

Rheum4U: Development and testing of a web-based tool for improving the quality of care for patients with rheumatoid arthritis

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Abstract

Objective

To develop a web-based tool (Rheum4U) to capture clinically meaningful data to direct treatment. Rheum4U integrates longitudinal clinical data capture of rheumatoid arthritis (RA) disease activity measures and patient-reported outcomes measures (PROMs). This study tests the feasibility, acceptability and efficiency of Rheum4U among patients and health care providers.

Methods

Rheum4U was developed in two phases: P1 design and development; and P2 pilot testing. P1: A working group of rheumatologists and researchers (n=13) performed a prioritisation exercise to determine data elements to be included in the platform. The specifications were finalised and supplied to the platform developer. Alpha testing was performed to correct initial software bugs. 18 testers (physicians, nurses and recruited non-patient lay-testers) beta tested Rheum4U for usability. P2: Rheum4U was piloted in 2 rheumatology clinics and evaluated for feasibility, efficiency and acceptability using interviews, observation and questionnaires with patients and healthcare providers.

Results

110 RA patients, 9 rheumatologists and 9 allied health providers participated in the pilot. Mean patient age was 53 years and 74% were female. The majority (86%) were satisfied or very satisfied with online data entry and 79% preferred it to paper entry. Healthcare providers found Rheum4U easy and clear to use (90%), and they perceived that it improved their job performance (91%). Completeness and easy availability of the patient information improved clinic efficiency.

Conclusion

Rheum4U highlights the benefits of a web-based tool for clinical care, quality improvement and research in the clinic and this study provides valuable information to inform full platform implementation.

Key words

rheumatoid arthritis, outcome measures, quality of life, web-based tool

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Introduction

Rheumatoid arthritis (RA) affects nearly 1% of the population (1-3) and is one of the most common clinical presentations to academic rheumatology clinics. Current guidelines emphasise early and targeted treatment strategies characterised by frequent assessment of patient status including tender and swollen joint counts, measurement of inflammatory markers, and ideally calculation of composite measures of disease activity (e.g. the Disease activity score-28, DAS28, the Clinical Disease Activity Score, CDAI or the Simplified Disease Activity Score, SDAI) that incorporate patient assessment of global disease activity (4, 5). Treatment can then be intensified to ensure patients achieve low disease activity or remission states. Using this targeted approach to treatment, known as a “treat to target” or T2T, has been shown to improve patient outcomes including quality of life (6), reduction in disability (6-8) and reduced radiographic changes (7, 9). As T2T has been linked to improved patient outcomes, the process of documenting disease activity routinely is an established performance measure in rheumatology in healthcare systems in the United States (10) and Europe (11). Beyond disease activity, there are a number of patient-reported outcome measures (PROMs) that are important to document in RA (12, 13). Typically, documentation of functional status and disease activity are often only captured for those patients who require access to biologic medications and other advanced therapies. Furthermore, important outcomes including quality of life, fatigue and working status are rarely measured outside of research settings. Moreover, the capture of patient comorbidities and smoking status may be infrequent or inconsistent, also leading to potential for gaps in care for RA patients (14). To help address these gaps in documentation, an RA core dataset has recently been proposed (15, 16). The premise of recording a core dataset is to support clinical documentation and quality of care.

In Canada, over 70% of rheumatologists have electronic medical records (EMRs) (17); however, many EMRs

have not been constructed to monitor rheumatology PROMs electronically. Furthermore, many EMRs are not capable of tracking, trending or extracting information to aid in the monitoring of disease activity and clinical outcomes specific to rheumatology patients. Consequently, there is suboptimal collection of data, and monitoring the quality of care that is delivered is not feasible or efficient, relying on time consuming chart reviews and audits. As part of a programme of quality improvement at our tertiary care centre, investigators aimed to develop a web-based platform, called Rheum4U, for real-time collection of core data set elements in the rheumatology clinic. The objective of this study was to describe the development of the Rheum4U platform and the results of the pilot testing in patients with RA, evaluating the feasibility, acceptability and efficiency of the platform for use in day-to-day care.

Methods

The study consisted of two main phases: Phase 1 - the design and development of Rheum4U; and Phase 2 - pilot testing the web-based tool.

