# Electronic health records in rheumatology: emphasis on automated scoring and additional use

J.G. Richter, G. Chehab, M. Schneider

*Policlinic for Rheumatology and Hiller Research Centre for Rheumatology, Medical Faculty, Heinrich-Heine-University Düsseldorf, Germany.*

*Jutta G. Richter, PD, Dr*
*Gamal Chehab, Dr*
*Matthias Schneider, Prof. Dr.*

*Please address correspondence to:*
*Dr Jutta G. Richter,*
*Policlinic for Rheumatology and Hiller Research Centre for Rheumatology, Medical Faculty,*
*Heinrich-Heine-University Düsseldorf,*
*Moorenstr. 5,*
*40225 Düsseldorf, Germany.*
*E-mail: richter@rheumanet.org*

*Received and accepted on September 20, 2016.*

*Clin Exp Rheumatol 2016; 34 (Suppl. 101): S62-S68.*



**Key words:** electronic medical record, electronic health record, health services research, patient-reported outcome measures

*Competing interests: none declared.*

**ABSTRACT**

*Electronic health records are increasingly used and frequently required from various regulatory authorities. Apart from their day-to-day use by health care professionals for routine clinical practice and/or the improvement of quality of care processes, patients with chronic inflammatory disease may become increasingly involved in the data retrieval process by self-monitoring and providing patient-reported (outcome) data. Among key features of electronic health records are automated scoring, visualisation of validated measures, and long-term systematic patient-centered data collection in a structured and standardised manner. Data derived from electronic health records are increasingly incorporated into patient-centered research, registries, and other secondary uses. Thus, electronic health records offer opportunities to improve knowledge and to create new process flows in rheumatology health care. The article summarises some of these opportunities in patient care, as well as an overview of secondary use scenarios. In addition, the article focuses on patients' active involvement in the disease management process via health information applications, reports on patients' perspectives, as well as some legal and regulatory matters concerning electronic health records.*

## Introduction

In recent years, patient management processes in the health care system have increasingly used electronic information technology. Reports have documented that electronic health records and other applications provided by health information technology may be associated with better outcomes (*e.g.* reductions in mortality, complications) and may reduce costs (1). A major development involves electronic versions of paper-based charts ('electronic medical record' resp. 'electronic health record') offering advanced patient care and other relevant key features as they *e.g.* increase legibility and lessen loss of charts. Irrespective of the way patient records are conducted, if not kept in a stringent way they might include redundant information requiring more time for reading when consulting and treating a patient.

However, a continuous trend towards an increased use of these electronic health record (EHRs) in routine care is recognised (2). The EHR facilitates patient centered research and other secondary usage options. Health care stakeholders and regulatory authorities demand electronic data capturing of patient-reported outcome measures (PROMs) to assess and assure quality of care. An electronic health record and other software applications with automated scoring can offer such standardised assessments (3). As introduction of EHR and other electronic patient data capturing systems as well as maintaining sustained uses are very complex issues that warrant integration of many different stakeholders of the health care system, the article summarises some of the opportunities that are provided by the use of electronic health records in routine patient care. An overview of secondary use scenarios is presented. In addition, it focuses on active involvement of patients in disease management via health information applications and patients' perspectives towards electronic data collection systems and their use in routine care. Relevant legal and regulatory aspects in the context of electronic health records and their data processing are addressed.

## 'Electronic medical record' and 'electronic health record' and their opportunities in today's care

The terms 'electronic medical record' (EMR) and 'electronic health record' (EHR) are often regarded as synonyms. However, a difference has been described: EMRs usually are implement-

ed and used in only one health care provider office or one clinic (https://www.healthit.gov). Data of EMRs usually cannot be shared with others, except when printed out or if provided by the system in an electronic document file format that adheres to the country-specific data security issues and sent to the one who made the request. EHRs go beyond EMRs and are regarded as repositories that can be accessed, filled, filed and shared from all authorised health care providers involved in patient's care (*e.g.* caring general practitioner, specialists, radiologists, laboratories, pharmacies, and emergency rooms) even from all over the country (https://www.healthit.gov).

EHRs include administrative and billing data (https://www.healthit.gov). Depending on the software application and similar to paper-based charts, EMRs and EHRs may contain data concerning patients' (socio-) demographic measures, diagnosis, ongoing and past medications, (usually slightly standardised) progress notes, vital signs, as well as radiology and/or laboratory results. The systems might enable health care providers to monitor patients' medical data and track them over time, see the data at a glance and also to identify patients for necessary follow-up and / or in-between visits. These key items are especially relevant for chronic, lifelong diseases. EMR/EHR systems might also include standardised physician judgments on the course of a patients' disease (*e.g.* disease activity scores as care quality measures) as well as patient-reported outcome data (3). These features are very important in Rheumatology, as diagnosis, management, and prognosis rely on standardised physician derived data and PROMs (4, 5). In Rheumatology clinical trials PROMs were as effective as other clinical data sources (*e.g.* laboratory tests) to identify active medications (6). Furthermore, rheumatologists regard patient history and physical examination as the most important sources of information for their diagnosis and patients' management (7). PROMs data seem to be more reproducible than physician derived data (*e.g.* disease activity scores relying on joint counts) (8).

