HSA - Cross-sectional Handicap-Health study - Informal caregivers

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General

Identification

Detailed name	Cross-sectional Handicap-Health study - Informal caregivers
Sign or acronym	HSA
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Disability/handicap
Health determinants	Healthcare system and access to health care services Lifestyle and behavior Social and psychosocial factors
Keywords	Informal caregivers, family and friends, aid, living conditions, dependence, health, handicap, quality of life

Scientific investigator(s) (Contact)

Name of the director	Soullier
Surname	Noémie
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Organization	DREES

Collaborations

Participation in projects, networks and consortia	Yes
Details	CNAF CNAV CNSA

Funding

Funding status	Public
Details	DREES

Governance of the database

Sponsor(s) or organisation(s) responsible	DREES
Organisation status	Public
Sponsor(s) or organisation(s) responsible	Insee
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Not-repeated cross-sectional studies (except case control studies)
Database recruitment is carried out by an intermediary	An administrative base or a register
Base or register (detail)	HSI-HSM survey file
Database recruitment is carried out as part of an interventional study	No

Database objective

Main objective	The principal objective of the "Informal caregivers" survey is to characterise non-professional caregivers (family, friends, neighbours, etc.) for individuals who have stated that they have trouble performing certain daily activities due to a handicap, a health problem or their age in the 2008 Handicap-Health survey. Conducted from April to September 2008, the survey includes 5,000 informal caregivers of handicapped individuals and dependent elderly individuals. This survey allows for the description

	and analysis of the living conditions and quality of life of individuals providing support to individuals they are close with (family, neighbours, friends, etc.) who stated that they have trouble in activities of daily life in the Handicap-Health survey in ordinary households in 2008 (handicapped or elderly individuals). It addresses an interest identified in the recent public debate (conference on Family in 2006, decree dated January 2007 allowing the arrangement of the right to respite for family caregivers), and addresses the initial questions from the Handicap-Health survey. It allows for knowledge of the motivations and manifestations of informal support, description and analysis of living conditions and quality of life of caregivers and the manner in which non-professional aid connects or does not connect with aid provided by professionals. The survey also allows for the detailed measurement of the consequences of aid on the daily life of the caregivers, on the professional, family and friendship plans. The general objective of the survey can be broken down into five sub-objectives: to create a portrait of caregivers from the social network, to gain knowledge of the configuration of aid and the conditions under which it is provided, to see how the caregiver's activity is reconciled with that of other caregivers, to understand the consequences of aid and the resulting needs, and lastly to gain knowledge of the representations that the caregivers have regarding their economic consent to the aid provided.
Inclusion criteria	The survey sample is made up of all of the caregivers named in the 2008 Handicap-Health survey, 16 years of age and older. The "Informal caregivers" survey is a supplemental section of the Handicap-Health survey in ordinary households conducted by Insee in 2008: when a person indicates in the Handicap-Health survey that he or she is aided by one or more non-professional caregivers, a quick description of the caregiver and the nature of the aid that he or she provides is requested from the surveyed individual. The contact information for the caregiver (or caregivers) is also collected (with a maximum of 3

cohabitating caregivers and 10 caregivers per surveyed individual): they constitute the sampling frame for the "Informal caregivers" survey.

The "Informal caregivers" study is limited to individuals 16 years of age or older. The individuals are questioned directly face to face by an Insee surveyor.

Population type

Age	Adolescence (13 to 18 years) 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	General population
Pathology	
Gender	Male Woman
Geography area	National
Detail of the geography area	France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2008
Date of last collection (YYYY or MM/YYYY)	2008

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	5 000

Data

Database activity	Data collection completed
Type of data collected	Declarative data

Declarative data (detail)	Face to face interview
Details of collected declarative data	The questionnaire for the "Informal caregivers" survey addresses the following topics: Lifestyle of the caregiver Nature of the relationship with the person receiving care Description of the aid Relationship with the professional caregivers for health and for the sector Consequences of the aid on social relationships Consequences of the aid on the career path Consequences of the aid on activities Needs of the caregiver Aid provided to other people with health problems or handicaps Estimation of the subjective and monetary value of the aid provided
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services Quality of life/health perception
Procedures	
Participant monitoring	No
Followed pathology	
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://www.drees.sante.gouv.fr/les-enquetes-handicap-sante,4267.html#sommaire_article
Access	
Terms of data access (charter for data provision, format of data, availability delay)	To be defined
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only