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ORIGINAL ARTICLE

Development, usability and acceptability of an integrated eHealth system for spondyloarthritis in the Netherlands (SpA-Net)

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ABSTRACT

Objective To develop and test the usability and acceptability of a disease-specific integrated electronic health (eHealth) system for spondyloarthritis (SpA) in the Netherlands ('SpA-Net').

Methods SpA-Net was developed in four phases. First, content and design were discussed with experts on SpA and patients. Second, the database, electronic medical record (EMR) and quality management system were developed. Third, multiple rounds of testing were performed. Fourth, the eHealth system was implemented in practice and feasibility was tested among patients through semistructured focus interviews (n=16 patients) and among care providers through feedback meetings (n=11 rheumatologists/fellows and 5 nurses).

Results After completion of the first three steps of development in 2015, SpA-Net was implemented in 2016. All patients included have a clinical diagnosis of SpA. Information on domains relevant to clinical record-keeping is prospectively collected at routine outpatient consultations and readily available to care providers, presented in a clear dashboard. Patients complete online questionnaires prior to outpatient visits. In February 2019, 1069 patients were enrolled (mean [SD] age 54.9 [14.1] years, 52.4% men). Patients interviewed (n=16) considered SpA-Net an accessible system that was beneficial to disease insight and patient–physician communication, and had additional value to current care. Care providers appreciated the additional information for (preparing) consultations. Barriers were the initial time required to adopt the EMR and the quantity of data entry.

Conclusion SpA-Net enables monitoring of patients with SpA and real-life data collection, and could help improve knowledge and optimise communication between patients and care providers. Both considered SpA-Net a valuable addition to current care.

Trial registration number NTR6740.

Key messages

What is already known about this subject?

- Patients, care providers and payers, each has different needs regarding care for spondyloarthritis (SpA) in daily practice.
- Disease-specific electronic health (eHealth) systems that are integrated in daily practice can serve the needs of the different parties involved.

What does this study add?

- We successfully developed and implemented an integrated eHealth system and quality registry for patients with SpA in the Netherlands (SpA-Net).
- SpA-Net enables regular monitoring of patients and real-life data collection, and is feasible and acceptable for use in clinical practice from both the patient's and care provider's perspective.

How might this impact on clinical practice?

- Systems such as SpA-Net can optimise communication, treatment decisions and patient empowerment, while simultaneously providing transparency and real-life data for research.

INTRODUCTION

Spondyloarthritis (SpA) is a chronic inflammatory rheumatic disease with a heterogeneous clinical presentation. It may follow a disabling disease course, leading to substantial impairment of health-related quality of life (HRQoL), and to substantial costs for society due to healthcare utilisation and work productivity loss.[1–3]

From the care provider's perspective, regular and personalised monitoring of disease activity, physical functioning, medication use, side effects and comorbidities is essential to improve and maintain patients' HRQoL. Patient-reported outcome measures (PROMs) could further support this process and may also directly contribute to patient-centred care.[4] Measuring outcomes that matter to patients is becoming increasingly important, as a way to learn and improve

healthcare, to support shared decision making and to secure sustainable healthcare.[5] However, regular monitoring using PROMs has not yet been widely implemented into clinical practice. Barriers against use are time constraints, administrative burden, lack of a digital system to capture PROMs, lack of training, motivation and reluctance to change.[6] In addition, it is unknown whether routine collection of PROMs leads to improved outcome for the individual patient in clinical practice.

From the patient's perspective, access to results of regular monitoring using PROMs could provide insight into their own health state. Patient empowerment and shared decision making are advocated as essential elements of high-quality clinical practice.[7] The patient and the rheumatologist decide together on the best possible management and define personal treatment goals, taking into account patient-specific context regarding comorbidities, adverse events, patient preference and preferred role, frequency of monitoring, and personal circumstances. To be involved in this process, patients need to be informed about their disease and management options, and vice versa, and the patient's voice needs to be heard. Good mutual communication is therefore essential. Furthermore, regular monitoring using PROMs can also be done electronically (ePROMS), which allows for telemonitoring with the potential to decrease the number of visits and reduce the burden for the patient.

From the payer's perspective, governments and insurers increasingly demand transparency on outcomes, safety and efficiency/costs of care. The concept of value-based healthcare (VBHC) delivery, that is, a healthcare system where the health outcomes achieved per euro spent (value) are maximised, was introduced more than a decade ago.[8] Regular and comprehensive measurement of relevant health outcomes is one of the core principles of VBHC.[8 9] On a related note, variations in medical practice were already acknowledged 50 years ago but have recently been gaining attention.[10] The extent to which this variation is 'unwarranted', that is, the consequence of a complex interaction between several medical and non-medical factors finally resulting in underuse or overuse of healthcare, should be minimised. Benchmarking and performance evaluation, as well as transparency on the results, can support this process. This requires an integrated, supported and cyclic process of improvement with a sufficient number of centres and patients.

Within the field of electronic health (eHealth, i.e., healthcare supported by information technology), new developments such as online monitoring tools could support high-quality, personalised and efficient care for patients with SpA. Most electronic medical records (EMRs) in their current form are not fit for chronic disease management, as relevant disease measures are often not available and ways to monitor the course of disease over time are lacking.[11] A disease-specific, integrated eHealth system, that is, a system that is central in the organisation of daily care, linked with existing EMRs and accessible for patients, can serve the needs of care providers, patients, payers and society.[8 12–18] In addition, from a scientific perspective, it would capture data for research. While some aspects, such as regular collection of (e)PROMs, have been successfully implemented in SpA, to our knowledge, a system for comprehensive disease management was not yet available in the Netherlands.

In order to facilitate integration of the patient's and the healthcare provider's perspective on quality of care, we aimed (1) to develop and implement an integrated eHealth system for (tele)monitoring and reporting of health-related data of patients with SpA in the Netherlands ('SpA-Net'), including an EMR and real-time quality management system, and (2) to test the usability and acceptability of this system among patients and care providers.