PROMs nowadays contribute to the monitoring of quality of care (*e.g.* as performance measures) on individual as well as on aggregate levels; they facilitate the immediate patient-physician-communication, improve patient satisfaction and knowledge, and also proofed to be beneficial for clinical shared decision making (9-13). Regulatory authorities are increasingly using PROMs for benefit assessments of medical interventions, and - in accordance with the longstanding established core set of endpoints for rheumatoid arthritis (RA) in clinical trials - their use in clinical trials has been ascertained by the authorities (14-16). Software applications that imply various (disease specific) quality indicators are suitable to optimise the delivery process of the mandatory data to health care insurances and other stakeholders involved in quality of care assurance in the nation-specific health care systems (17). Not only due to the heterogeneity of systems but also due to differences in features and characteristics system validation studies are obligatory, as all users must be able to rely on correct data storage, automated score calculation, data transfer, data security, etc.

Available technological infrastructures for electronic medical data capture that include EHR/EMRs but also other, partly 'registered user-restricted' data capture applications with and without PROMs facilitate real-time and long-term systematic patient-centered data collection as integral components of care (3, 13, 18). Usually they run on various hardware devices and operating systems. Systems and other related technologies allow smart orchestration of data collection, analyses, and reporting and thus provide numerous prospects for routine patient care and medical research with up-to-date data (17). They contribute to more efficiency of the complex clinical workflows as they accelerate information transfer between patients and physicians (19). Lesser processing steps, avoidance of unnecessary, duplicate data collection and raised flexibility of data capture (*e.g.* frequencies and locations) help achieving this goal (18-22). Data capture flexibility toward required specific treatment regimens or disease phases might be supported, as new technologies and devices might simplify context-based customisation of outcomes and other quality indicators (23).

EHRs and other patient documentation software-systems that collect patients' clinical data and PROMs bear the potential to support modern treatment concepts (*e.g.* tight control) as they enable time-stamped, real-time flagging of important, clinically relevant symptoms that might be surveyed more frequently (in definable time intervals) to acquire broadened views on individual disease courses (13, 17). Automated event monitoring for defined thresholds as well as included electronic PROMS might indicate reduced physical health and other undesired health related outcomes and thus support triaging of patients who need closer attention in their caring process (*e.g.* adaption of treatment plans and/or diagnostic processes) (17, 24, 25). EHRs might contribute to improved cooperation and communication processes along care transitions (26). Rapid and facilitated benchmarking of individual outcomes with definable, scalable respectively large control groups get realistic. However, legal, ethical, and financial issues and dilemmas must be considered when using an EHR as summarised by Sittig *et al.* (27).

## EHRs and their opportunities for patient-centered research and other secondary uses

Although distribution and use vary among different countries, EHRs are becoming a key data source for health-related research (28). Analysis on a larger scale by aggregating data from different EHRs in a central database enables investigations of large cohorts (up to representing a valid national sample) and associations of clinical data and manifestations that have a long latency from exposure to outcomes, that might include time-varying exposures, and/or are subject to secular trends (*e.g.* concerning medication regimes) (29). The use of an EHR/EMR and the application of advances in informatics allow the identification of patients at risk for certain outcomes and might contribute to improvement

of quality of care (30). The wish to share data nationally and internationally, to identify clinical phenotypes and other data that might lead to development and evaluation of 'new treatment algorithms', will surely influence the future of Rheumatology care, but requires high levels of standardisation that have hardly been implemented and have further challenges (2).

EHRs have been used for description of the quality of care *e.g.* for the evaluation of rheumatologists performance and for population-based research (31). Ledwich *et al.* valued EHRs as effective tools for improving quality of care in patients receiving immunosuppressive medication when they include definable alerts that support to adhere to clinical guidelines and pathway (32). In principle, the narrative data in free text fields of EHRs have the potential to define disease outcomes (*e.g.* (non-) response to treatment, side effects) but have the major disadvantage that they require further (still mostly manual) processing (33). When free text fields are minimised and data are captured in a standardised structured fashion, they are more informative than free text.

Malaviya *et al.* published on a specialty-specific EMR application that also includes Rheumatology specific electronic outcome measures (*e.g.* Disease Activity Score 28 (DAS28), Clinical Disease Activity Index (CDAI), Simple Disease Activity index, (SDAI) Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath Ankylosing Spondylitis Functional Index (BASFI), Bath Ankylosing Spondylitis Metrology Index (BASMI). They report the clinical and academic advantages of such an EMR as they were able to see more patients, reduce waiting lists, and simplify clinical research – one of the main secondary use objectives (34). However, as this might not reflect physicians' overall experiences more research on these issues seems warranted.

