

# Changing attitudes towards online electronic health records and online patient documentation in rheumatology outpatients

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## Abbreviations:

|      |                                   |
|------|-----------------------------------|
| EHR  | electronic health record          |
| RA   | rheumatoid arthritis              |
| SLE  | systemic lupus erythematosus      |
| SpA  | spondyloarthritis                 |
| FFbH | Hannover Functional Questionnaire |
| n.a. | Not available                     |
| n.s. | Not significant                   |

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## ABSTRACT

**Objective.** *The Internet supports interactive patient assessments, online documentation and access to online electronic health records (EHRs), but little is known about the acceptance of these features and trends in rheumatology patients. Therefore, we studied patients' attitudes and willingness to participate in online patient (self-)documentation.*

**Methods.** *We interviewed 153 consecutive outpatients with rheumatoid arthritis, systemic lupus erythematosus or spondyloarthritis using a paper-based self-administered questionnaire. To detect recent trends in patients' perception we compared our 2006 data to the results of our survey conducted in 2001. P-values provided in the abstract reflect the comparisons from 2001 and 2006.*

**Results.** *Patients were predominantly female (69.3%; n.s.), mean age was 45.7±14.4 years (n.s.), and 68.6% (+18.6% compared to 2001; p<0.001) reported regular Internet use. Confidence in the Internet and reliability of online information were rated unchanged to 2001. Internet users appreciated to access their EHR online in 68.6% (+13.8% compared to 2001; p<0.01), (self-)monitor the course of their disease online in 80.0%, and answer outcome questionnaires online in 67.6%. Internet users considered computers as valuable instruments in the patient-doctor relationship (88.4%), 58.8% were not convinced that computer use influences the relationship positively.*

**Conclusion.** *Attitudes of patients with rheumatic disorders (Internet users and non-users) towards online EHRs have improved since 2001, online applications for patient assessments and disease (self-)management in rheumatology seem feasible now. Nevertheless, unchanged low confidence rates in the Internet and in the reliability of medical information derived from the Internet should sound a note of caution regarding the implementation of such services.*

## Introduction

Medical data derived by electronic (self-)tracking can deliver information that might improve patient management

especially in chronic diseases (1). A number of reports show that the Internet is a feasible medium for health related communication and for the conduction of epidemiology studies, clinical trials, patient assessments, and patient interventions even in routine care (2-6). Little is known about patients' attitudes towards online electronic health records (EHRs), online patient (self-)documentation and outcome assessments, as well as their willingness to participate in these services in rheumatology (7). As attitudes may change over time we evaluated patients' interest in online EHRs in comparison to a cohort we studied five years earlier and their willingness to participate in self-reported online documentation and assessments (7). Due to the sensitive nature of medical data and security concerns a careful evaluation of these issues is mandatory before integrating Internet based interactive services in routine care.

## Patients and methods

In 2006, 172 consecutive patients with rheumatoid arthritis (RA), systemic lupus erythematosus (SLE) or spondyloarthritis (SpA) regularly scheduled in our university Rheumatology outpatient clinic were invited to participate in a cross-sectional study. Nineteen patients refused participation due to various Internet unrelated reasons (no interest, missing time, accompanying child). 153 outpatients (61 RA, 60 SLE, 32 SpA) consented to complete a paper-based self-administered questionnaire based on the questionnaire successfully applied in our evaluation in 2001 including identical questions (6, 7). Patients' sociodemographic characteristics were collected on the basis of the data set used by the German collaborative arthritis centres, and self-reported functional disability was measured applying the Hannover Functional Questionnaire (FFbH) (6). We compared our current data with those reported by our group in 2001 covering 326 patients with inflammatory rheumatic diseases (7). Detailed information on patients' Internet use, their online needs and requirements have been published in this journal (6). Signed patients' informed consents were obtained. Approval had been re-

ceived from the local ethic committee. Statistical computations used Statview® 5.01, SAS Institute Inc., Cary NC, 1999. All parametric and non-parametric tests were performed two-tailed. *P*-values less than 0.05 were considered significant. According to a power analysis 80-150 persons had to be interviewed in the 2006 study to detect a deviation of 15% to 20% from the Internet use rate in the 2001 study and to reach a power of 90%.

