

TRIAL-OH - Cohort of Haematological Patients Admitted to Intensive Care: Long-Term Quality of Life

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General	
Identification	
Detailed name	Cohort of Haematological Patients Admitted to Intensive Care: Long-Term Quality of Life
Sign or acronym	TRIAL-OH
General Aspects	
Medical area	Hematology
Health determinants	Healthcare system and access to health care services Lifestyle and behavior Social and psychosocial factors
Keywords	long term, haematology, intensive care, assessment, quality of life
Scientific investigator(s) (Contact)	
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Unit	UMR S-717, Prof. Sylvie Chevret
Organization	Intensive care department, Saint-Louis Hospital
Collaborations	
Funding	
Funding status	Mixed
Details	Hospital Clinical Research Programme (PHRC);

French Society of Intensive Care Nurses; Ministry of Health

Governance of the database

Sponsor(s) or organisation(s) responsible Saint-Louis Hospital

Organisation status Public

Additional contact

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 carried out as part of an interventional study No

Database objective

Main objective To assess long-term quality of life (at 1 and 2 years) for haematology patients that survived ICU admission and to model the outcome of this following discharge from ICU.

Inclusion criteria Patients with leukaemia, lymphoma and multiple myeloma in 17 departments throughout France and Belgium.

Population type

Age Adulthood (19 to 24 years)
Adulthood (25 to 44 years)
Adulthood (45 to 64 years)

Population covered Sick population

Gender Male
Woman

Geography area International

Detail of the geography area France and Belgium

Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2010
Date of last collection (YYYY or MM/YYYY)	2013
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1,376
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data
Details of collected clinical data	Disease status and treatment, Sepsis-Related Organ Failure Assessment (SOFA) score, performance index, comorbidity, etiological diagnoses.
Declarative data (detail)	Phone interview
Details of collected declarative data	Quality of life (SF-36)
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization
Procedures	
Data collection method	500 surviving patients at day 90 and their friends or relatives (one person per patient, most often the spouse) will be contacted 12 to 15 months following discharge from ICU to complete the following questionnaires: SF-36 (36 questions on quality of life), Hospital Anxiety and Depression Scale (14 questions on depressive and anxiety symptoms)

and Impact of Event Scale (22 questions on post-traumatic stress). Patients admitted to hospital at time of contact will be contacted again 15 days following discharge from hospital.

Participant monitoring Yes

Details on monitoring of participants At 1 and 2 years

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://jco.ascopubs.org/content/31/22/2810.long>

Access

Terms of data access (charter for data provision, format of data, availability delay) To be decided.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only