In 2015 Newman *et al.* reported that currently available EHRs are usually not ideal for an optimised disease management in patients with chronic rheumatic diseases due to a number of given limitations as *e.g.* unavailability of outcome measures and time consuming documentation (35). As a consequence, they developed the electronic data capture, aggregation, and display system named "Rheum-PACER" (Patient Centric Electronic Redesign) that was successfully implemented in 3 Rheumatology practices and that is said to have universal applicability. The use of the system was strongly correlated to disease control, and improvements in quality and efficiency of care as well as in productivity were documented (35).

The 'Rheumatology Informatics System for Effectiveness (RISE)' is a national EHR-enabled registry started by the American College of Rheumatology that "allows passive collection of data on quality of care without individual patient informed consent". It gathers data on numerous quality measures and has been set up to "provide an infrastructure for improving quality of care, to fulfill national performance reporting requirements, and to serve as a unique data source to generate new knowledge" (36). Meaningful use of EHRs has already been connected to reimbursements by rebates avoiding negative payment adjustments or incentive payments (see http://www.rheumatology.org/I-Am-A/Rheumatologist/Registries/Quality-Reporting-Programs). The system will be used for the development of an RA specific performance outcome measure and implementation of electronic clinical quality measures (37, 38).

Ursum *et al.* explored data from EMRs from the Netherlands Institute for Health Services Research Primary Care database to study hospital admission rates due to cardiovascular diseases (CVD) in inflammatory arthritis and control patients, and reported increased hospital admission rates respectively higher CVD burden among patients with inflammatory arthritis (39). For patients with systemic sclerosis Redd *et al.* ana-lysed EMR data to detect patients at risk for scleroderma renal crisis. Here, the opportunity to improve quality of care comes to the fore, *e.g.* by education of the caring physicians or setting red flags in the EMR system (30). Baker *et al.* were able to use EMR data in combination with the US Veterans Affairs Rheumatoid Arthritis (VARA) Registry to identify factors associated with long-term changes in body mass index (40). Furthermore, pseudonymised linkage of cross sectional study data (patient questionnaires) to general practitioners' and hospital records' data has been used to explore relevant predictors of poor outcomes in ankylosing spondylitis (41).

Being aware of the still present weakness and given limits of EHRs (*e.g.* deficits from coded data, difficulties in the analysis of textual data, redundant information due to unnecessary repetitions from those entering data) they might via application of 'indicator markers' and/or cost-effective machine learning methods respectively algorithms help to (early) classify cases as 'rheumatoid arthritis' and reduce delay in diagnosis (28, 42, 43) and in consequence might contribute to improved descriptions of disease prevalence. Based on the wealth of information (structured and unstructured) in an EMR, Lin *et al.* built an automatic CASE/NON-CASE classification algorithm for an automated methotrexate-induced liver toxicity phenotype discovery in patients with RA. The algorithm showed accurate results (44). Other EMR-based patient cohorts including 4,453 patients with RA were used to develop and validate an algorithm that enables the study of coronary artery disease across different chronic diseases (45). Similarly, algorithms have been applied to identify 'ankylosing spondylitis' in the THIN (The Health Improvement Network, UK) EHR database; and one of the evaluated algorithm is now proposed for pharmaco-epidemiologic studies in THIN (29).

Another example is the collection and evaluation of drug allergy alert data from data of electronic health records (data from n=611,192 persons) from two large academic hospitals in Boston, MA (USA) showing an increase of drug allergy alert overrides (46). In the Australian Optimising Patient outcomes in Australian rheumatology (OPAL) registry, a point of care-derived observational registry, participating rheumatologists use the same outcome measures including EMR. This infrastructure allows the OPAL registry to follow more than 14,000 patients with RA based

on data derived from everyday clinical care and is able to answer research questions (47). The database was used to identify clinical situations that prevent patients with RA to achieve low disease activity or remission according to present remission criteria (48). Olsen *et al*. successfully developed a method to capture data directly from the local EHR (same EHR system in all participating centres) and transfer them into the Electronic Data Capture (EDC) system used for the Norwegian Disease-Modifying Anti-Rheumatic Drugs (NOR-DMARD) registry. From there the data are made available to authorised researchers and have already been used for research (49). Despite the advantage of electronic patient data collection systems some registries continue with paper-based data acquisition for register's reasonable reasons (50).

EHR data can also be applied for genetic studies. For example, Kurremann *et al*. linked EHR data with biospecimens for genetic research in a case-control cohort with RA patients (51).

