRCA genetic mutation carriers
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	National
Detail of the geography area	Multicentric cohort (29 centres throughout France)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	11/1999
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1425
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data Paraclinical data Biological data

Clinical data (detail)	Medical registration
Declarative data (detail)	Paper self-questionnaire
Paraclinical data (detail)	Imaging

Biological data (detail)	Type of samples taken: Blood, tumour tissue
Presence of a biobank	No

Health parameters studied	Health event/morbidity Health event/mortality
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Procedures

Data collection method	Self-administered questionnaire: from a paper questionnaire (manual input) Interview: from a paper questionnaire (manual input)
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Participant monitoring	Yes
Details on monitoring of participants	Follow-up duration: 10 years

Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://www.hal.inserm.fr/GENEPSO
Description	List of publications in HAL

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=genepso+OR+24889689[uid]+OR+22378286[uid]
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 Data may be used by industrial teams
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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