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