## Results

Detailed sociodemographic data of our 2006 and 2001 cohorts are provided in Table I.

### Internet use and time spent online

Regular Internet use was reported by 68.6% of our patients for a mean period of  $5.0 \pm 2.6$  years (median 5.0 years) with no significant differences between the disease groups. Internet use was independent of gender (n.s.), but, significantly, age and profession/education dependent: more younger and more higher educated patients used the Internet ( $p < 0.001$ ;  $p < 0.01$ ). For details on patients' Internet use and time spent online see (6).

### Confidence in the Internet and reliability of information

Independently of gender, age, patients' profession/education, and the rheumatic disease, confidence in the Internet was rated as  $3.2 \pm 1.3$  and reliability of (medical) information that can be retrieved from the Internet as  $2.8 \pm 1.2$  (mean  $\pm$  standard deviation (SD)) on 6-step Likert scales. Internet non-users rated confidence in the Internet and the reliability of online information significantly worse than Internet users ( $p < 0.001$ ;  $p < 0.001$ ).

### Online (self-) documentation and self-monitoring of medical data

Among regular Internet users, 68.6% said they would appreciate the opportunity to access their medical data through EHRs maintained on the Internet (see Fig. 1). This interest to use online EHRs was statistically independent of gender, age, the rheumatic disease, and patients' functional disability. In addition, 35.4% of the Internet non-users were interested in accessing their

**Table I.** Patients sociodemographic data comparison 2001–2006 (percentages are given as valid percent, denominators may vary from question to question; n.a. not available; n.s. not significant, *p*-values refer to the comparison 2001–2006) .

| Patients characteristics                                   | 2001<br>(n=326) | 2006<br>(n=153) | <i>p</i> -value<br>$\chi^2$ -test |
|------------------------------------------------------------|-----------------|-----------------|-----------------------------------|
| Response rate                                              | 81.5%           | 88.9%           |                                   |
| Female                                                     | 230 (71.2%)     | 106 (69.3%)     | n.s.                              |
| Age years                                                  |                 |                 | n.s.                              |
| <30 years                                                  | 35 (10.8%)      | 24 (15.7%)      |                                   |
| 30-39 years                                                | 76 (23.4%)      | 35 (22.9%)      |                                   |
| 40-49 years                                                | 69 (21.2%)      | 34 (22.2%)      |                                   |
| 50-59 years                                                | 65 (20.0%)      | 27 (17.6%)      |                                   |
| $\geq 60$ years                                            | 80 (24.6%)      | 33 (21.6%)      |                                   |
| Mean disease duration in years                             | n.a.            | $9.2 \pm 7.7$   | n.a.                              |
| Functional disability measured by FFbH                     |                 |                 | n.a.                              |
| Normal functioning (FFbH score >70)                        | n.a.            | 112 (73.2%)     |                                   |
| some deterioration in functioning<br>(FFbH score 70–50)    | n.a.            | 23 (15.0%)      |                                   |
| extremely severe functional disability<br>(FFbH score <50) | n.a.            | 18 (11.8%)      |                                   |
| Vocational education                                       |                 |                 | n.s.                              |
| None                                                       | 27 (10.9%)      | 24 (16.1%)      |                                   |
| Vocational training                                        | 116 (46.9%)     | 80 (53.7%)      |                                   |
| Technical college                                          | 35 (14.2%)      | 16 (10.7%)      |                                   |
| University of applied sciences                             | 30 (12.2%)      | 11 (7.4%)       |                                   |
| University                                                 | 39 (15.8%)      | 18 (12.1%)      |                                   |
| Employment situation                                       |                 |                 | n.s.                              |
| Employed                                                   | 131 (52.4%)     | 79 (52.7%)      |                                   |
| Unemployed                                                 | 9 (3.6%)        | 13 (8.7%)       |                                   |
| Housewife/-men                                             | 50 (20.0%)      | 19 (12.6%)      |                                   |
| Retired                                                    | 60 (24.0%)      | 39 (26.0%)      |                                   |

medical data online. No significant association of this issue with patients' profession/education or confidence in the Internet was found.