PATIENTS AND METHODS

Development of SpA-Net

The development of SpA-Net was carried out according to an iterative process of four phases: (1) content and design, (2) technical development of database and EMR, (3) internal and external testing, and (4) implementation. Rheumatologists, nurses experienced with care for patients with SpA and trained patient research partners were involved during various phases of development. Detailed information on the development of SpA-Net and the roles of the stakeholders is described in online supplementary file 1. SpA-Net is registered in the Netherlands Trial Registry.

Content and design

In 2014 and 2015, rheumatologists (experts in the field of SpA), nurses and two experienced patient research partners were consulted on the design and content of SpA-Net. To ensure that SpA-Net would capture all domains essential for clinical record-keeping in SpA, a 'core set' was defined. Based on evidence from literature review and expert opinion, domains and instruments were selected from existing Assessment of SpondyloArthritis international Society/Outcome Measures in Rheumatology (ASAS/OMERACT) and Group for Research and Assessment of Psoriasis and Psoriatic Arthritis/OMERACT (GRAPPA/OMERACT) sets,[19 20] and several other disease-specific as well as generic domains and instruments were added. Also, indicators of quality of care and patient experience of care were included. In order to prevent abundant and unnecessary data collection, intervals were set per questionnaire (table 1). Whenever possible, use of free-text fields was avoided to allow for standardised and structured data capture.[12] Altogether, we aimed for an inclusive, efficient core set with domains that were relevant for daily practice (as opposed to research registries, which usually have extensive sets of questionnaires and are less efficient in daily practice). We further decided that aggregated data on quality indicators from participating centres should

Table 1 Domains, instruments and questionnaires included in SpA-Net

Domain	Reported by	Instrument	Interval (minimum)*
Demographic characteristics	Patient	Questionnaire (education, marital state, employment, alcohol, smoking)	1 year
Work, productivity	Patient	WPAI[41]	6 months
Quality of life, health state	Patient	SF-36,[42] EQ-5D,[43] ASAS Health Index[44]	1 month (SF-36), 6 months (EQ-5D, ASAS Health Index)
Physical function	Patient	BASFI,[45] HAQ-S[46]	6 months
Patient global	Patient	NRS (global disease activity last week)	1 month
Fatigue	Patient	Fatigue question of BASDAI[47]	Every visit
Pain	Patient	VAS	1 month
Experience with care	Patient	Modified PREM[48]	1 year
Medical history, comorbidity	Physician	NA	Updated every visit
Medication use	Physician	NA	Updated every visit
Adverse events	Physician, patient	NA	Updated every visit
SpA manifestations	Physician	Checklist: inflammatory back pain, peripheral arthritis, enthesitis, dactylitis, psoriasis, uveitis, IBD, elevated CRP, NSAID response, recent GI or urogenital infection, positive family history, sacroiliitis on X-ray/MRI, HLA-B27 status	Updated every visit
Disease activity	Physician, patient	ASDAS,[49] BASDAI,[47] CRP, ESR	Every visit
Physician global	Physician	VAS (disease activity)	Every visit
Spinal mobility	Physician	Chest expansion, occiput to wall, modified Schober, cervical rotation, lateral spinal flexion	On indication
Peripheral symptoms	Physician	SJC66, TJC68, presence and location of dactylitis, presence and location of enthesitis in 65 sites	Every visit
Skin/Nail involvement	Physician	Body surface area, presence of nail psoriasis	On indication
Laboratory results	Physician	Haemoglobin, white blood cell count, platelet count liver/renal function	On indication

*Minimum interval between assessments of the domain. Visits to the rheumatologist are not predefined, but scheduled according to the opinion of the care provider. Consequently, the interval between assessments of domains can vary among patients but will never be shorter than the minimum interval reported here.
ASAS, Assessment of SpondyloArthritis International Society; ASDAS, Ankylosing Spondylitis Disease Activity Score; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; BASFI, Bath Ankylosing Spondylitis Functional Index; CRP, C reactive protein; EQ-5D, EuroQoL-5D; ESR, erythrocyte sedimentation ratio; GI, gastrointestinal; HAQ-S, Health Assessment Questionnaire for Spondyloarthropathies; HLA-B27, human leucocyte antigen B27; IBD, inflammatory bowel disease;NA, not applicable; NRS, Numerical Rating Scale; NSAID, non-steroidal anti-inflammatory drug; PREM, patient-reported experience measure; SF-36, 36-Item Short Form Health Survey; SJC, swollen joint count; SpA, spondyloarthritis; TJC, tender joint count; VAS, Visual Analogue Scale; WPAI, Work Productivity and Activity Impairment.

become available in SpA-Net to gain insight into practice variation. As SpA-Net aimed to closely follow the patient in daily practice, we decided that visits to the rheumatologist using SpA-Net should not be according to a predefined schedule but instead left to the discretion of the care provider.

Technical development and infrastructure

The technical system behind SpA-Net was developed by Transparency in Healthcare (TiH, www.tihealthcare.nl) in 2015, specialised in the development of software for collecting and monitoring clinical and patient-reported data. The SpA-Net registry is incorporated within DREAM (Dutch Rheumatoid Arthritis Monitoring), a collaboration of Dutch rheumatology practices that aims to improve the quality of patient care, to provide transparency on treatment results and costs, and to produce data for scientific research. For the purpose of collecting, storing and using comprehensive data on patient outcomes, a web-based data acquisition and storage system was developed, which can be linked to, and integrated with, the EMRs of patients in local hospitals. Information on laboratory markers of inflammation can be extracted from the hospital information management system. Data storage and maintenance in SpA-Net meet all Dutch and European legal requirements, and is in line with regulations on the protection of personal data (NEN7510, ISO2700 and the EU General Data Protection Regulation).

Testing

After the initial development phase, SpA-Net was evaluated in a test environment during multiple rounds of internal and external testing in 2015 and 2016. These rounds were aimed at both improving different aspects of the system and bug-testing. Results from testing were reported monthly to the development team to ensure rapid cycles of improvement.