EHRs might also contribute to patient recruitment for clinical trials, but further developments, implementation processes, recommendations, and regulations appear necessary and relevant (52, 53). Just recently, the FDA published the paper 'Use of Electronic Health Record Data in Clinical Investigations - Guidance for Industry' (54).

**Electronic PROMs in health information applications and their opportunities for patients' active involvement in their care**

EHRs and other patient documentations systems with integrated PROMs might also give the patient an opportunity to obtain a diversified view on his or her individual disease course and related issues, to engage in the disease management and to increase her/his empowerment. However, patients will usually not be well educated in interpreting the data resp. scores displayed to them electronically and user training might thus be necessary. In addition, one needs to keep in mind that outcome assessment is still underdeveloped in rheumatology practice (55), and guidelines regarding what scores represent a clinically relevant issue, either in absolute terms or long-term changes in the individual's score remain missing for some PROMs (9).

Nonetheless, several studies have been performed on the large armamentarium of EHRs/patient documentation system and ePROMs available in Rheumatology but also in other disciplines (26, 56, 57). In a meta-analysis Gwaltney *et al*. showed that electronic and paper measures of ePROMS produce equivalent scores (57). Similarly, Campbell *et al*. reported equivalence (56), but further validations of electronic versions of standardised instrument are necessary as bias can never be excluded. A Rheumatology specific recent overview focusing on ePROMS is available and the manuscript of Kiltz *et al*. adds some interesting facts (17, 58). A high number of patients prefer ePROMS and usually report positive attitudes towards them and their use (19, 56). However, to pose minimal burden, the number of ePROMS applied to the patients should be limited even if they make data available fast (3).

Due to the rise in connectivity and widely spread as well as highly valued mobile devices that can assist information gathering the range of time and locations where physicians, staff and patients can complete assessments (*e.g*. at home, waiting room) has significantly enlarged (3). Thus, beside the 'traditional' EHRs Apps that have been programmed for data collection and have already been evaluated (21, 59). Richter *et al*. compared patients' data entry of a set of PROMs (FFbH/HAQ, RADAI) using an App on a Smartphone to paper-pencil versions. Scores obtained by patients direct data entry on the Smartphone did not differ from the paper-pencil scores (59). Strengths and weaknesses of Apps and mobile health in the routine rheumatology service were summarised by El Miedany (60). Furthermore, Azevedo *et al*. provide an overview on Smartphone Apps for management of rheumatic diseases and related problems (54).

In Germany, various Rheumatology-specific patient documentation systems that can be used as 'add on systems' to EHRs in hospitals and private practices are available and have been used for health services research (http://dgrh.de/documed.html). They also incorporate PROMs that can be filled by the patients themselves (19) and/or have interfaces to further external mobile applications that allow ePROMs documentation. Schacher *et al*. examined the usability of three German Rheumatology-specific patient documentation systems and concluded that they provide valid data with better data quality than the paper versions (62). In addition, the NIH supported 'Patient-Reported Outcomes Measurement Information System' (PROMIS) is available for use (see http://www.healthmeasures.net/explore-measurement-systems/promis). The 'Electronic Recording of Outcome Measures for Inflammatory arthritis and Ankylosing spondylitis-EROMIA' system, a hospital-based integrated monitoring database, implemented visual feedback for the patients as they were allowed to view the course of their disease on the computer. This approach had a positive and significant impact on the disease activity control compared to standard care where the patient were able to check former forms filled in (63). Recently, a modern telemonitoring system including a website platform that also implies remotely filled in patient-reported outcome measures has successfully been applied to faster achieve remission in early RA (64).

Meanwhile, web portals allow patients to access their EHR via the internet from home or other places. Patients' interest in online access of their EHR has been reported for more than ten years (65). In RA, Van der Vaart *et al*. published in 2011 that two-third of the patients reported interest in accessing their electronic medical record to monitor symptoms (66). Direct access to the medical documents and caring process apart from the regular physician visits might lead to more patient empowerment (67). However, this hypothesis is still under discussion. Van der Vaart *et al*. also evaluated web portal EMR access in 360 RA patients, of whom 54% used and evaluated the portal. The authors appreciated the portal as a valuable addition to the care process (67). However, some patients might be

unfamiliar with notes and scores made available to them, and detailed patient education is necessary. Training of the staff involved in the new electronic caring process is also mandatory as staff members seem to play a key role in sustained implementation and utilisation (25, 68).

Spencer *et al*. reported that patients with chronic rheumatic diseases agree to share their anonymised electronic patient record for research. Considering the raised security concerns patients' engagement throughout the complete research process (*e.g*. via dynamic electronic consents and feedback loops) is appreciated and seems mandatory (69). In general, electronic health information systems need to be user-friendly and should pose minimal burden to reach successful integration and sustained use while offering additional benefits to health care professionals (26). Knowing that there are still limitations of current electronic data capture systems, early involvement of all stakeholders in the development and implementation processes is recommended to improve acceptance (26, 70).

