
Digital health assessment in rheumatology: current and future possibilities

F.S. Catarinella¹, W.H. Bos²

¹Brightfish B.V., Hoofddorp, the Netherlands;
²Reade Rheumatology, Amsterdam, the Netherlands.

Fabio S. Catarinella, MD
Wouter H. Bos, MD, PhD

Please address correspondence to:
Dr Wouter Bos,
Department of Rheumatology, Reade,
Dr Jan van Breemenstraat 2,
1056 AB Amsterdam, the Netherlands.
E-mail: w.bos@reade.nl

Received and accepted on September 20,
2016.

Clin Exp Rheumatol 2016; 34 (Suppl. 101):
S2-S4.

© Copyright CLINICAL AND
EXPERIMENTAL RHEUMATOLOGY 2016.

Key words: E-health, patient-reported
outcomes, mobile Apps, rheumatoid
arthritis

ABSTRACT

Digital assessment and graphical feedback of patient-reported outcome measures such as the Health Assessment Questionnaire (HAQ) could increase empowerment and involvement of patients in their own care process. The App ecosystem that Reade is building is an example of how digital assessment using mobile devices can be integrated into existing hospital IT infrastructure.

Introduction

Patient expectations of health care services continue to grow and the numbers of patients with (combinations of) chronic diseases, including patients with rheumatoid arthritis (RA) and comorbidities, are increasing due to the aging of the western populations. In a series of publications, health economist Michael Porter (1-3) makes a case for working towards value for patients as the overarching goal for health care delivery, with value defined as patient-reported outcomes (PROs) relative to costs. As such, outcomes that are important and meaningful to patients, such as pain, function, fatigue, sleep, emotional wellbeing, physical wellbeing and coping/self-management determine the reward for all other actors in the system. PROs have been found to be at least as informative as formal joint counts, laboratory and radiographic data for the assessment of RA activity at baseline, change during interventions, and are predictive of long-term outcomes such as premature death and work disability (4-7). Furthermore, PROs also bring additional information in the assessment of RA since there is a discordance between the patient's and the physician's perspective (8-14). The implementation of eHealth and empowerment of patients to be involved in their own care process, have been suggested to modernise health care, reduce costs and preserve the

values to which health care systems aspire: delivering the same foundation of evidence-based care, no matter where a patient lives or whom a patient sees.

Health assessment questionnaires

The Health Assessment Questionnaire (HAQ), published in 1980 by the Stanford Arthritis Center (15) is among the most-widely used PRO instruments that represent a model of patient-oriented outcome assessment. Various collection methods have been validated, such as by telephone, mail and in the outpatient clinic. The HAQ, and the modified version MDHAQ/RAPID3 (Multi-Dimensional Health Assessment Questionnaire/Routine Assessment of Patient Index Data) correlates well to clinical outcome measures such as DAS28 and provides valuable additional information on RA activity in addition to clinical measures, laboratory results and radiographs. (16-17)

Following the trend of Value Based Health Care (VBHC) instruments like the HAQ/MDHAQ play an increasingly important role in modern medicine. This puts certain requirements on the associated infrastructure, clinical workflow and most importantly, it requires time and effort of the care providers who are already burdened with many administrative tasks. In order to circumvent these problems, we need to find a way to incorporate PROs in both the patient and care provider's daily workflow.

Digital health assessment

In order to alleviate some of the issues related to paper forms, doctors and nurses typing results in an Electronic Medical Record (EMR) or the inability of most EMRs such as our own to fully integrate PROs, Reade started a new project at the end of 2015 to cope with these problems.

The first goal was to digitise PROs, allowing electronic questionnaire assess-

Competing interests: none declared

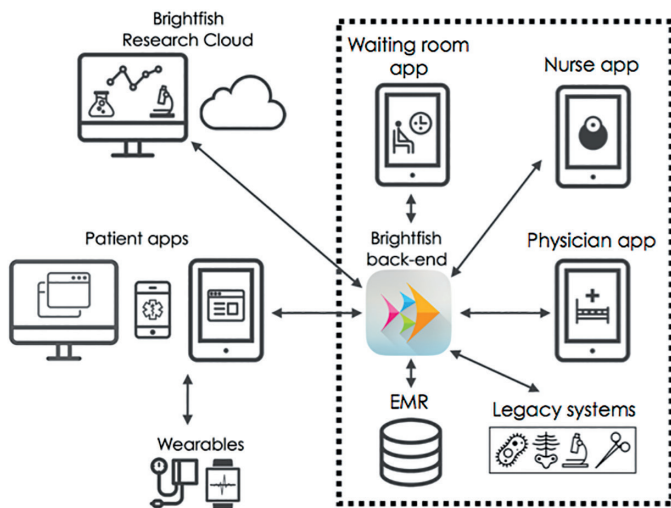


Fig. 1. IT infrastructure to support Apps and Electronic Medical Record (EMR) connections.

