

# SANOIA - SANOIA : An online Patient Personal Health Record

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## 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

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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)<br>Adulthood (19 to 24 years)<br>Adulthood (25 to 44 years)<br>Adulthood (45 to 64 years)<br>Elderly (65 to 79 years)<br>Great age (80 years and more)                                                                                                                                                                                           |
| Population covered                         | Sick population                                                                                                                                                                                                                                                                                                                                                               |
| Gender                                     | Male<br>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 2012  
n = 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+Salamnia+A\[author\]%29+AND+SANOIA](http://www.ncbi.nlm.nih.gov/pubmed/?term=%28Servy+H[author]+OR+Salamnia+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