

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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Name of the director	Mion

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Unit	SERVICE EXPLORATIONS FONCTIONNELLES DIGESTIVES ? HOPITAL EDOUARD HERRIOT
Collaborations	
Funding	
Funding status	Public
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 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
Health parameters studied	Quality of life/health perception
Procedures	
Data collection method	Self-administered questionnaire: entry from a paper questionnaire; Interviews: entry from a paper questionnaire; Clinical examinations: handwritten.
Participant monitoring	Yes
Details on monitoring of participants	3 years
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI
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
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may not be used by academic or industrial teams
Access to aggregated data	Access on specific project only
Access to individual data	No access