Phase 1: Design and development of the Rheum4U platform

A working group of members including clinical and research-based rheumatologists (n=13) from the Division of Rheumatology at the University of Calgary, active in research and quality improvement efforts, collaborated to determine the data elements to be included in the Rheum4U platform while considering the core dataset (15) and existing data collection in the clinics. The process of designing and developing Rheum4U entailed a number of stages that are summarised in Figure 1. In Stage 1, the working group performed a series of prioritisation exercises to determine the necessary data elements for inclusion in the platform, and finalised the data element specifications. As the platform was designed for everyday use in the clinic, elements were selected based on the need to collect them for point of care decision-making. Consideration was also given to elements that were important for monitoring quality of

care and long-term patient outcomes. The platform was developed by the Epidemiology Coordinating and Research (EPICORE) centre using Microsoft SQL Server for the database and Microsoft Visual Studio for the web-based forms. Following development of the platform, an iterative process of testing was then conducted before implementation of the platform in the clinic setting (Stage 2). In Stage 3, beta testing was completed by physicians, nurses and non-patient public members (n=18) to assess usability of the platform and feedback was evaluated and incorporated into the platform before implementation in clinic. After completion of preliminary platform testing, the research team conducted a series of meetings with the administrative, clinical and management staff to present the platform and seek input on the implementation process. The team performed 'dry runs' in the clinic setting to finalise the logistical procedures for implementation of Rheum4U at two rheumatology clinics (Phase 2).

Phase 2: Pilot Test Study

The objective of the pilot study was to test the feasibility, efficiency, and acceptability of online submission of data via tablet or desktop computer by patients, clinical staff, and clinicians at the two tertiary care rheumatology outpatient clinics. Both clinics are located in Calgary, Alberta, and affiliated with the University of Calgary: the Richmond Road Diagnostic and Treatment Centre (RRDTC) and the South Health Campus (SHC) rheumatology clinics.

Participants

A convenience sample of RA patients engaged in care at the participating rheumatology clinics was enrolled in the study between August 2016 and April 2017. Inclusion criteria were: 18 years or older with a confirmed or suspected diagnosis of RA; attending one of the two participating rheumatology clinics, able to speak and understand English, and willing to provide consent for study participation. While all RA patients completed the Rheum4U clinical and platform evaluation questionnaires, a sub-sample also consented to participate in interviews to obtain their

perspectives on the platform (see Appendix for interview guide).

Eighteen healthcare providers (9 rheumatologists and 9 allied health providers) participated in the pilot evaluation and 13 consented to formal interviews.

Recruitment process

The process for recruiting patients for the pilot study is shown in Appendix Figure 1. Eligible patients were recruited at the time of booking their clinical appointment by the administrative staff. Those who consented to participate were contacted by the research coordinator by email and provided a link to access the platform and complete the clinical forms one week prior to their appointment at home on a tablet or computer. If the patient was unable to complete the forms prior to their appointment, an iPad was available in the clinic waiting room to complete them at their appointment.

Instruments and data elements included in Rheum4U for clinical care

The following instruments and data elements were part of the Rheum4U platform and collected from patients participating in the pilot: Demographics (age, sex, ethnicity, total household income, highest level of education completed, marital status and postal code); Health History (including comorbidities, smoking status, marijuana and alcohol use); Clinical Health Assessment Questionnaire (CLINHAQ, including a patient global, pain, fatigue and sleep visual analogue scales, VAS) and Work Productivity and Activity Impairment (WPAI) (18, 19).

In addition to patient-reported data, healthcare providers recorded the following in Rheum4U: tender and swollen joint counts on a homunculus, diagnosis and date of diagnosis, physician global assessment on a 100-point visual analogue scale (VAS), and the rheumatology medications taken and recommended. The data captured by the nurses included: height, weight, and blood pressure, C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR). The DAS28 (both ESR and CRP versions) and CDAI scores were automatically calculated.

Evaluation of the feasibility, acceptability and efficiency of the Rheum4U platform

A number of approaches were used to assess the feasibility, acceptability and efficiency of the Rheum4U platform from the perspectives of patients and healthcare providers.

Feasibility: One to two research coordinators were present at all clinics where Rheum4U was being piloted and they observed patient and healthcare provider usage of the platform. The feasibility of online entry of data in the platform was assessed by documenting logistic system and/or platform issues identified during the pilot by participants.