the scores during visits the patient will gain an understanding in the benefits of filling in the questionnaires during each visit. This will also add to the sense of control and empowerment, because the results of completing a questionnaire are tangible and have an effect. Finally, electronic data capture is reported to improve response ratios, decrease error rates and is generally perceived as more user-friendly than traditional paper questionnaires. (18-19).

Future possibilities

The second phase of the above mentioned program is to extend our PRO infrastructure outside the walls of the hospital. In order to do this, we are building a Reade App which will be released in all large App stores, like Apple’s AppStore and Google’s Play Store. The Apple iOS App is nearing its first public release (end of summer 2016), allowing patients to assess and send completed HAQ/MDHAQ questionnaires from the comfort of their homes, or *e.g.* while waiting for the bus. By using the native notification options of smartphones patients no longer receive

ment, but more importantly, integrating the clinical data like laboratory results, radiology reports and severity scores with the PROs. Integrating clinical outcomes and PROs required a modification to the IT infrastructure, building a new system on top of the EMR, the legacy systems and the various other data sources in the hospital. (Fig. 1) This is mandatory if one wants to truly integrate patient data across all systems. At the same time new data like

scores resulting from PROs had to be written back to the appropriate destination, in our case the EMR, in order for care providers to actually see the outcomes in real-time during outpatient clinic visits. By fully integrating clinical and patient-reported outcomes the care provider has a better insight with regards to disease activity, treatment effect and other issues that might otherwise go unnoticed. Secondly, by discussing



Fig. 2. Examples of the iPad and iPhone Apps.

e-mails with instructions, the App itself can notify a patient to complete a questionnaire. Completed questionnaires will be instantly transformed to easily readable and comprehensible scores, so the patient gets useful feedback and can interpret the results without the need of a care provider. This is done by showing results in a graphical way, supplemented with context and reference values when applicable (Fig. 2).

Another exciting feature that becomes available when using smartphones is the availability of built-in sensors such as accelerometers and gyroscopes. We are currently performing a Proof-of-Concept with 15 RA patients and 15 control users to assess their gait characteristics and correlating these with RAPID3 scores and laboratory results. We use Apple's ResearchKit to collect surveys, sensor data and consent declarations. We eventually hope to deploy activity measurements as an additional parameter in assessing disease activity and treatment progress.

The App ecosystem that we are building will lower the burden for patients to start sharing their health information with their care provider, in the form of PRO's, activity monitoring and structured complaint/symptom reporting, and it will likely also increase compliance and give patients a better understanding of their disease.

Conclusion

The expected results of such a mobile eHealth infrastructure potentially impacts important issues related to RA management and are relevant to many different stakeholders at different levels: *Patients:* e-monitoring can decrease the burden of patients to visit the health care facility for minor check-ups. Furthermore, e-monitoring will empower patients to manage their own illness. The use of PROs ensures that patient important aspects of RA are registered and monitored in a standardised way. Real-time insight in their own care process will lead to increased compliance from patients with their treatment plans. Allowing patients to add care data to their own EMR record increases awareness and empowerment.

Clinicians: rheumatologists are pro-

vided with additional information to optimally understand and treat their patients. There will be more dedicated time for complicated patient care.

Scientific community: a new patient-centered method to optimise data collection in rheumatology care will become available, expanding the field of research on health monitoring in RA.

Society: It is expected that adoption of e-Health applications can substitute some of the care provided by physicians. This makes health care less expensive. Patients that do not have to come to the clinic on a regular basis, increase their productivity, which is a (financial) benefit to society. Also, evaluating new treatments and reassessing current treatments becomes easier and cheaper, allowing more stringent selection and reimbursement policies.

In RA, outcomes that are important and meaningful to patients, such as pain, function, fatigue, sleep, emotional wellbeing, physical wellbeing and coping/self-management determine the reward for all other actors in the system. Giving patients an e-health tool to measure and receive feedback on these domains should improve empowerment (satisfaction, confidence with the system) and facilitate patient initiated care, creating an value-based health care system for RA.