Furthermore, 80.0% of the Internet users and 33.3% of the Internet non-users were interested in self-monitoring the course of their disease online (see Table II). Willingness to answer outcome questionnaires online was reported by 67.6% of the Internet users and 15.0% of the Internet non-users. SLE patients considered the prospect of completing online questionnaires more interesting than RA and SpA patients. Further data are provided in Table II.

### Role of computers in the patient-doctor relationship

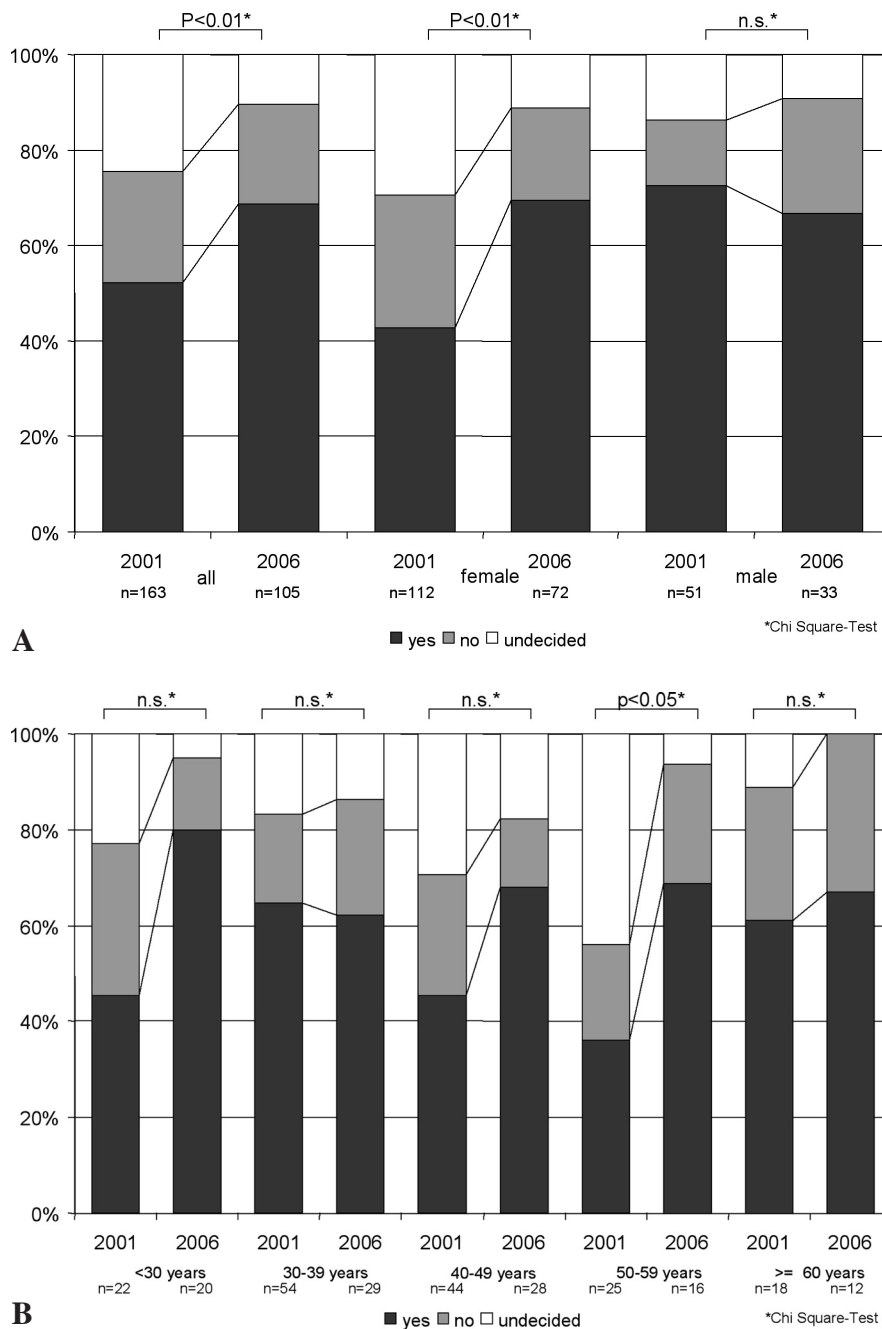
Without correlation to age, gender or underlying disease, computers were appreciated as beneficial instruments in the patient-doctor relationship by 88.4% of the Internet users and 61.9% of the non-users. Nevertheless, 58.8% of the Internet users and 65.9% of the non-users were not convinced that computer use improves patient-doctor interactions.

