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## **Patient e-health platform for Rheumatoid Arthritis: accuracy and adherence factors**

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### **Key words**

personal health records, rheumatoid arthritis, accuracy factors, adherence

### **Running head**

PHRs for RA: accuracy and adherence factors

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**Author contributions**

TP, ST, PL designed the study and wrote the protocol. ST, TP enrolled patients. HS was responsible for data management. ST was responsible for the records analysis. VP was responsible for statistical analysis. TP, VP, ST, PL were responsible for data interpretation. TP drafted the manuscript. All authors were involved in writing the manuscript and approved the final version.

## **Abstract**

**Background:** Personal health records (PHRs) are patient-controlled repositories, capturing health data entered by individuals and providing information related their care. These tools improve treatment adherence but data are scarce concerning tool adherence. The accuracy of the self-recorded data remains controversial. We assessed how support measures improve PHR adoption determined the factors that influence the accuracy of self-recorded data and tool adherence of RA patients.

**Methods:** A controlled randomized study with a PHR tool with integrated electronic health records developed by SANOIA. RA patients with ACR/EULAR 2010 criteria with web access randomized into 3 groups: Group 1 patients were given written information to create and manage a PHR; Group 2 patients received written information and a web technician hotline 48 hours after inclusion; Group 3 patients began their PHR with their rheumatologist during the consultation.

**Results:** 56 RA patients were included (female: 73%, mean age: 57.1, mean DAS28: 3.04, mean RAPID-3: 2.93). Self-reported data accuracy was significantly higher in Groups 2 (73.7%) and 3 (82.4%) than in Group 1 (45.0%), ( $P = 0.04$ ). Patient adherence was higher in Group 2 (78.9%) compared with Groups 1 (55.0%) and 3 (58.8%) ( $P = 0.45$ ). Accuracy was correlated to adhesion ( $P < 0.0001$ ). Gender, age, disease duration and activity, treatments, and patient level of interest were not correlated to data accuracy or patient adherence.

**Conclusion:** Information accuracy collected with PHR was relevant and better when patients were initially assisted either by their physician or by non-medical phone support. We also observed better adherence when patients were initially assisted.

## **Background**

Personal health records (PHRs) are tools enabling patients to collect patient-reported outcomes (PROs) and to report their medical conditions. The aim of such patient-controlled services is to help individuals play a more active role and to contribute to shared decisions in chronic diseases such as rheumatoid arthritis (RA). These tools have shown their ability to improve treatment adherence [1–3] but data are scarce concerning adherence to the tool itself. For instance, 153 patients with rheumatic disease consecutively interviewed reported that although they appreciated having access to their online electronic health records, they expressed low confidence rates in the Internet [4]. This lack of confidence may impact patient adherence. The accuracy of self-recorded data related to medical condition in e-health platforms also remains controversial.

Our goal was to assess how support measures, technical or medical, could improve electronic personal health record system (PHR) adoption and to determine the accuracy of self-recorded data and RA patient tool adherence modifying factors.

## **Materials and methods**

### ***Electronic personal health records tool***

Sanoia has developed a web tool integrated with electronic personal health records which offers full privacy protection using an innovative anonymity technique [5]. The tool already included numerous factors related to chronic disease such as vaccination records and history. It can also be designed for a specific disease, in our case RA, and

proposes an adapted PROs evaluation, such as the Routine Assessment of Patient Index Data (RAPID-3) [6].

### ***Patients***

Inclusion criteria : outpatients fulfilling the ACR/EULAR 2010 criteria for rheumatoid arthritis [7]. As our aim was to assess factors associated with PHR adhesion and data accuracy, we focused only on patients able to use the e-PHR, so patients without web access were not invited to participate in the study.

### ***Study Design***

We conducted a prospective controlled randomized study. From February to March 2011, the five participating rheumatologists proposed to their consecutive RA patients to use an e-health platform and aimed at collecting patient-related outcomes (PROs) and medical conditions. Each rheumatologist had a randomization list

Patients were randomized into 3 groups: Group 1 patients were given simple written information about how to create and manage their file on the Sanoia platform; Group 2 patients received written information and support to manage their files on the platform via a web-technician hotline 48 hours after inclusion; and Group 3 patients started their Sanoia platform files with their rheumatologist during the consultation.

Patients were randomized individually by each rheumatologist. Each patient fulfilling inclusion criteria and accepting to participate in the study was assigned sequentially to a group according to his order of inclusion by his/her rheumatologist. This method was preferred to bloc randomization in order to maximize the balance of group effectiveness

even if some rheumatologists include few patients in a context of competitive recruitment.

### ***Collected data***

#### *Adherence Assessments*

Patients were considered as tool adherent if they connected at least twice and as non-adherent if they connected once or never between baseline (M0) and the 3-month evaluation (M3). Adherence was also assessed at 6 months (M6).

#### *Accuracy Assessment*

We collected the following data: demographics, disease activity data including the disease activity score (DAS-28) and the RAPID-3 [6,8], the amount and accuracy of self-recorded data, ongoing treatment at baseline and 3 months after. For the latter, we focused on medical history, current treatment, consultations, underlying events reporting and other points of interest such as the vaccine situation, smoking status, contraception, imaging. Information accuracy was compared with rheumatologist medical records considered as the gold standard. All the records were assessed by the same reviewer (ST) and scored as following: medical history (0–4 points), current treatment (0–4 points), vaccine status (0–1 point) and known allergies (0–1 point), for a maximum score of 10. A good accuracy score was defined as  $>9/10$ .

