

# ICE : Informal Carers of the Elderly - Longitudinal Study on Chronic Disease Caregivers: New Forms of Optimised Support for Quality of Life, Cost and Wellness

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## General

### Identification

Detailed name	Longitudinal Study on Chronic Disease Caregivers: New Forms of Optimised Support for Quality of Life, Cost and Wellness
Sign or acronym	ICE : Informal Carers of the Elderly
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CCTIRS (11/05/2015) ; CNIL (23/06/2015) : N°914646) ; CPP Est II (4/11/2016) ; amendement n°1 (18/09/2017), amendement n°2 (23/10/2017) amendement n°3 (19/03/2018), amendement n°4 (24/09/2018)

### General Aspects

Medical area	Cancer research Cardiology Geriatrics Neurology Ophthalmology Urology, andrology and nephrology
Health determinants	Healthcare system and access to health care services Lifestyle and behavior Others (specify)
Keywords	caregivers, life trajectory, Health Quality of life, elders, chronic diseases, social support

### Scientific investigator(s) (Contact)

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Unit	INSERM UMR 1098
Organization	CHU

## Collaborations

Participation in projects, networks and consortia	Yes
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Details	Besançon hospital - Dijon hospital-Centre Georges François Leclerc-Pôle de Gériatrie et d'innovation-University of Burgundy-Franche-Comté
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## Funding

Funding status	Mixed
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Details	- Novartis Pharma Laboratory - CNSA (National Solidarity Fund for Autonomy) - Roche Foundation - INCa (French National Cancer Institute) - CARSAT Burgundy Franche-Comté (Pension Insurance and Occupational Health Fund)
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## Governance of the database

Sponsor(s) or organisation(s) responsible	Besançon Hospital
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Organisation status	Public
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Presence of scientific or steering committees	Yes
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## Additional contact

Name of the contact	Pozet
Surname	Astrid
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Unit	UMQVC (INSERM 1098)

Organization	CHU de Besançon
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 care professionals A selection of health institutions and services
Database recruitment is made on the basis of:	Another treatment or procedure
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Caregiver is identified during clinical consultation for recent chronic disease diagnosis using an identification questionnaire.
Database objective	
Main objective	To identify caregiver needs and expectations in order to consider the establishment of new forms of optimised support for quality of life, cost and wellness.
Inclusion criteria	<ul style="list-style-type: none"> <li>- male and female</li> <li>- adult</li> <li>- informal caregivers assisting a relative that is at least 60 years old with a recently diagnosed chronic condition</li> <li>- residing in Burgundy or Franche-Comté</li> </ul>
Population type	
Age	<ul style="list-style-type: none"> <li>Adulthood (19 to 24 years)</li> <li>Adulthood (25 to 44 years)</li> <li>Adulthood (45 to 64 years)</li> <li>Elderly (65 to 79 years)</li> <li>Great age (80 years and more)</li> </ul>
Population covered	General population
Pathology	
Gender	<ul style="list-style-type: none"> <li>Male</li> <li>Woman</li> </ul>

Geography area	Regional
French regions covered by the database	Bourgogne Franche-Comté
Detail of the geography area	Burgundy and Franche-Comté
<b>Data collection</b>	
<b>Dates</b>	
Date of first collection (YYYY or MM/YYYY)	2013
<b>Size of the database</b>	
Size of the database (number of individuals)	[1000-10 000[ individuals
Details of the number of individuals	8,604
<b>Data</b>	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Cost data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Internet self-questionnaire Face to face interview Phone interview
Details of collected declarative data	Quarterly interviews conducted by a social worker.
Presence of a biobank	No
Health parameters studied	Health care consumption and services Quality of life/health perception Others
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
<b>Procedures</b>	

Data collection method	Data collected by a social worker.
Participant monitoring	Yes
Monitoring procedures	Monitoring by contact with the participant (mail, e-mail, telephone etc.)
Details on monitoring of participants	Monitoring the life trajectory of caregivers during caregiving support relationship over 5 years.
Links to administrative sources	No

## Promotion and access

### Promotion

Link to the document [Pozet\\_Trials\\_16.pdf](#)

### Access

Dedicated website <https://www.etude-ice.org/accueil>

Terms of data access (charter for data provision, format of data, availability delay) Contact the person in charge.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only