### Comparisons 2001–2006

Detailed comparisons of our data between 2001 and 2006 are depicted in Table I, Table II and Fig. 1. Internet use and the interest in accessing their own medical data in an EHR maintained on an Internet server significantly increased in patients with rheumatic diseases (+18.6% for Internet use ( $p < 0.001$ ), +13.8% for interest in online EHR ( $p < 0.01$ )). Nevertheless, Internet users in 2006 rated their confidence in the Internet and the reliability of information retrieved from the Internet unchanged to 2001.

## Discussion

Overall, our patients' Internet use and time spent online are comparable to general trends in Germany and match published results in various (non-)rheumatology diseases (6). Our patients demonstrate high interest in access of EHRs, participation in patient-derived assessments, and self-monitoring their disease over the Internet, irrespective of gender, age, underlying rheumatic disease, functional disability and pre-existing Internet use.



**Fig. 1A.** Interest in online EHR comparison 2001-2006 (Internet user: complete group and gender subgroups; *p*-values refer to the comparison 2001-2006). **B.** Age related interest in online EHR (Internet user; *p*-values refer to the comparison 2001-2006).

Compared with our results retrieved in 2001, patients' interest in online access to EHR has improved over time. Although acceptance was lower than recently reported on haematology patients, more than two thirds of our Internet users and even one third of our Internet non-users reported interest in accessing their EHR via Internet (8). Moreover, approximately 80% of our Internet-users and one third of our In-

ternet non-users were interested in self-monitoring the course of their disease online. Our results confirm previous findings that patients are interested in taking more responsibility for their personal health and anticipate the changing role from a passive to an active partner when appropriate online applications are provided (9, 10). Feasibility of patients' online access to their EHR has already been proven (11-13). As computerised

self-reported outcome questionnaires support disease activity reporting, efficacy, and safety assessments, patients' interests in online (self-)documentation and EHRs maintained on the Internet offer new challenging opportunities to physicians, providers of health care and web services (14).

In contrast to the increasing interest in online services confidence in the Internet and in reliability in Internet-derived information were rated unchanged compared to 2001, a central-tendency in scoring became evident. We interpret this as patients' inability to make clear estimates of online security. To increase confidence and reliability and to protect patients from unrecognised risks it will be necessary to provide only highly secured accesses to sensitive online medical data (e.g. EHRs) and to allocate high quality and trustworthy medical information (6, 11, 13). Physicians should therefore recommend websites to their patients that contain information that have been professionally reviewed and verified (10). Additionally, some organisations now certify health information on the Internet (e.g. <http://www.hon.ch/>) and offer seals of approval. Furthermore, important issues in the design of Internet-based systems for patient-reported outcomes have already been published and should be considered carefully before application of such tools (9, 15). Moreover, besides privacy, confidentiality and security issues patients' informed consent need to be obtained in advance to comply with legal regulations.

#### Limitations

Comparisons between 2001 and 2006 are generally hampered by the rapid development of the Internet and some data concerning patients' attitudes may have changed already since the collection of our data. As only 4 patients of our 2006 cohort participated in the 2001 survey, intra-individual follow-ups were impossible. The 2001 cohort consisted of patients with a broader spectrum of inflammatory rheumatic diseases than the participants investigated recently. We studied a limited group of rheumatic patients and therefore, generalisation of our data to other patient groups, e.g. pa-

tients with degenerative diseases, is not admissible. We exclusively focussed on patients from a university outpatient clinic; data from non-university centres would be interesting. Further studies are necessary.