## Legal and regulatory aspects

When implementing IT solutions for data collection and storage of patients' clinical (self-reported) data among others data security, analytic and practical issues as well as complex licenses' and legal aspects need to be considered, and it is mandatory to obtain patients' informed consent for electronic data transfer (*e.g*. via (wireless) local area networks), local as well as external storage, and processing (71). To protect patients from data theft and misuse, data avoidance and minimisation issues must be taken into account, but the extent might change according to the underlying rheumatic disease and the responsible regulatory authorities as well as ongoing changes of data security related laws and provisions (72). Additionally, more recent discussions focus on software being regarded as medical devices when used for clinical decision making. This ends up in complex regulatory and classification processes of the software as well as time consuming and costly administrative acts.

## Conclusions

EHRs/EMRs as well as other electronic patient documentation systems supply collection of medical data and information on health related topics. Long-term systematic patient-centered data collection – integral components of individuals' care – have become available via structured, standardised and longitudinally build documentation opportunities and automated scorings. Thus, they already allow modern real-time clinical routine patient care with high quality standards and facilitate patients to participate in their health care process immediately. Advanced systems and new electronic tools will provide even more explicit prospects for clinical data collection and key features tailored to individual needs in different treatment and disease phases. The integration of mobile devices to EHRs and existing patient documentation systems might lead to more frequent, remote and continuous documentation of key outcome parameters' and other measures facilitating new optimised treat-to-target and individual management concepts. In addition, data from EHR become available for research, registries, and other secondary usage and will thereby lead to improved knowledge and new process flows in Rheumatology health care. Legal and regulatory aspects should always be kept in mind.

## References


1. AMARASINGHAM R, PLANTINGA L, DIENER-WEST M, GASKIN DJ, POWE NR: Clinical information technologies and inpatient outcomes: a multiple hospital study. *Arch Intern Med* 2009; 169: 108-14.
2. GAYWOOD I, PANDE I: Preparing for electronic health records. *Rheumatology* (Oxford) 2015; 54: 1537-8.
3. JENSEN RE, ROTHROCK NE, DEWITT EM *et al*.: The role of technical advances in the adoption and integration of patient-reported outcomes in clinical care. *Med Care* 2015; 53: 153-9.
4. SARGIOUS A, LEE SJ: Remote collection of questionnaires. *Clin Exp Rheumatol* 2014; 32 (Suppl. 85): S168-72.
5. PINCUS T: Patient questionnaires and formal education as more significant prognostic markers than radiographs or laboratory tests for rheumatoid arthritis mortality--limitations of a biomedical model to predict long-term outcomes. *Bull NYU Hosp Jt Dis* 2007; 65 (Suppl. 1): S29-36.
6. PINCUS T, CASTREJÓN I: Are patient self-report questionnaires as 'scientific' as biomarkers in 'treat-to-target' and prognosis in rheumatoid arthritis? *Curr Pharm Des* 2015; 21: 241-56.
7. CASTREJÓN I, MCCOLLUM L, TANRIOVER MD, PINCUS T: Importance of patient history and physical examination in rheumatoid arthritis compared to other chronic diseases: results of a physician survey. *Arthritis Care Res* 2012; 64: 1250-5.
8. UHLIG T, KVIEN TK, PINCUS T: Test-retest reliability of disease activity core set measures and indices in rheumatoid arthritis. *Ann Rheum Dis* 2009; 68: 972-5.
9. SNYDER CF, AARONSON NK: Use of patient-reported outcomes in clinical practice. *Lancet* 2009; 374 :369-70.
10. VALDERAS JM, KOTZEVA A, ESPALLARGUES M *et al*.: The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res* 2008; 17: 179-93.
11. HETLAND ML: DANBIO--powerful research database and electronic patient record. *Rheumatology* 2011; 50: 69-77.
12. DEUTSCH A, SMITH L, GAGE B, KELLEHER C, GARFINKEL D: National Quality Forum Patient Reported Outcomes (PROs) Workshop #1 July 30-31, 2012 Workshop Summary [Internet]. Available from: https://www.qualityforum.org/Calendar/2012/07/Patient-Reported_Outcomes--Workshop_-_2012-07-30.aspx
13. BENNETT AV, JENSEN RE, BASCH E: Electronic patient-reported outcome systems in oncology clinical practice. *CA Cancer J Clin* 2012; 62: 337-47.
14. BOERS M, TUGWELL P, FELSON DT *et al*.: World Health Organization and International League of Associations for Rheumatology core endpoints for symptom modifying antirheumatic drugs in rheumatoid arthritis clinical trials. *J Rheumatol* 1994; 41 (Suppl.): 86-9.
15. FOOD AND DRUG ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES: Guidance for industry: Patient-reported outcome measures: Use in medical product development to support labeling claims. [Internet]. Available from: http://www.fda.gov/ downloads/Drugs/Guidances/UCM193282.pdf
16. Institute for Quality and Efficieny in Health Care. General Methods (benefit assessment) [Internet]. 2015. Available from: https://www.iqwig.de/en/methods/methods-paper.3020.html
17. RICHTER JG, KAMPLING C, SCHNEIDER M: Electronic patient reported outcome measures (e-PROMS) in Rheumatology. *In*: EL MIEDANY Y (Ed.): Patient Reported Outcome Measures in Rheumatic Diseases. Springer; 2016.
18. CHUNG AE, BASCH EM: Incorporating the patient's voice into electronic health records through patient-reported outcomes as the 'review of systems'. *J Am Med Inform Assoc* 2015; 22: 914-6.
19. RICHTER JG, BECKER A, KOCH T *et al*.: Self-assessments of patients via Tablet PC in routine patient care: comparison with standardised paper questionnaires. *Ann Rheum Dis* 2008; 67: 1739-41.
20. GREENWOOD MC, HAKIM AJ, CARSON E, DOYLE DV: Touch-screen computer systems