Acceptability: Interviews with consenting patients and healthcare providers were semi-structured and conducted over 10–20 minutes. The interviews with patients took place after their clinical appointment or at a time more convenient to them. The healthcare provider interviews were either by phone or in person. Interviews were audio recorded and transcribed for analysis.

Questions were based on an interview guide that included three to five open-ended semi-structured questions about users' experiences with the platform developed to elicit participants' views on the feasibility, acceptability and efficiency of using the platform in clinic. In addition to the interviews, a Perceived Ease of Use (PEU) (20) questionnaire was collected from patients and healthcare providers following completion of clinical data entry into the platform. The PEU is a validated 6-item questionnaire rated on 7-point Likert scale that determines user acceptance of information technology (in this case Rheum4U). A 3-question satisfaction survey, with three 5-point Likert scale questions, was also collected from patients to determine acceptability of completing forms online. A Perceived Usefulness (PU) questionnaire (20) was completed by healthcare providers to assess the use of the platform in relation to enhanced job performance.

Finally, to evaluate efficiency, completion times were measured for the CLINHAQ on paper and the electronic version on Rheum4U with a convenience sample of 10 participants. As described

above, clinic flow was also observed by research coordinators and additional information on efficiency was captured during participant interviews.

Data analysis

The statistical package, Oracle SQL Developer 4.1.5.21, was used to conduct data analysis. Descriptive statistics were used to summarise baseline clinical features and survey results using proportions, means, standard deviation (SD) or medians and interquartile ranges (IQR), depending on data normality. Field notes and transcripts from the post-evaluation interviews with patients and healthcare providers were imported into NVivo 11 Pro for Windows, to facilitate qualitative analysis. Braun and Clarke's (21) method of thematic analysis was used to analyse the qualitative data, which was organised around the central themes of feasibility, acceptability and efficiency. Thematic analysis was also used to identify sub-themes.

Ethics

Patients individually consented to use of their data for research purposes. The project was approved by the University of Calgary Research Ethics Board (REB15-0628).

Results

During Phase 1 of the study, the Rheum4U platform was developed (Fig. 1) and preliminary testing was conducted. The elements included in the final platform are shown in Table I and a sample screenshot of the interface is shown in Figure 2.

Pilot testing Rheum4U - participant baseline characteristics

Demographic and clinical characteristics of patients are shown in Table II. There were 110 patients with a mean age of 53 (SD 14) years and 74% were female and 75% were of European ancestry. The median duration of disease was 5.7 (IQR 9.9) years. Just over a quarter of patients (26%) had a bachelor's degree and 26% had a college or non-university certificate or diploma, 17% had a high school certificate or equivalent and 8% had no certificate, diploma or degree.

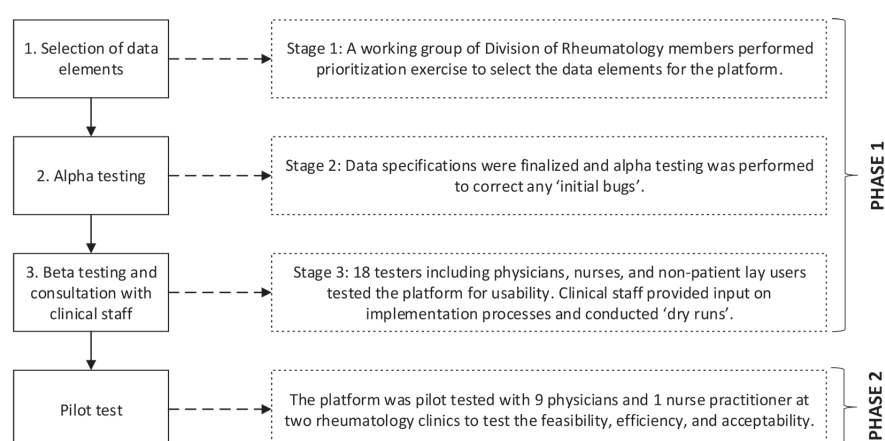


Fig. 1. Development process of Rheum4U platform.

Table I. Data elements selected for collection from each user group.

Patients	Physicians	Allied Health Professionals
Baseline demographics	Swollen and Tender Joint Count ^a	Physical assessment (height, weight, blood pressure)
Health history (including smoking status and alcohol use)	Diagnosis	ESR ^b
CLINHAQ ^c	Physician Global Assessment	CRP ^d
WPAI ^e (18, 19)	Medications	Medications

^aThe Disease Activity Score 28 (DAS28) and the Clinical Disease Activity Index (CDAI) were automatically calculated based on entered information.