Implementation

After identification of barriers and facilitators for successful implementation, a multifaceted implementation strategy was developed.[21 22] SpA-Net was initially implemented into clinical practice in two centres, followed by an extension to other centres. Part of the implementation strategy was engaging those who have to record data.[23] To motivate rheumatologists and stimulate dynamic refinement of SpA-Net, staff meetings were organised every 2 months to evaluate the usability of SpA-Net in practice, discuss bugs encountered, demonstrate updated system features and provide feedback to care providers on the use of SpA-Net. After every meeting, feedback from staff was communicated to the development team. Care providers thus helped shape SpA-Net and embed it into clinical practice.

As part of the implementation strategy, patients were informed about SpA-Net on an individual basis during outpatient visits and accompanied by a demonstration of SpA-Net.

Usability and acceptability of SpA-Net

A usability and acceptability study was planned to evaluate satisfaction, accessibility and experiences with SpA-Net in clinical practice from the users' perspective (patients and care providers).

In November and December 2017, a sample of patients with SpA were recruited from the Maastricht University Medical Center to participate in focus group interviews (see online supplementary file 2 for a detailed description of the methodology). Interviews were planned with approximately five patients each, until data saturation was reached. Inclusion criteria were a clinical SpA diagnosis, age ≥18 years, at least two visits to the rheumatology clinic since implementation of SpA-Net and mastery of the Dutch language. Eligibility for inclusion was considered on a case-by-case basis, aiming for a sample that reflected the full spectrum of the SpA population. To prevent selection bias, patients did not have to actively participate in SpA-Net. Prior to the interviews, SpA-Net was briefly demonstrated to any patients in the focus groups that had no experience with the system. In semistructured focus group interviews, the accessibility and usability of SpA-Net, and whether patients perceived SpA-Net had an effect on disease understanding and on quality of care in daily practice, were assessed. In the same period, rheumatologists and nurses were interviewed in multiple group sessions on the usability of SpA-Net, the role of SpA-Net in (preparing) consultations and the perceived effect of SpA-Net on the quality of care.

Data analysis

Descriptive statistics were used to summarise the characteristics of the total population in SpA-Net and the participants in the focus group interviews. Patient interviews were audiotaped and transcribed verbatim. Using NVivo V.11 software, transcripts were coded and meaningful quotes were structurally classified into themes and subthemes for analysis (see online supplementary file 2).[24] All statistical analyses were performed using R V.3.1.4.

RESULTS

In order to serve its purpose as an integrated (tele)monitoring system, SpA-Net was designed and developed as a secure web page (http://www.mijnreumacentrum.nl) compatible with tablet devices. TiH provides technical support to care providers and patients.

Development: content

SpA-Net is meant to provide a comprehensive view of the patient. Domains captured by PROMs include disease activity, physical function, pain, global assessment of disease activity, work participation and HRQoL. These data are complemented with clinical measures on spinal mobility and peripheral joint involvement, physician's global assessment of disease, laboratory values and imaging data. In addition, demographic and socioeconomic status, medical history, comorbidities and