References

1. VERDIER JM: Redefining health care: Creating value-based competition on results. Porter ME, Teisberg EO, *J Policy Anal Manage* 2007; 26: 968-70.
2. PORTER ME: A strategy for health care reform - toward a value-based system. *N Engl J Med* 2009; 361: 109-12.
3. PORTER ME: What is value in health care? *N Engl J Med* 2010; 363: 2477-81.
4. BARRETT EM: The impact of rheumatoid arthritis on employment status in the early years of disease: A UK community-based study. *Rheumatology* 2000; 39: 1403-9.
5. SOKKA T: Similar prediction of mortality by the health assessment questionnaire in patients with rheumatoid arthritis and the general population. *Ann Rheum Dis* 2004; 63: 494-7.
6. PINCUS T, YAZICI Y, BERGMAN MJ: RAPID3, an index to assess and monitor patients with rheumatoid arthritis, without formal joint counts: Similar results to DAS28 and CDAI in clinical trials and clinical care. *Rheuma Dis Clin North Am* 2009; 35: 773-8.
7. HAZES JM, TAYLOR P, STRAND V, PURCARU O, COTEUR G, MEASE P: Physical function

improvements and relief from fatigue and pain are associated with increased productivity at work and at home in rheumatoid arthritis patients treated with certolizumab pegol. *Rheumatology* 2010; 49: 1900-10.

8. VAN TUYL LH, PLASS AM, LEMS WF *et al.*: Discordant perspectives of rheumatologists and patients on COBRA combination therapy in rheumatoid arthritis. *Rheumatology* 2008; 47: 1571-6.
9. BARTON JL, IMBODEN J, GRAF J, GLIDDEN D, YELIN EH, SCHILLINGER D: Patient-physician discordance in assessments of global disease severity in rheumatoid arthritis. *Arthritis Care Res* 2010; 62: 857-64.
10. NEVILLE C, CLARKE AE, JOSEPH L, BELISLE P, FERLAND D, FORTIN PR: Learning from discordance in patient and physician global assessments of systemic lupus erythematosus disease activity. *J Rheumatol* 2000; 27: 675-9.
11. SZTAJNBOK F, CORONEL-MARTINEZ DL, DIAZ-MALDONADO A *et al.*: Discordance between physician's and parent's global assessments in juvenile idiopathic arthritis. *Rheumatology* 2007; 46: 141-5.
12. KHAN NA, SPENCER HJ, ABDAA E *et al.*: Determinants of discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care Res* 2012; 64: 206-14.
13. CASTREJÓN I, YAZICI Y, SAMUELS J, LUTA G, PINCUS T: Discordance of global estimates by patients and their physicians in usual care of many rheumatic diseases: Association with 5 scores on a multidimensional health assessment questionnaire (MDHAQ) that are not found on the health assessment questionnaire (HAQ) *Arthritis Care Res* 2014; 66: 934-42.
14. LINDSTRÖM EGHOLM C, KROGH NS, PINCUS T *et al.*: Discordance of global assessments by patient and physician is higher in female than in male patients regardless of the physician's sex: Data on patients with rheumatoid arthritis, axial Spondyloarthritis, and Psoriatic arthritis from the DANBIO registry. *J Rheumatol* 2015; 42: 1781-5.
15. FRIES JF, SPITZ P, KRAINES RG, HOLMAN HR: Measurement of patient outcome in arthritis. *Arthritis Rheum* 1980; 23: 137-45.
16. BRUCE B, FRIES J: The health assessment questionnaire (HAQ). *Clin Exp Rheumatol* 2005; 23 (Suppl. 39): S14-18.
17. PINCUS T, SWEARINGEN C, BERGMAN M, YAZICI Y: RAPID3 (routine assessment of patient index data 3), a rheumatoid arthritis index without formal joint counts for routine care: Proposed severity categories compared to disease activity score and clinical disease activity index categories. *J Rheumatol* 2008; 35: 2136-47.
18. ARTS DGT, DE KEIZER NF, SCHEFFER G-J: Defining and improving data quality in medical registries: a literature review, case study, and generic framework. *J Am Med Inform Assoc* 2002; 9: 600-11.
19. WORKMAN TA: Engaging Patients in Information Sharing and Data Collection: The Role of Patient-Powered Registries and Research Networks. Rockville (MD): Agency for Healthcare Research and Quality (US), 2013.