#### *Main outcomes*

The 2 primary outcomes were the adherence at M3, defined as the proportion of patients who connected at least 2 times between baseline and 3 months, and the accuracy of the patient self-declared data, defined as the proportion of patients with a good accuracy score.

### *Statistical Analysis*

We compared reporting accuracy and adherence among the groups. Accuracy was assessed as a dichotomous variable. Patients with a good accuracy score, i.e. >9/10, were scored 1. Patients with an accuracy score  $\leq 9/10$  or with missing data were scored 0.

We also assessed the impact of the following variables on accuracy and adherence: age (age as a continuous variable and age > 60 years yes/no), gender, disease duration, co-morbidities, baseline disease activity (DAS28, RAPID-3), treatments including biologics and corticosteroids and the patient's level of interest in the e-PHR tool. The patient's interest was assessed on a 0–10 numerical scale.

Continuous data were described by means (SD) and categorical variables were expressed as frequencies and percentages. To compare groups, we used Chi-square (Fisher when Chi-square application conditions were not met), Mann-Whitney and Kruskal-Wallis tests (depending on categorical/continuous variables and the number of modalities of the categorical variables). SPSS 17.0 version was used for management and statistical analysis.

### **Results**

We included 56 RA patients, with 20, 19 and 17 patients in Groups 1, 2 and 3 respectively. Their main baseline characteristics were the following: female: 73%, mean age: 57.1 years, mean DAS28: 3.04 and mean RAPID-3: 2.93. Detailed characteristics are reported in Table 1.



The proportion of patients who did not use the PHR tool was 35.0%, 21.1% and 19.6% in Groups 1, 2 and 3 respectively. Self-reported data accuracy was significantly higher in Groups 2 (73.7%) and 3 (82.4%) than in Group 1 (45.0%), ( $p < 0.04$ ) (Figure 1). Moreover, two patients reported medical events that were not in their physician medical records: a history of tuberculosis in a Group 3 patient and a costal chondroma in a Group 2 patient.

Patient adherence was higher in Group 2 (78.95%) compared with those of Groups 1 (55.0%) and 3 (58.8%) ( $P = 0.45$ ) at 3 months. Mean ITT frequency connections are presented in Table 2. Among the patients who connected at least once ( $N = 13$  for Group 1, 16 for Group 2 and 17 for Group 3), the mean number of connections between baseline and M3 was 10.3, 19.3 and 12.2 in Groups 1, 2 and 3 respectively. Adherence remained stable in Group 2 at 6 months (78.9%), whereas it decreased in Groups 1 and 3 (respectively 15.0% and 47.1%). Connection frequencies are presented in Table 2.

Accuracy was correlated to adherence ( $P < 0.0001$ ). Gender, age, disease duration, activity of disease (DAS28, RAPID-3), treatments including biologics and corticosteroids, and patient level of interest were not correlated to data accuracy (Table 3). These variables were also not correlated to patient adherence.

## **Discussion**

This is the first study showing how support measures can influence adoption, adherence to PHR and the accuracy of recorded information. The quality of the information collected with PHR was meaningful and better when patients were initially

assisted either by their physician or by non-medical phone support. Agreement between self-report information on PHR and medical records have been assessed with various results with regards to the disease [9–14]. Comparisons have shown good agreement for diabetes, hypertension, pulmonary disease, cerebrovascular disease and myocardial infarction while other comparisons found low agreement for heart failure, chronic bronchitis, chronic obstructive pulmonary disease, hypertension, osteoporosis, osteoarthritis and RA [9,14–22]. In a large community-based cohort, low agreement was found between the 2,893 participating patients and their GP, especially for RA (kappa: 0.17 [0.23-0.11] [14]. In RA patients, over-reporting was associated with the male gender, a higher number of diseases and a lower physical and mental quality of life. A higher number of diseases was also associated with underreporting. We did not collect a quality of life variable, but in our RA sample, gender and comorbidities were not correlated with record accuracy. The study sample size was small and possibly not powerful enough to demonstrate a correlation with the potential factors, such as biologic and corticosteroid treatment.

The mode of questionnaire administration can affect data quality. Survey responses are different with regards to the type of mode (e.g. self-administered versus interview modes, mail versus telephone interviews, telephone versus face-to-face interviews) [23–25]. As expected, our results confirm that patients that have been supported in the process, either with a technician without medical knowledge or with an MD, have better data collection accuracy. It may appear to be the support itself and not its quality because we found no difference between the methods of support, but the sample size of our study was insufficient to determine differences between the 2

support groups. Technical or medical support also improved adoption of and adherence to the PHR tool.

In conclusion, our results suggest good or very good agreement between self-reported data with a PHR tool and medical records for RA patients. This agreement is improved with a technical or medical process support that also improves adoption and adherence to the tool. Our results confirm that a patient with the right level of support could be a source of reliable data collection, opening new paths that should be confirmed over a longer time period and from an economic point of view.

## Table and Figure Legends

Table 1: Baseline characteristics

Table 2: PHR tool adherence in the 3 groups at M3 and M6 (ITT)

Table 3: Accuracy factors

Figure 1: Proportion of patients with reported data of good accuracy on the e-PHR tool

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