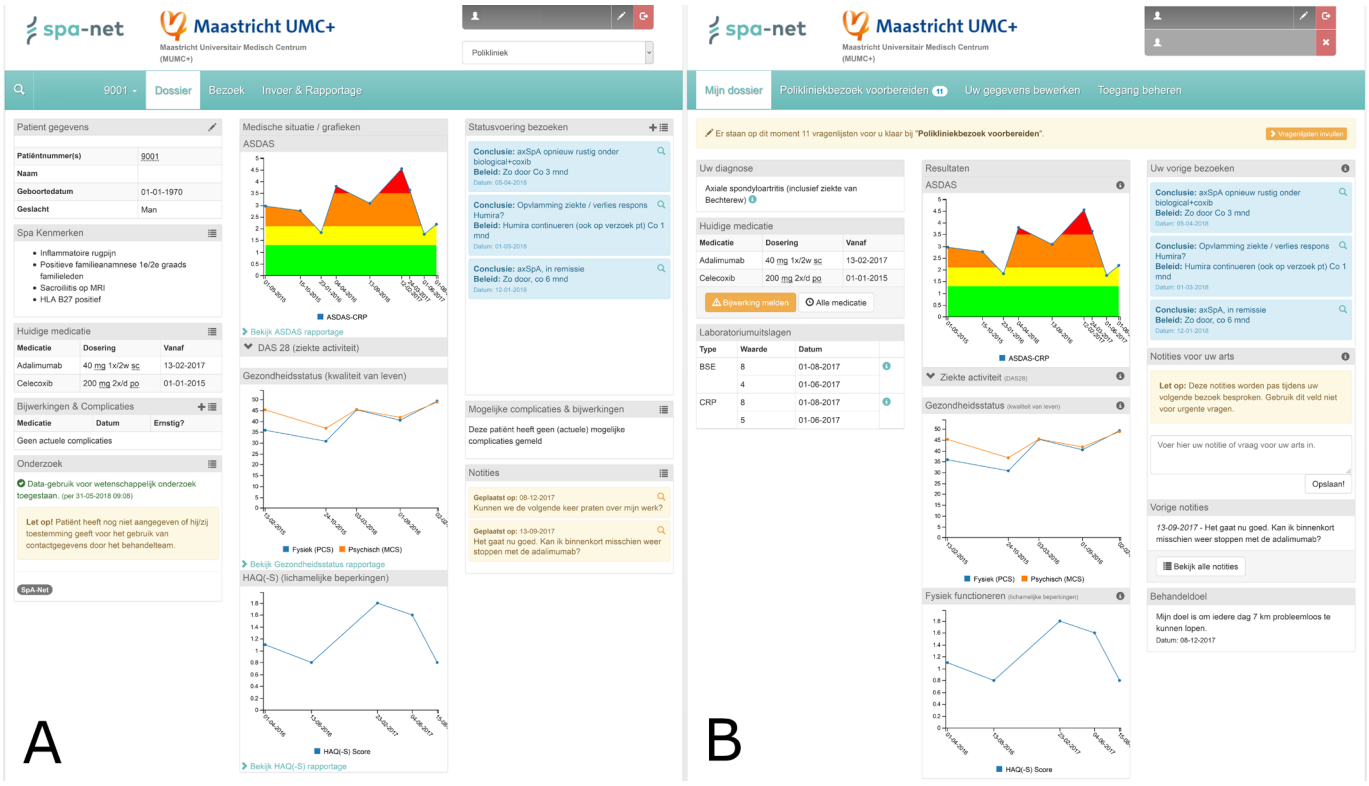

Figure 1 Side-by-side view of the care provider's dashboard (A) and the patient's dashboard (B) in SpA-Net. The care provider's dashboard (A) includes the patient's personal information, (past) presence of SpA features, current medication use, summary of most recent visits, patient's notes, and graphical representations of ASDAS, SF-36 and HAQ-S. The patient's dashboard (B) presents an excerpt of their EMR, which contains information regarding diagnosis, recent laboratory results, results from questionnaires, current medication and most recent outpatient visits. In addition, patients have the option to report possible side effects and can leave notes for their care provider. For patients, all items are accompanied by understandable explanations and information is presented in graphs whenever possible. ASDAS, Ankylosing Spondylitis Disease Activity Score; EMR, electronic medical record; HAQ-S, Health Assessment Questionnaire for Spondyloarthropathies; SF-36, 36-Item Short Form Health Survey; SpA, spondyloarthritis.

extra-articular manifestations, lifestyle factors, medication use, and adverse events are collected (table 1). Of note, data on all medications, prescribed for SpA or another condition, are collected. A patient-reported experience measure is included to assess patient experiences with care. Finally, individual treatment goals can be registered and monitored.

Development: design

SpA-Net was designed to replace the existing EMR for patients with SpA, thereby also avoiding double entry. For care providers, SpA-Net is split into three tabs: (1) Dashboard, (2) Visit and (3) Data Input & Reporting. The Dashboard provides an overview, and includes patients' personal information, presence of SpA features, current medication use, summary of recent visits, patients' notes and graphical representations (graphs) of disease activity, HRQoL and functioning (figure 1). The disease activity graph is colour-coded to aid quick interpretation, using the cut-offs as defined by ASAS (figure 2).[25] The Visit tab allows care providers to enter a new outpatient visit, and includes a selection of items relevant for clinical record-keeping, such as a manikin for joint involvement and enthesitis. These items are completed on indication. Adverse events are recorded for record-keeping, and are also automatically reported to the Netherlands Pharmacovigilance Centre (Lareb). The Data Input & Reporting tab includes all items of SpA-Net and can be used to complete missing items outside of visits. Besides these three tabs, there is an additional dashboard where care providers can access aggregated data on clinical indicators for quality improvement, comparing their centre with other centres (figure 3). Patients can also access SpA-Net (figure 1). After being introduced to SpA-Net, they receive a login and password. Two-factor verification is mandatory for all patients. For them, all clinical information is accompanied by clickable pop-ups with understandable explanations in lay language. The clinical information includes the diagnosis, a list of current and past medication, recent laboratory results, graphs of disease activity, HRQoL and functioning, and care provider's notes of recent outpatient visits. Patients can report possible side effects to medication and leave notes for their care provider, for example on topics they wish to discuss during their next visit. For urgent matters, such as serious suspected side effects, patients are explicitly instructed to contact the outpatient clinic by phone

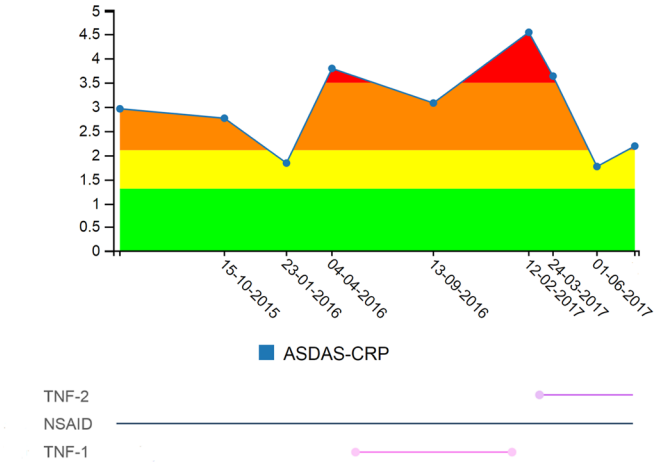

Figure 2 Graph in SpA-Net reporting the evolution of ASDAS in relation to medication use over time, care provider's perspective. In SpA-Net, detailed graphs of ASDAS (shown), SF-36 (not shown) and HAQ-S (not shown) are presented together with the patient's medication use over time. The ASDAS graph is colour-coded (traffic light, using the cut points as recommended by the ASAS) to aid quick interpretation. ASAS, Assessment of SpondyloArthritis international Society; ASDAS, Ankylosing Spondylitis Disease Activity Score; CRP, C reactive protein; HAQ-S, Health Assessment Questionnaire for Spondyloarthropathies; NSAID, non-steroidal anti-inflammatory drug; SF-36, 36-Item Short Form Health Survey; TNF, tumour necrosis factor.

or email. Questionnaires are available for the patient to complete prior to each consultation. In between visits, patients can complete questionnaires for self-monitoring, depending on the minimum interval (see table 1).