^bErythrocyte sedimentation rate.

^cClinical Health Assessment Questionnaire.

^dC-reactive protein.

^eWPAI: Work Productivity and Activity Impairment Questionnaire.

Median baseline HAQ scores were 0.38 (IQR 1.13) and median DAS28-ESR scores were 2.31 (IQR 2.53).

Feasibility and ease of use

Patient and healthcare provider ratings of ease of use of the platform from the PEU questionnaire were universally high (See Tables III and IV), indicating that patients and healthcare providers felt that the platform was easy to use. Similarly, satisfaction scores (Table III) indicated that patients were very satisfied with completing their forms online (86%) and that they rated the online data entry somewhat better or much better than paper entry (79%). Patients also responded that they were generally very comfortable with using computer technology (89%).

The patients and healthcare providers found the platform easy to use; however, issues related to functionality and internet connectivity were identified

(see Appendix). A minor issue raised by some of the patients was that each page had to be saved before moving on and they felt this should be automatic. Another patient discovered the page justification was affected on the tablet layout. Providers requested some modifications to the formatting of the assessment page by having the physician global come after the homunculus and having an option for selecting that there were no tender/swollen joints. A major obstacle, identified in the sub-theme of internet connectivity, was poor connectivity at one site resulting in some unsaved forms and data loss.

Efficiency

The median time for 10 patients to complete the paper form of the CLIN-HAQ was 4 minutes 46 seconds. It was observed that some patients were called to have their vital signs taken resulting in a delay in paper form com-

Rheum4U

PATIENT ID: SHC-00006 VISIT DATE: 17-Aug-2016
HAQ: 2.250 Patient Global: 39

Clinical Diagnosis: Date of Diagnosis:

Clinical Diagnosis: Rheumatoid Arthritis Date of Diagnosis: 17-Aug-2016

Physician Global:

Height: cm Weight: kg BMI: kg/m²
B/P: / mmHg
☐ CRP and ESR results are not available
CRP: Last CRP Date:
ESR: Last ESR Date:

	Scale	Remission	Low/Minimal	Moderate	High/Severe	
DAS28 CRP:	3.28	0 - 0.4	< 2.6	≥ 2.6 to < 3.2	≥ 3.2 to ≤ 5.1	> 5.1
DAS28 ESR:	2.69	0 - 0.4	< 2.6	≥ 2.6 to < 3.2	≥ 3.2 to ≤ 5.1	> 5.1
CDAI:	18.4	0 - 78	≤ 2.8	> 2.8 to 10.0	> 10.0 to 22.0	> 22.0

Joint Count Type:

Swollen Joints: / 28 / 88
Tender Joints: / 28 / 88

Fig. 2. Rheum4U platform assessment page sample.

pletion. In one case, a patient did not fully complete the paper version of the CLINHAQ before being seen by the physician. In comparison, the median time taken for completion of the online CLINHAQ form for all those completing the electronic version of the form was 4 minutes 16 seconds. Over half of patients (69%) completed the forms up to the CLINHAQ form online prior to their clinic appointment date, and 31% completed the forms on the visit date. Patient and physician comments on the main theme of efficiency and sub-themes of form completeness and dual data entry are shown in the Appendix. Based on the interview data, patients expressed that they liked having the flexibility to complete the forms in advance of their clinic appointment and some perceived that it saved them time. They found the process more relaxing

to do at their leisure instead of being rushed to complete the standard paper forms in the waiting room. Physicians also felt that the information was more readily available and more complete, helping with the efficiency of the clinic appointments.

A major barrier identified from the healthcare perspective was in dual data entry for some variables. For example, medications may be entered by some physicians in an EMR and then re-entered into Rheum4U. Other physicians transferred HAQ and DAS28 scores from Rheum4U to their EMRs for clinical reporting.

Acceptability

Patient experiences with the acceptability of the platform were largely positive while healthcare provider experiences were more mixed and more

areas for improvement were identified. Interview comments under the theme of acceptability, the sub-themes of future functionality and integration, and medications are shown in the Appendix. Patients and providers expressed a desire to move away from paper charts and forms entirely and to better utilise electronic means to capture and view data. Physicians in particular wanted the platform integrated into the existing EMR with the ability to graph trends in patient status (*e.g.* disease activity, functional status).

