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

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General

Identification

Detailed name	Longitunal 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