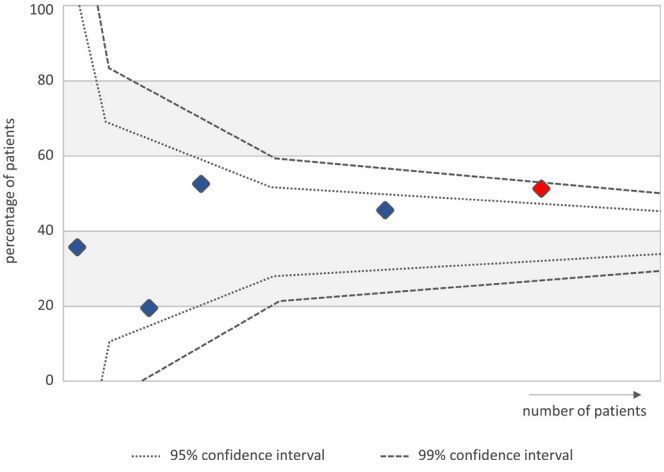

Figure 3 Example of graph of aggregated data on clinical indicators for quality improvement in SpA-Net, care provider's perspective. In order to stimulate performance evaluation and benchmarking, aggregated data on relevant clinical indicators of care are presented in a separate dashboard in SpA-Net. For illustrative purposes, an example is shown presenting the proportion of patients with an ASDAS <2.1 For the care provider's centre (red dot) in comparison with other participating centres (blue dots). ASDAS, Ankylosing Spondylitis Disease Activity Score.

Development: testing

A multitude of bugs and errors were encountered during 10 rounds of testing. These included error screens, incomplete questionnaires, errors in formulas used to calculate composite scores and accepting extreme values. All bugs and errors were fixed. The most recent version (V.1.11.0) of SpA-Net was launched in June 2018.

Development: implementation and use in practice

SpA-Net was launched into practice in May 2016 in two rheumatology centres. All rheumatologists and nurses were trained with a manual and practised in a test environment before use in practice. Use of SpA-Net was not mandatory for care providers in participating centres, but strongly encouraged through motivational interviewing and peer pressure. Some care providers quickly adopted SpA-Net, whereas others were more hesitant. Personal assistance for care providers was available, if needed.

Outpatients with a clinical diagnosis of SpA were consecutively included in SpA-Net and prospectively monitored. On inclusion, patients were educated on SpA-Net, received an information booklet and were instructed to prepare each visit by completing the PROMs in the week prior to the consultation date.

A number of additional actions were taken to increase participation in SpA-Net. First, a dedicated nurse was tasked with assisting those who need help with logging in or using SpA-Net. Second, we introduced a touch-screen tablet PC at the clinic, for those without internet access or who have forgotten to complete the questionnaires at home. Third, monthly open evenings were organised for patients with questions and general information meetings for patients twice a year. Of note, the open evenings had very low attendance, likely due to the availability of the dedicated nurse at the time of outpatient visits (a more feasible option for patients). Internal and external benchmarking is done annually and summarised results are published in an annual report.

Once SpA-Net was successfully implemented in the two initial adopting centres, steps were undertaken to increase awareness on SpA-Net among Dutch rheumatologists by presentations at the annual meeting of the Dutch Rheumatology Society, local hospital visits with demonstrations and written information in the Dutch Rheumatology journal. In February 2019, 1069 patients from five centres had been enrolled in SpA-Net (table 2), and inclusion is ongoing.

Usability and acceptability study

Accessibility, usability, satisfaction of use and experiences with SpA-Net in clinical practice from the perspective of both patients and care providers were assessed through focus group interviews and feedback meetings, respectively. Sixteen patients were interviewed (4 groups, 3–5 patients per interview), after which information saturation was reached. Included patients had axial, peripheral, or combined axial and peripheral SpA with or without concomitant psoriasis, inflammatory bowel disease and/

Table 2 Characteristics of patients included in SpA-Net as of February 2019

Variable	Total group (N=1069)	Completed, n (%)
Age, years	54.9 (14.1)	1069 (100.0)
Male, n (%)	560 (52.4)	1069 (100.0)
Symptom duration, years	16.0 (11.3)	528 (49.4)
HLA-B27-positive, n (%)	300 (46.2)	650 (60.8)
Diagnosis*		1069 (100.0)
Axial SpA, n (%)	339 (31.7)	
Peripheral SpA, n (%)	96 (9.0)	
Axial and peripheral SpA, n (%)	55 (5.1)	
Psoriatic arthritis, n (%)	510 (47.7)	
Reactive arthritis, n (%)	5 (0.5)	
IBD-associated arthritis, n (%)	28 (2.6)	
Undifferentiated SpA, n (%)	36 (3.4)	
ASDAS-CRP	2.3 (1.0)	500 (46.8)
BASDAI	4.3 (2.2)	640 (59.9)
BASFI	3.3 (2.5)	550 (51.4)
HAQ-S	0.7 (0.6)	465 (43.5)
VAS pain	3.9 (2.6)	706 (66.0)
Patient global	4.0 (2.6)	674 (63.0)
Physician global	1.6 (1.7)	693 (64.8)
SJC	0.5 (1.3)	606 (56.7)
TJC	1.1 (3.1)	606 (56.7)
SF-36-PCS	39.9 (10.0)	551 (51.5)
SF-36-MCS	48.8 (11.3)	549 (51.4)
EQ-5D	0.8 (0.2)	382 (35.7)
ASAS-HI	5.7 (3.4)	382 (35.7)
Medication use, current†		1021 (95.5)
NSAID, n (%)	554 (54.3)	
csDMARD, n (%)	418 (40.9)	
bDMARD, n (%)	391 (38.3)	
tsDMARD, n (%)	2 (0.2)	

Values expressed as mean (SD) unless stated otherwise. If a patient had multiple scores on an instrument, the first score since enrolment in SpA-Net was used.
*Clinical diagnosis as made by the rheumatologist.
†Percentages apply to population with registered medication. In 48 patients (4.5%), no medication was registered.
ASAS-HI, Assessment of SpondyloArthritis International Society Health Index; ASDAS, Ankylosing Spondylitis Disease Activity Score; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; BASFI, Bath Ankylosing Spondylitis Functional Index; bDMARD, biological disease-modifying antirheumatic drug; CRP, C reactive protein; csDMARD, conventional synthetic disease-modifying antirheumatic drug; EQ-5D, EuroQoL-5D; HAQ-S, Health Assessment Questionnaire for Spondyloarthropathies; HLA-B27, human leucocyte antigen B27; IBD, inflammatory bowel disease; MCS, Mental Component Summary; NSAID, non-steroidal anti-inflammatory drug; PCS, Physical Component Summary; SF-36, 36-Item Short Form Health Survey; SJC, swollen joint count; SpA, spondyloarthritis; TJC, tender joint count; tsDMARD, targeted synthetic disease-modifying antirheumatic drug; VAS, Visual Analogue Scale.