in the rheumatology clinic offer a reliable and user-friendly means of collecting quality-of-life and outcome data from patients with rheumatoid arthritis. *Rheumatology* 2006; 45: 66-71.
21. STRONG LE: The past, present, and future of patient-reported outcomes in oncology. *Am Soc Clin Oncol Educ Book* 2015; e616-620.
22. SUDANO JJ, KOFFORD B, WOTMAN S: Using tablet PC's in dental practice research: technology, cost savings, and direct data entry 'on the go'. *J Public Health Dent* 2005; 65: 244-5.
23. SNYDER CF, WU AW, MILLER RS, JENSEN RE, BANTUG ET, WOLFF AC: The role of informatics in promoting patient-centered care. *Cancer J* 2011; 17: 211-8.
24. EL MIEDANY Y: Adopting patient-centered care in standard practice: PROMs moving toward disease-specific era. *Clin Exp Rheumatol* 2014; 32 (Suppl. 85): S40-46.
25. SMITH SK, ROWE K, ABERNETHY AP: Use of an electronic patient-reported outcome measurement system to improve distress management in oncology. *Palliat Support Care* 2014; 12: 69-73.
26. JENSEN RE, SNYDER CF, ABERNETHY AP *et al*.: Review of electronic patient-reported outcomes systems used in cancer clinical care. *J Oncol Pract* 2014; 10: e215-222.
27. SITTIG DF, SINGH H: Legal, ethical, and financial dilemmas in electronic health record adoption and use. *Pediatrics* 2011; 127: e1042–7.
28. NICHOLSON A, FORD E, DAVIES KA *et al*.: Optimising use of electronic health records to describe the presentation of rheumatoid arthritis in primary care: a strategy for developing code lists. *PloS One* 2013; 8: e54878.
29. DUBREUIL M, PELOQUIN C, ZHANG Y, CHOI HK, INMAN RD, NEOGI T: Validity of ankylosing spondylitis diagnoses in The Health Improvement Network. *Pharmacoepidemiol Drug Saf* 2016; 25: 399-404.
30. REDD D, FRECH TM, MURTAUGH MA, RHIANNON J, ZENG QT: Informatics can identify systemic sclerosis (SSc) patients at risk for scleroderma renal crisis. *Comput Biol Med* 2014; 53: 203-5.
31. ADHIKESAVAN LG, NEWMAN ED, DIEHL MP, WOOD GC, BILI A: American College of Rheumatology quality indicators for rheumatoid arthritis: benchmarking, variability, and opportunities to improve quality of care using the electronic health record. *Arthritis Rheum* 2008; 59: 1705-12.
32. LEDWICH LJ, HARRINGTON TM, AYOUB WT, SARTORIUS JA, NEWMAN ED: Improved influenza and pneumococcal vaccination in rheumatology patients taking immunosuppressants using an electronic health record best practice alert. *Arthritis Rheum* 2009; 61: 1505-10.
33. ANANTHAKRISHNAN AN, CAGAN A, CAI T *et al*.: Identification of nonresponse to treatment using narrative data in an electronic health record inflammatory bowel disease cohort. *Inflamm Bowel Dis* 2016; 22: 151-8.
34. MALAVIYA AN, GOGIA SB: Development, implementation and benefits of a rheumatology-specific electronic medical record application with automated display of outcome measures. *Int J Rheum Dis* 2010; 13: 347-60.
35. NEWMAN ED, LERCH V, BILLET J, BERGER A, KIRCHNER HL: Improving the quality of care of patients with rheumatic disease using patient-centric electronic redesign software. *Arthritis Care Res* 2015; 67: 546-53.
36. YAZDANY J, MYSLINSKI R, FRANCISCO M *et al*.: A National Electronic Health Record-Enabled Registry in Rheumatology: The ACR's Rheumatology Informatics System for Effectiveness (RISE) [Internet]. ACR Meeting Abstracts. [cited 2016 Aug 15]. Available from: http://acrabstracts.org/abstract/a-national-electronic-health-record-enabled-registry-in-rheumatology-the-acrs-rheumatology-informatics-system-for-effectiveness-rise/
37. SUTER LG, BARBER CE, HERRIN J *et al*.: American College of Rheumatology White Paper on Performance Outcome Measures in Rheumatology. *Arthritis Care Res* 2016; 68: 1390-401.
38. YAZDANY J, MYSLINSKI R, MILLER A *et al*.: Methods for Developing the American College of Rheumatology's Electronic Clinical Quality Measures ('eCQMs'). *Arthritis Care Res* 2016 Jul 7;
39. URSUM J, NIELEN MMJ, TWISK JWR *et al*.: Cardiovascular disease-related hospital admissions of patients with inflammatory arthritis. *J Rheumatol* 2015; 42: 188-92.
40. BAKER JF, CANNON GW, IBRAHIM S, HAROLDSEN C, CAPLAN L, MIKULS TR: Predictors of longterm changes in body mass index in rheumatoid arthritis. *J Rheumatol* 2015; 42: 920-7.
