SANOIA - SANOIA : An online Patient Personal Health Record

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Last update : 07/08/2025 | Version : 3 | ID : 5201

General

Identification

Detailed name	SANOIA : An online Patient Personal Health Record
Sign or acronym	SANOIA

General Aspects

Medical area	Hematology Rheumatology
Health determinants	Lifestyle and behavior Medicine
Keywords	Rheumatology ; Patient reported Outcomes (PRO) ; treatment; RAID score, RAPID-3 score ; quality of life, Electronic Health Data

Scientific investigator(s) (Contact)

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Organization	AIMSU - Association pour l'Information Médicale en Situations d'Urgences -

Collaborations

Funding

Funding status	Mixed
Details	Fonds européens et de valorisation de la Recherche CNRS (incubateur)Bourse UCB France ; Nordic AMGEN - Recherche et développement de médicaments issus de la biotechnologie

Governance of the database

Sponsor(s) or organisation(s) responsible	AIMSU - Association pour l'Information Médicale en Situations d'Urgences - SANOIA
Organisation status	Private

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 carried out as part of an interventional study	No
Additional information regarding sample selection.	Survey 1: Sample of patients fulfilling the criteria (Rheumatoid Arthritis) among patients in the rheumatology department of Hôpital Sainte Marguerite, University Hospital of Marseille and private rheumatologists in the PACA region. Survey 2: Sample of patients hospitalized Idiopathic Thrombocytopenic Purpura (ITP) between 2000 and 2010 in Hôpital de la Conception, University Hospital of Marseille.

Database objective

Main objective	The French Society of Rheumatology (SFR) and the Patient Association ANDAR have partnered since

	early 2012 to disseminate a new tool (SANOIA) allowing patients to record and track their personal health data and contribute to their monitoring. This tool drives major expectations in terms of epidemiology. In fact, the information anonymously entered by the patient, about his medical condition and coping of the disease are aggregatable for research. After a phase of evaluation, SANOIA is currently deployed on two medical conditions: Survey 1: Assess the feasibility and the adoption of SANOIA a personal health record freely available for patients with rheumatoid arthritis. In December 2012, 2,902 RA patients were registered. Survey 2: Assess the feasibility and the adoption of SANOIA, a personal health diary freely accessible, which has been adapted for patients with a rare disease thrombocytopenic purpura. ". We look out to extend the tool to other medical conditions.
Inclusion criteria	Patients with rheumatoid arthritis, adult fulfilling the ACR criteria for classification (1987, American College of Rheumatology) with Internet access (Survey 1) Patients aged between 18 and 75 years diagnosed with chronic thrombocytopenic purpura according to international guidelines, with permanent access to the Web, and without psychiatric disorder (Survey 2).

Population type

Age	Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) 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	National
Detail of the geography area	France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2010

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	n = 56 for RA Patients. Extended to 2,902 patients in December 2012n = 72 for ITP Patients

Data

Database activity	Current data collection
Type of data collected	Declarative data
Declarative data (detail)	Paper self-questionnaire
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption

Procedures

Data collection method	Survey 1: The contents of the SANOIA patient Health Datasheet in the study, completed alone or with assistance according to the group assignment, was compared for three months to the contents of their medical records, held by their rheumatologist- according to the completeness of information on treatment, comorbidities and history. Survey 2: demographic and medical data, as well as the evaluation of the quality of life related to health using the electronic Health Datasheet SANOIA were assessed at baseline and at 1, 3 and 6 months via questionnaire sent by postmail. The use of SANOIA Health Datasheet was evaluated by a specific questionnaire and by measuring the frequency of weblogs of each patient.
Participant monitoring	Yes
Details on monitoring of participants	Voice call
Links to administrative sources	No

Promotion and access

Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=%28Servy+H[author]+OR+Selamnia+A[author]%29+AND+SANOIA
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Open to any organization Research, private or public, but subject to instruction for an ethical notice issued by the French Society of Rheumatology.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only