or anterior uveitis (table 3). Fifteen of these 16 patients (94%) had been introduced to SpA-Net before, and 8 (50%) considered themselves to actively and consistently use SpA-Net. Patients considered the layout of SpA-Net to be clear, well accessible and intuitive. They felt SpA-Net was a valuable addition to current care, and improved communication and patient involvement. Patients appreciated having access to their EMR with lay-term explanations. In addition, they valued the increased insight into their disease over time and the option to add notes. Points of improvement were the login process and providing insight into the conclusion and plan from the care provider after each visit. Patients not actively using SpA-Net did so because of either long-term stable disease or because they did not want to be occupied with their disease in their spare time. Of note, patients who were initially not enthusiastic about SpA-Net became interested when they learnt about the possibilities. A member check was carried out, and interviewed patients had no comments on the summarised results of the interviews.

Table 3 Characteristics of patients participating in the focus group interviews

Variable	Total group (N=16)
Age, years	62.6 (41–78)
Male, n (%)	6 (37.5)
Household composition	
Living alone, n (%)	2 (12.5)
Partner without children, n (%)	10 (62.5)
Partner with children, n (%)	3 (16.7)
Other family member(s), n (%)	1 (6.3)
Educational attainment	
Low, n (%)	3 (18.8)
Middle, n (%)	8 (50)
High, n (%)	5 (31.3)
Employment	
Full-time/part-time, n (%)	3 (16.7)
Retired/housekeeping/caregiver, n (%)	9 (50)
Unemployed, n (%)	2 (11.1)
Work disabled, n (%)	4 (22.2)
Smoking status	
Never, n (%)	7 (43.8)
Current, n (%)	3 (18.8)
Former, n (%)	6 (37.5)
Alcohol consumption, yes, n (%)	11 (68.8)
Phenotype	
Axial SpA, n (%)	5 (31.3)
Peripheral SpA, n (%)	5 (31.3)
Axial and peripheral SpA, n (%)	6 (37.5)
Symptom duration, years	17.5 (1–66)
Extra-articular manifestations	
Psoriasis, n (%)	7 (43.8)
Anterior uveitis, n (%)	4 (25.0)
Inflammatory bowel disease, n (%)	3 (18.8)
Any extra-articular manifestation, n (%)	11 (68.8)

Values expressed as median (range) unless stated otherwise.
SpA, spondyloarthritis.

Furthermore, seven rheumatologists, four residents in rheumatology and five nurses were interviewed during group meetings on the use of SpA-Net in daily practice. Care providers appreciated the additional information for (preparing) their consultations, the insight gained into the evolution of important outcomes such as disease activity and HRQoL over time in relation to medication use, and the ease of prescribing medication. Barriers against use were the initial time required to adopt the EMR, the number of 'clicks' and the quantity of data entry during consultations. Rheumatologists felt the latter could be at the expense of patient–clinician interaction, especially for patients who did not complete the questionnaires prior to their visit. Of note, rheumatologists supported by nurses during visits experienced less barriers when using SpA-Net. All remarks were converted into action plans for further improvement. During subsequent interviews, rheumatologists stated they used SpA-Net more frequently and consistently.

DISCUSSION

Here, we described the successful development and implementation in daily practice of an integrated eHealth system and quality registry for patients with SpA in the Netherlands. Both patients and care providers considered SpA-Net feasible and acceptable for use in clinical care.

Over the last two decades, a multitude of cohorts and registries have been developed for SpA. While patients registries can technically be considered to be cohorts, registries such as SpA-Net have an important advantage over typical cohort studies[23 26] as they provide a real-world view of all aspects of clinical practice and can be used to evaluate care as it is actually provided.[26] What sets SpA-Net apart from most existing registries is its full integration in daily care as an EMR, inclusion of all subtypes of SpA and the key role for the patient. In the Netherlands, SpA-Net is the first quality registry for all subtypes of SpA. Similar quality registries have been successfully operating in Denmark and Sweden.[27–29]

Increasingly, healthcare is shifting from physician-centred to patient-centred. Patients feel the need to be informed and involved.[30] PROMs are considered essential in patient-centred care. Sharing PROM results with patients in a comprehensible way can improve the patient's knowledge, communication and trust.[31] ePROMs have several advantages over paper-based assessments.[18] Remote collection of questionnaires is usually faster[32] and results in better data capture with less missings.[33] Furthermore, ePROMs are accepted, and even preferred, by patients with rheumatic disease in routine practice.[32 34 35] ePROMs and paper-based PROMs lead to comparable results in most studies.[36] SpA-Net combines these facets, by remote collection and presentation of PROMs over time in relation to the treatments provided, to the care provider and patient in an understandable way. Notwithstanding, it has yet to be shown whether regular collection of PROMs in daily practice really leads to improved outcome for the individual patient. Personalised monitoring systems such as SpA-Net will play a pivotal role in this regard.

As became evident during the current study, most patients who were interviewed appreciated SpA-Net, especially the way it improved communication, stimulated patient involvement and provided the opportunity to monitor their own health state. These findings are in line with previous studies on eHealth in rheumatology.[14 37] In a pretest–posttest study investigating an online portal in rheumatoid arthritis (RA), a relevant proportion of patients felt that using the web portal increased their involvement in disease management

(44%) and understanding of care providers' explanation (24%).[14] Another study supported the potential benefits of eHealth for quality of care, as the use of a newly developed, disease-specific eHealth system in patients with RA was associated with achieving low disease activity over time while at the same time maintaining patient satisfaction and improving physicians' productivity.[11]

SpA-Net was usable and acceptable in clinical practice. At the same time, several barriers were found. From the care provider's perspective, especially time constraints and burden of data entry during consultations were frequently reported. The burden of data registration is a factor that hinders how a quality registry can lead to quality improvement, as the time spent on data registration could instead be spent on other improvement efforts.[38] In this regard, integration in daily care is necessary.[15 16] By using SpA-Net as an EMR, data collection by care providers has become part of the standard clinical workflow. In order to further ease this burden for both care providers and patients, we strived towards a simple, yet comprehensive and intuitive system, and developed a core set of domains with a limited number of instruments. Also, the rheumatologists in this study reported that the burden of data entry decreased over time, and thus at least partly could be attributed to the initial transition period. Additionally, support by a dedicated nurse seemed to lower the burden for rheumatologists.