## Conclusion

Attitudes of patients with rheumatic diseases (Internet users and non-users) towards online EHRs have improved over five years. Use of online applications - patient assessments and disease (self-)management - seems feasible in Rheumatology. However, careful implementation of these tools and follow-up studies are necessary to assure that patients become more active, integrated partners, thus contributing substantially to effective and improved disease (self-) management strategies and quality of life. Further studies should assess changes in patients' attitudes and should include patients with other rheumatic diseases.

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**Table II.** Internet users' positive interest in self-monitoring the disease online and answering outcome questionnaires online by subgroups in 2006 (percentages vary due to missing values and changing denominators; *p*-values refer to data from 2006, note: missing statistical differences between the subgroups are to be interpreted with caution as the absolute numbers of patients in the subgroups are low).

|                                                         | Positive interest in self-monitoring the disease online<br>n=72<br>(n=90 internet user answered the question) | <i>p</i> -value<br>$\chi^2$ -test | Positive interest in answering outcome questionnaires online<br>n=71<br>(n=105 internet user answered the question) | <i>p</i> -value<br>$\chi^2$ -test |
|---------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|-----------------------------------|---------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| Sex                                                     |                                                                                                               | n.s.                              |                                                                                                                     | n.s.                              |
| Female                                                  | 52 (81.3%)                                                                                                    |                                   | 50 (69.4%)                                                                                                          |                                   |
| Male                                                    | 20 (76.9%)                                                                                                    |                                   | 21 (63.6%)                                                                                                          |                                   |
| Age                                                     |                                                                                                               | n.s.                              |                                                                                                                     | n.s.                              |
| < 30 years                                              | 15 (75.0%)                                                                                                    |                                   | 15 (75.0%)                                                                                                          |                                   |
| 30-39 years                                             | 21 (80.8%)                                                                                                    |                                   | 20 (68.9%)                                                                                                          |                                   |
| 40-49 years                                             | 21 (87.5%)                                                                                                    |                                   | 19 (67.9%)                                                                                                          |                                   |
| 50-59 years                                             | 8 (72.7%)                                                                                                     |                                   | 11 (68.8%)                                                                                                          |                                   |
| ≥ 60 years                                              | 7 (77.8%)                                                                                                     |                                   | 6 (50.0%)                                                                                                           |                                   |
| Disease                                                 |                                                                                                               | n.s.                              |                                                                                                                     | n.s.                              |
| RA                                                      | 21 (72.4%)                                                                                                    |                                   | 22 (57.9%)                                                                                                          |                                   |
| SLE                                                     | 35 (83.3%)                                                                                                    |                                   | 36 (81.8%)                                                                                                          |                                   |
| SpA                                                     | 16 (84.2%)                                                                                                    |                                   | 13 (56.5%)                                                                                                          |                                   |
| Functional disability (FFbH)                            |                                                                                                               | n.s.                              |                                                                                                                     | n.s.                              |
| normal functioning (FFbH score >70)                     | 59 (78.7%)                                                                                                    |                                   | 58 (65.9%)                                                                                                          |                                   |
| some deterioration in functioning (FFbH score 70-50)    | 9 (90.0%)                                                                                                     |                                   | 8 (72.7%)                                                                                                           |                                   |
| extremely severe functional disability (FFbH score <50) | 4 (80.0%)                                                                                                     |                                   | 5 (83.3%)                                                                                                           |                                   |
| Vocational education                                    |                                                                                                               | n.s.                              |                                                                                                                     | n.s.                              |
| None                                                    | 10 (100.0%)                                                                                                   |                                   | 9 (90.0%)                                                                                                           |                                   |
| Vocational training                                     | 42 (84.0%)                                                                                                    |                                   | 40 (72.7%)                                                                                                          |                                   |
| Technical college                                       | 6 (85.7%)                                                                                                     |                                   | 5 (50.0%)                                                                                                           |                                   |
| University of applied sciences                          | 5 (62.5%)                                                                                                     |                                   | 5 (50.0%)                                                                                                           |                                   |
| University                                              | 7 (58.3%)                                                                                                     |                                   | 10 (58.8%)                                                                                                          |                                   |