

ORALIA - Monitoring a cohort with anal incontinence in the Rhône-Alpes area

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General

Identification

Detailed name Monitoring a cohort with anal incontinence in the Rhône-Alpes area

Sign or acronym ORALIA

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

General Aspects

Medical area Urology, andrology and nephrology

Health determinants Iatrogenic

Keywords Medical treatment, surgical treatment, perineal re-education, additional diagnostic examinations, absence from work

Scientific investigator(s) (Contact)

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Collaborations

Funding

Funding status	Public
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Details PHRC 2007

Governance of the database

Sponsor(s) or organisation(s) responsible Hospices civils de Lyon

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 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. Prospective Closing date for inclusion not determined:

Database objective

Main objective To assess treatment outcome (by medical, surgical

and physiotherapy treatment) for patients with anal incontinence included in the ORALIA cohort and to measure any observed improvement to symptoms and quality of life. Secondary objectives: - to study the development of associated perineal disorders: constipation, urinary incontinence, sexual issues, - to estimate treatment costs proposed to patients based on their measured impact.

Inclusion criteria	Anal incontinence: Wexner score greater than 5/20
Population type	
Age	Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Auvergne Rhône-Alpes
Detail of the geography area	Rhône Alpes
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	10/2002
Size of the database	
Size of the database (number of individuals)	[500-1000[individuals
Details of the number of individuals	621
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data Paraclinical data

Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Face to face interview Phone interview
Paraclinical data (detail)	Anorectal manometry, anal endosonography, defecography, electrophysiological exploration, pelvic MRI.

Presence of a biobank	No
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Health parameters studied	Quality of life/health perception
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Procedures

Data collection method	Self-administered questionnaire: entry from a paper questionnaire; Interviews: entry from a paper questionnaire; Clinical examinations: handwritten.
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Participant monitoring	Yes
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Details on monitoring of participants	3 years
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Links to administrative sources	Yes
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Linked administrative sources (detail)	PMSI
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Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=%28Damon+H[author]+OR+Mion+F[author]%29+AND+ORALIA
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Description	List of publications in Pubmed
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Access

Terms of data access (charter for data provision, format of data, availability delay)	Data may not be used by academic or industrial teams
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Access to aggregated data	Access on specific project only
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Access to individual data	No access
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