About half of the interviewed patients did not feel the need to actively use SpA-Net. These patients provided us insight into possible barriers to becoming an active user. Two previous studies showed that, if online access was provided, about half of the respondents accessed their EMR.[14 39] Reasons for not using the portal were lack of internet access, lack of spare time or not being interested. Furthermore, patients who are older, lower educated, have lower health literacy and/or lower computer literacy could be less likely to use eHealth systems such as SpA-Net.[14 33 34 39] It is essential that systems meant to assess and improve quality of care are inclusive, especially as those patients who are less likely to participate might be those who would benefit most from improvements in care delivery.[7] In 2017, 97% and 88% of Dutch residents aged 12 years or older and 65 years or older, respectively, had internet access.[40] With the support of a nurse, we strived to involve as many patients as possible in SpA-Net. It should be noted that currently no data on the actual usage of the system by patients are available, and a future study will address this.

In order to successfully implement and maintain integrated monitoring and quality managements systems, overcoming barriers of change is essential. Besides a strong commitment of both care providers and patients as discussed above, the social (culture, current practice), organisational (resources, support) and economical (financing of care) context are relevant.[21 22] For SpA-Net, a bottom-up approach was chosen, meaning that participation for centres is voluntary. The successful implementation of SpA-Net in both academic and general hospitals supports the transferability of this system within the Netherlands. As long as regular monitoring of outcome relevant to patients is not mandatory, full implementation of quality management systems will be difficult, if not impossible. Bundle payments, or payment for the care of a patient's medical condition across the entire care cycle, will stimulate implementation of quality management systems and acceptance of PROMs and other outcomes relevant to patients. In this regard, decreasing the administrative and reporting burden of process quality indicators to increase transparency on outcome could prove beneficial.[5] Systems such as SpA-Net will be necessary to capture those indicators relevant for high-quality care.

In conclusion, we developed and implemented an integrated eHealth system and quality registry (SpA-Net) for patients with SpA in the Netherlands. SpA-Net enables regular monitoring of patients with SpA and could help optimise knowledge and communication between patients and care providers, facilitate treatment decisions, stimulate patient empowerment, support VBHC and provide data for patient-centred research. Both patients and care providers considered SpA-Net a valuable addition to current care for SpA.

