

# - Longitudinal study on patients with locked-in syndrome: quality of life and evolution over a 6-year period

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Last update : 07/24/2015 | Version : 1 | ID : 73183

## General

### Identification

Detailed name	Longitudinal study on patients with locked-in syndrome: quality of life and evolution over a 6-year period
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

### General Aspects

Medical area	Disability/handicap Neurology Rare diseases
Pathology (details)	locked-in syndrome
Health determinants	Social and psychosocial factors Others (specify)
Others (details)	Quality of life
Keywords	Locked-in-syndrome; quality of life; Anamnestic Comparative Self-Assessment; determinants

### Scientific investigator(s) (Contact)

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Unit	Médecine Physique et Réadaptation
Organization	AP-HP

## Collaborations

Participation in projects, networks and consortia No

## Funding

Funding status Public

Details APHP

## Governance of the database

Sponsor(s) or organisation(s) responsible AP-HP

Organisation status Public

Presence of scientific or steering committees No

## 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 population file

Database recruitment is carried out as part of an interventional study No

Additional information regarding sample selection. This study was performed with the active collaboration of the French Association of Locked-in syndrome (ALIS)

### Database objective

Main objective We performed a survey of a population of LIS patients to describe the course of the QoL of LIS patients over a 6-year period and to determine the potential predictive factors of QoL changes over time.

Inclusion criteria The inclusion criteria were the following: adult patients, patients with LIS diagnoses according to

the description of Plum and Posner [17] (i.e., complete or near-total loss of motor function, preservation of eye movements, anarthria, and preserved consciousness and intellectual function), and patients who agreed to participate. The exclusion criteria were the following: minors, and patients with major motor recuperation.

## Population type

Age  
 Adulthood (25 to 44 years)  
 Adulthood (45 to 64 years)  
 Elderly (65 to 79 years)

Population covered  
 Sick population

Gender  
 Male  
 Woman

Geography area  
 National

Detail of the geography area  
 France

## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY)  
 2007

Date of last collection (YYYY or MM/YYYY)  
 2013

### Size of the database

Size of the database (number of individuals)  
 < 500 individuals

Details of the number of individuals  
 Questionnaires were sent to 197 patients in 2007, the same questionnaire was sent again in 2013 to the 67 patients who responded in 2007.

## Data

Database activity  
 Current data collection

Type of data collected  
 Declarative data

Declarative data (detail)  
 Paper self-questionnaire

Details of collected declarative data  
 sociodemographic data, including gender, age, living status, marital status, children, educational level,

income, and religious status; type of LIS (total, classical, or partial), disease duration, etiology, physical/handicap status (gastrostomy, tracheotomy, urinary probe, pain, wheelchair use), communication ability, psychological status (presence of anxiety/depression and suicidal thoughts), self-reported QoL as assessed with the Anamnestic Comparative Self-Assessment (ACSA), French Reintegration to Normal Living Index (RNLI) (participation in recreational and social activities and movement in the community), end-of-life issues, i.e., the wish to be reanimated and willing for euthanasia.

Presence of a biobank

No

Health parameters studied

Quality of life/health perception

Quality of life/perceived health (detail)

Self-reported QoL as assessed with the Anamnestic Comparative Self-Assessment (ACSA), which provides an overall global assessment of the quality of life.

## Procedures

Participant monitoring

Yes

Links to administrative sources

No

## Promotion and access

### Promotion

Other information

Rousseau MC., Baumstarck K., Alessandrini M., Blandin V., Billette de Villemeur T., Auquier P. Quality of life in patients with locked-in syndrome: evolution over a 6-year period. *Orphanet Journal of rare Diseases* ; 2015 : 10(1):88.

### Access

Presence of document that lists variables and coding procedures

No

Terms of data access (charter for data provision, format of data, availability delay)

This study was performed with the active collaboration of the French Association of Locked-in syndrome (ALIS), a non-profit association that was created in 1997 to help and support LIS patients and their families. The contact information of the LIS patients was provided by the ALIS, questionnaires were sent by ALIS to LIS patients in 2007 and in 2013, then the patients completed the self-report questionnaires.

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only