

ELIPPSE 40 - Longitudinal study of the psychosocial impact of breast pathology

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General

Identification

Detailed name Longitudinal study of the psychosocial impact of breast pathology

Sign or acronym ELIPPSE 40

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL

General Aspects

Medical area Cancer research

Health determinants Social and psychosocial factors

Keywords relapse, life after acute episode of illness, Health episodes, death, side effects

Scientific investigator(s) (Contact)

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Organization	IRD
Collaborations	
Funding	
Funding status	Mixed
Details	Région PACA, INCa, Cancéropôle, FDF, Action concertée Incitative (ACI) du Ministère de la Recherche, DGS, Association pour la Recherche sur le Cancer (ARC).
Governance of the database	
Sponsor(s) or organisation(s) responsible	Institut National de la Santé et de la Recherche Médicale
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
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 Other bodies active in creating this cohort: CMNSS, CRAM-DRSM, RSI Sample 1: all women enrolled had a valid medical questionnaire, had completed the questionnaire at 28 months and who were working at the time of diagnosis (266 women). Sample 2: all women with a valid medical questionnaire and who responded to follow-up questionnaires at 28 months (331 women). Sample 3: face-to-face interview with 21 women concerning the development of their professional situation following a minimum of 16 months after breast cancer diagnosis Closing date for inclusion:01/01/2010
Database objective	

Main objective	General objective: to study - long-term quality of life and follow-up (5 to 10 years) of breast cancer survivors below the age of 40 (18 to 40 years old) within the Provence-Alpes-Côte d'Azur (PACA) region. - the impact of cancer and treatment on reproduction - children's experiences - return to work, access to first-time employment - body image - adherence to treatment, in particular hormonal therapy - access to loans and insurance.
Inclusion criteria	Women between 18 and 40 years old who have been diagnosed with a long-duration disease (LDD) for breast cancer confirmed by biopsy between July 2005 and July 2011, and living in either the PACA region or Corsica. Women with distant metastasis at diagnosis or severe psychiatric disorders were excluded, as well as those who were unable to complete the telephone questionnaire.
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population
Gender	Woman
Geography area	Regional
French regions covered by the database	Corse Provence - Alpes - Côte d'Azur
Detail of the geography area	PACA Region and Corsica
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	10/2005
Date of last collection (YYYY or MM/YYYY)	01/2015
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of	377

individuals

Data

Database activity Current data collection

Type of data collected Declarative data

Declarative data (detail) Phone interview

Presence of a biobank No

Health parameters studied Quality of life/health perception

Procedures

Data collection method Self-administered questionnaire: from paper questionnaire (manual input) Interview: direct input
Clinical Examinations: handwritten (manual input)
Interviews by telephone using CATI (computer-assisted collection) method

Participant monitoring Yes

Details on monitoring of participants Follow-up duration: 5 years

Links to administrative sources Yes

Linked administrative sources (detail) CRAM

Promotion and access

Promotion

Link to the document <http://tinyurl.com/Pubmed-ELIPPSE-40>

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, access according to questionnaires and databases, access for other teams may only be possible upon completion of studies and following our own data mining, except when directly collaborating on specific topics. Data may be used by industrial teams Access according to industry collaboration will be timely considered based on specific studies without structural support

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only