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REFERENCES

1. Boonen A, Brinkhuizen T, Landewe R, *et al*. Impact of ankylosing spondylitis on sick leave, presenteeism and unpaid productivity, and estimation of the societal cost. *Ann Rheum Dis* 2010;69:1123–8.
2. Strömbeck B, Englund M, Bremander A, *et al*. Cost of illness from the public payers' perspective in patients with ankylosing spondylitis in rheumatological care. *J Rheumatol* 2010;37:2348–55.
3. Castillo-Ortiz JD, Ramiro S, Landewé R, *et al*. Work outcome in patients with ankylosing spondylitis: results from a 12-year followup of an international study. *Arthritis Care Res* 2016;68:544–52.
4. El Miedany Y. Adopting patient-centered care in standard practice: PROMs moving toward disease-specific era. *Clin Exp Rheumatol* 2014;32.
5. Porter ME, Larsson S, Lee TH. Standardizing patient outcomes measurement. *N Engl J Med* 2016;374:504–6.
6. Locklear T, Miriovsky BJ, Willig JH, *et al*. Strategies for overcoming barriers to the implementation of patient-reported outcomes measures [cited 2018 March 3rd]. Available: https://www.nihcollaboratory.org/Products/Strategies-for-OvercomingBarriers-to-PROs.pdf
7. Smolen JS, Schöls M, Braun J, *et al*. Treating axial spondyloarthritis and peripheral spondyloarthritis, especially psoriatic arthritis, to target: 2017 update of recommendations by an international Task Force. *Ann Rheum Dis* 2018;77:3–17.
8. Porter ME, Teisberg EO. How physicians can change the future of health care. *JAMA* 2007;297:1103–11.
9. Porter ME. A strategy for health care reform--toward a value-based system. *N Engl J Med* 2009;361:109–12.
10. Wennberg JE. Time to tackle unwarranted variations in practice. *BMJ* 2011;342:d1513.
11. Newman ED, Lerch V, Billet J, *et al*. Improving the quality of care of patients with rheumatic disease using patient-centric electronic redesign software. *Arthritis Care Res* 2015;67:546–53.
12. Richter JG, Chehab G, Schneider M. Electronic health records in rheumatology: emphasis on automated scoring and additional use. *Clin Exp Rheumatol* 2016;34:S62–S68.
13. Coates LC. Implementing the findings of the TICOPA trial in clinical practice: challenges in implementation and how information technology can bridge the gap. *Clin Exp Rheumatol* 2016;34:S73–S74.
14. van der Vaart R, Drossaert CHC, Taal E, *et al*. Impact of patient-accessible electronic medical records in rheumatology: use, satisfaction and effects on empowerment among patients. *BMC Musculoskelet Disord* 2014;15.
15. Sokka T. Go, Go, GoTreatIT! *Clin Exp Rheumatol* 2016;34(5 Suppl 101):S91–S95.
16. Catarinella FS, Bos WH. Digital health assessment in rheumatology: current and future possibilities. *Clin Exp Rheumatol* 2016;34:S2–S4.
17. Sargious A, Lee SJ. Remote collection of questionnaires. *Clin Exp Rheumatol* 2014;32:S-168–172.
18. Kiltz U, Boonen A, Braun J, *et al*. Electronic assessment of disease activity and functioning in patients with axial spondyloarthritis: challenges and unmet needs. *Clin Exp Rheumatol* 2016;34:S57–S61.
19. Landewé R, van Tubergen A. Clinical tools to assess and monitor spondyloarthritis. *Curr Rheumatol Rep* 2015;17.
20. Gladman DD, Mease PJ, Strand V, *et al*. Consensus on a core set of domains for psoriatic arthritis. *J Rheumatol* 2007;34:1167–70.
21. Grol R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. *Med J Aust* 2004;180:S57–60.
22. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. *The Lancet* 2003;362:1225–30.
23. Gliklich R, Dreyer N, Leavy M. *Registries for Evaluating Patient Outcomes: A User's Guide. Two volumes.(Prepared by the Outcome DEcIDE Center [Outcome Sciences, Inc., a Quintiles company] under Contract No. 290 2005 00351 TO7.) AHRQ Publication No. 13 (14)-EHC111*. Rockville, MD: Agency for Healthcare Research and Quality, 2014.
24. Polit DF, Beck CT. *Essentials of nursing research: appraising evidence for nursing practice*. 7th ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins, 2010.
25. Machado P, Landewé R, Lie E, *et al*. Ankylosing spondylitis disease activity score (ASDAS): defining cut-off values for disease activity states and improvement scores. *Ann Rheum Dis* 2011;70:47–53.
26. Inman R, Sieper J. *Oxford textbook of axial spondyloarthritis*. First edition, 2016.
27. Eriksson JK, Askling J, Arkema EV. The Swedish rheumatology quality register: optimisation of rheumatic disease assessments using register-enriched data. *Clin Exp Rheumatol* 2014;32(5 Suppl 85):S-147–149.
28. de Thurah A, Stengaard-Pedersen K, Axelsen M, *et al*. Tele-Health followup strategy for tight control of disease activity in rheumatoid arthritis: results of a randomized controlled trial. *Arthritis Care Res* 2018;70:353–60.
29. Hetland ML. DANBIO: a nationwide registry of biological therapies in Denmark. *Clin Exp Rheumatol* 2005;23:S205–7.
30. Segan JD, Briggs AM, Chou L, *et al*. Patient-perceived health service needs in inflammatory arthritis: a systematic scoping review. *Semin Arthritis Rheum* 2018;47:765–77.
31. 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.
32. Salaffi F, Gasparini S, Ciapetti A, *et al*. Usability of an innovative and interactive electronic system for collection of patient-reported data in axial spondyloarthritis: comparison with the traditional paper-administered format. *Rheumatology* 2013;52:2062–70.
33. Wilson AS, Kitas GD, Carruthers DM, *et al*. Computerized information-gathering in specialist rheumatology clinics: an initial evaluation of an electronic version of the short form 36. *Rheumatology* 2002;41:268–73.
34. MacKenzie H, Thavaneswaran A, Chandran V, *et al*. Patient-reported outcome in psoriatic arthritis: a comparison of web-based versus paper-completed questionnaires. *J Rheumatol* 2011;38:2619–24.
35. 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.
36. Campbell N, Ali F, Finlay AY, *et al*. Equivalence of electronic and paper-based patient-reported outcome measures. *Qual Life Res* 2015;24:1949–61.
37. van der Vaart R, Drossaert CHC, Taal E, *et al*. Patient preferences for a hospital-based rheumatology interactive health communication application and factors associated with these preferences. *Rheumatology* 2011;50:1618–26.
38. Eldh AC, Fredriksson M, Halford C, *et al*. Facilitators and barriers to applying a national quality Registry for quality improvement in stroke care. *BMC Health Serv Res* 2014;14.
39. Koevoets R, de Glas NA, le Bourlout C, *et al*. Autonomous online health assessment Questionnaire registry in daily clinical practice. *Rheumatology* 2013;52:883–7.
40. . Internet: access, use and facilities [database on the Internet]. Central Bureau Statistics, StatLine [cited March 9th 2018]. Available: http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=83429NED&D1=0&D2=0,3-6&D3=0&D4=a&HD=180308-1235&STB=G1,G2,T,G3
41. Reilly MC, Gooch KL, Wong RL, *et al*. Validity, reliability and responsiveness of the work productivity and activity impairment questionnaire in ankylosing spondylitis. *Rheumatology* 2010;49:812–9.
42. Ware JE, Sherbourne CD. The mos 36-item short-form health Survey (SF-36). I. conceptual framework and item selection. *Med Care* 1992;30:473–83.
43. EuroQol G. EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199–208.
44. Kiltz U, van der Heijde D, Boonen A, *et al*. Development of a health index in patients with ankylosing spondylitis (ASAS HI): final result of a global initiative based on the ICF guided by ASAS. *Ann Rheum Dis* 2015;74:830–5.
45. Calin A, Garrett S, Whitelock H, *et al*. A new approach to defining functional ability in ankylosing spondylitis: the development of the bath ankylosing spondylitis functional Index. *J Rheumatol* 1994;21:2281–5.
46. Daltroy LH, Larson MG, Roberts NW, *et al*. A modification of the health assessment questionnaire for the spondyloarthropathies. *J Rheumatol* 1990;17:946–50.
47. Garrett S, Jenkinson T, Kennedy LG, *et al*. A new approach to defining disease status in ankylosing spondylitis: the bath ankylosing spondylitis disease activity index. *J Rheumatol* 1994;21:2286–91.
48. Bosworth A, Cox M, O'Brien A, *et al*. Development and validation of a patient reported experience measure (PREM) for patients with rheumatoid arthritis (rA) and other rheumatic conditions. *Curr Rheumatol Rev* 2015;11:1–7.
49. Lukas C, Landewé R, Sieper J, *et al*. Development of an ASAS-endorsed disease activity score (ASDAS) in patients with ankylosing spondylitis. *Ann Rheum Dis* 2009;68:18–24.