41. COOKSEY R, BROPHY S, DENNIS M *et al*.: Severe flare as a predictor of poor outcome in ankylosing spondylitis: a cohort study using questionnaire and routine data linkage. *Rheumatology* (Oxford) 2015; 54: 1563-72.
42. ZHOU S-M, FERNANDEZ-GUTIERREZ F, KENNEDY J *et al*.: Defining disease phenotypes in primary care electronic health records by a machine learning approach: a case study in identifying rheumatoid arthritis. *PloS One* 2016; 11: e0154515.
43. CHUNG CP, ROHAN P, KRISHNASWAMI S, MCPHEETERS ML: A systematic review of validated methods for identifying patients with rheumatoid arthritis using administrative or claims data. *Vaccine* 2013; 31 (Suppl. 10): K41-61.
44. LIN C, KARLSON EW, DLIGACH D *et al*.: Automatic identification of methotrexate-induced liver toxicity in patients with rheumatoid arthritis from the electronic medical record. *J Am Med Inform Assoc JAMIA* 2015; 22: e151-161.
45. LIAO KP, ANANTHAKRISHNAN AN, KUMAR V *et al*.: Methods to Develop an Electronic Medical Record Phenotype Algorithm to Compare the Risk of Coronary Artery Disease across 3 Chronic Disease Cohorts. *PloS One* 2015; 10: e0136651.
46. TOPAZ M, SEGER DL, SLIGHT SP *et al*.: Rising drug allergy alert overrides in electronic health records: an observational retrospective study of a decade of experience. *J Am Med Inform Assoc* 2016; 23: 601-8.
47. TYMMS K, LITTLEJOHN G: OPAL: a clinician driven point of care observational data management consortium. *Clin Exp Rheumatol* 2014; 32 (Suppl. 85): S150-52.
48. TYMMS K, ZOCHLING J, SCOTT J *et al*.: Barriers to optimal disease control for rheumatoid arthritis patients with moderate and high disease activity. *Arthritis Care Res* 2014; 66: 190-6.
49. OLSEN IC, HAAVARDSHOLM EA, MOHOLT E, KVIEN TK, LIE E: NOR-DMARD data management: implementation of data capture from electronic health records. *Clin Exp Rheumatol* 2014; 32 (Suppl. 85): S158-62.
50. RICHTER A, Y. MEISSNER, A. STRANGFELD, A. ZINK: Primary and secondary patient data in contrast: the use of observational studies like RABBIT. *Clin Exp Rheumatol* 2016; 34; (Suppl. 101): S79-86.
51. KURREEMAN F, LIAO K, CHIBNIK L *et al*.: Genetic basis of autoantibody positive and negative rheumatoid arthritis risk in a multiethnic cohort derived from electronic health records. *Am J Hum Genet* 2011; 88: 57-69.
52. DUGAS M, LANGE M, MÜLLER-TIDOW C, KIRCHHOF P, PROKOSCH H-U: Routine data from hospital information systems can support patient recruitment for clinical studies. *Clin Trials Lond Engl* 2010; 7: 183-9.
53. SCHREIWEIS B, TRINCZEK B, KÖPCKE F *et al*.: Comparison of electronic health record system functionalities to support the patient recruitment process in clinical trials. *Int J Med Inf* 2014; 83: 860-8.
54. U.S. FOOD AND DRUG ADMINISTRATION: Use of Electronic Health Record Data in Clinical Investigations - Guidance for Industry [Internet]. [cited 2016 Aug 15]. Available from: http://www.fda.gov/downloads/Drugs/GuidanceCompliance RegulatoryInformation/Guidances/UCM501068.pdf
55. CUSH JJ, CURTIS JR: Treat-to-target (T2T) and measuring outcomes in RA care: a 2014 longitudinal survey of US rheumatologists. *Athritis Rheumatol* 2014; 66: (11 Suppl.): S48.
56. CAMPBELL N, ALI F, FINLAY AY, SALEK SS: Equivalence of electronic and paper-based patient-reported outcome measures. *Qual Life Res* 2015; 24: 1949-61.
57. GWALTNEY CJ, SHIELDS AL, SHIFFMAN S: Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. *Value Health J Int Soc Pharmacoeconomics Outcomes Res* 2008; 11: 322-33.
58. KILTZ, U; BOONEN A; BRAUN J; RICHTER J.G.: Electronic assessment of disease activity and functioning in patients with axial spondyloarthritis: challenges and unmet needs. *Clin Exp Rheumatol* 2016; 34; (Suppl. 101): S57-61.
59. RICHTER JG, KAMPLING C, CHEHAB G *et al*.: Mobile Medical Documentation of Patient-reported-Outcome [abstract]. *Arthritis Rheumatol* 2015; 67 (Suppl 10). Available from: http://acrabstracts.org/abstract/mobile-medical-documentation-of-patient-reported-outcome/ [accessed 2016 Sep 30]
60. EL MIEDANY Y: e-Rheumatology: are we ready? *Clin Rheumatol* 2015; 34: 831-7.
61. AZEVEDO ARP, DE SOUSA HML, MONTEIRO JAF, LIMA ARNP: Future perspectives of Smartphone applications for rheumatic diseases self-management. *Rheumatol Int* 2015; 35: 419-31.
62. SCHACHER B, ALTEN R, PACHECO E *et al*.:

Projektförderung der AGRZ: Einsatz von IT-Dokumentationssystemen in der rheumatologischen Patientenversorgung - Anwendungserprobung und Usability-Vergleich der Softwaresysteme Ardis, Documed.rh und Rheumadok. *Z Für Rheumatol* 2009; 68 (Suppl. 1): 34.

63. EL MIEDANY Y, EL GAAFARY M, PALMER D: Assessment of the utility of visual feedback in the treatment of early rheumatoid arthritis patients: a pilot study. *Rheumatol Int* 2012; 32: 3061-8.
64. SALAFFI F, CAROTTI M, CIAPETTI A *et al*.: Effectiveness of a telemonitoring intensive strategy in early rheumatoid arthritis: comparison with the conventional management approach. *BMC Musculoskelet Disord* 2016; 17: 146.
65. RICHTER JG, BECKER A, KOCH T *et al*.: Changing attitudes towards online electronic health records and online patient documentation in rheumatology outpatients. *Clin Exp Rheumatol* 2010; 28: 261-4.
66. VAN DER VAART R, DROSSAERT CHC, TAAL E, VAN DE LAAR MAFJ: Patient preferences for a hospital-based rheumatology Interactive Health Communication Application and factors associated with these preferences. *Rheumatology* (Oxford) 2011; 50: 1618-26.
67. VAN DER VAART R, DROSSAERT CHC, TAAL E, DROSSAERS-BAKKER KW, VONKEMAN HE, VAN DE LAAR MAFJ: Impact of patient-accessible electronic medical records in rheumatology: use, satisfaction and effects on empowerment among patients. *BMC Musculoskelet Disord* 2014; 15: 102.
68. SCHICK-MAKAROFF K, MOLZAHN A: Strategies to use tablet computers for collection of electronic patient-reported outcomes. *Health Qual Life Outcomes* 2015; 13: 2.
69. SPENCER K, SANDERS C, WHITLEY EA, LUND D, KAYE J, DIXON WG: Patient perspectives on sharing anonymized personal health data using a digital system for dynamic consent and research feedback: A Qualitative Study. *J Med Internet Res* 2016; 18: e66.
70. HARTZLER A, MCCARTY CA, RASMUSSEN LV *et al*.: Stakeholder engagement: a key component of integrating genomic information into electronic health records. *Genet Med Off J Am Coll Med Genet* 2013; 15: 792-801.
71. NEWMAN JC, FELDMAN R: Copyright and open access at the bedside. *N Engl J Med* 2011; 365: 2447-9.
72. European Union. General Data Protection Regulation [Internet]. Available from: http://eur-lex.europa.eu/legal-content/DE/TXT/?uri=uriserv%3AOJ.L_.2016.119.01.0001.01.DEU&toc=OJ%3AL%3A2016%3A119%3ATOC