Under the sub-theme of medications, patients wanted to be able to enter their own medications and healthcare providers indicated that patient entry would be educational for patients as well as time saving. Only common medications used in rheumatology are recorded in Rheum4U; some providers

Table II. Sociodemographic and clinical characteristics.

Sociodemographic and clinical characteristics	(n=110)
Gender	n (%)
Female	81 (74%)
Age	Mean (SD)
	53.0 (13.7)
^a Ethnicity	n (%)
European	83 (76%)
Non-European	38 (35%)
Education level	n (%)
No certificate, diploma or degree	9 (8%)
High school certificate or equivalent	19 (17%)
Apprenticeship or trades certificate or diploma or other	39 (35%)
Baccalaureate degree or higher	37 (34%)
Preferred not to say	6 (5%)
Income level	n (%)
\$5,000 - \$35,999	12 (11%)
\$36,000 - \$66,999	20 (18%)
\$67,000 - \$96,999	10 (9%)
\$97,000 +	28 (26%)
Preferred not to say	40 (36%)
RA disease characteristics	^b n, Median, IQR, range
RA disease duration (years)	108 ; 5.7; 7.8; 0.0–32.1
HAQ scores	0.38; 1.13; 0–2.75
^c DAS28 (ESR)	57; 2.31; 2.53; 0–6.95
DAS28 (CRP)	102; 2.46; 1.84; 1.21–6.38
^d CDAI scores	5.10; 12.00; 0–52.00

^aPatients could indicate more than one Ethnicity.

^bn is reported for measures with a denominator <110 (RA disease duration and DAS28 scores).

Note 3 patients out of 110 that were diagnosed with RA after their first study visit were excluded for disease duration calculation.

^cDAS28, 28-joint Disease Activity Score.

^dCDAI, Clinical Disease Activity Index.

suggested that all patient medications should be included.

Discussion

This study describes the development of the Rheum4U platform for collection of clinical characteristics and PROMs for monitoring the quality of care for patients with RA, and highlights two key findings. First, online data entry was feasible, efficient and acceptable to patients. Secondly, while the majority of healthcare providers concurred, some concerns were raised about dual connectivity with existing systems for charting.

Our findings of patient acceptability and ease of use of electronic data entry are in agreement with Greenwood *et al.* (22) who investigated the collection of patient self-administered outcome data using touch screens at an outpatient clinic including the HAQ, VAS scales for pain, fatigue and global arthritis activity and the Rheumatoid Arthritis Quality of Life (RAQoL) Questionnaire. Almost all of the patients (98%) rated the touch screens as very or quite easy compared to paper versions. Simi-

Table III. Perceived ease of use (20) of online completion and patient satisfaction.

Items		Respondents (%)						
		Extremely likely	Quite likely	Slightly likely	Neither	Slightly unlikely	Quite unlikely	Extremely unlikely
Learning to operate an iPad, tablet or computer to complete my/patient medical forms would be easy for me	*Patients	61	28	3	5	1	2	2
	*Healthcare providers	50	40	0	10	0	0	0
I would find it easy to get an iPad, tablet or computer to do what I want it to do to complete my/patient medical forms	Patients	70	20	4	3	1	1	2
	Healthcare providers	40	40	10	0	0	10	0
My interaction with an iPad, tablet or computer to complete my/patient medical forms would be clear and understandable	Patients	60	32	3	3	1	1	1
	Healthcare providers	60	20	10	10	0	0	0
I would find an iPad, tablet or computer to be flexible to interact with to complete my/patient medical forms	Patients	60	30	4	3	1	1	2
	Healthcare providers	40	30	20	0	0	10	0
It would be easy for me to become skillful at using an iPad, tablet or computer to complete my/patient medical forms	Patients	60	30	4	3	2	1	1
	Healthcare providers	50	40	10	0	0	0	0
I would find an iPad, tablet or computer easy to use to complete my/patient medical forms	Patients	61	31	4	2	1	1	1
	Healthcare providers	60	30	0	0	10	0	0
Satisfaction survey		Patient response (n=110)						
Satisfied or very satisfied with online form completion		86%						
Online data entry somewhat better or much better than paper entry		79%						
Comfortable or very comfortable with using computer technology generally		89%						

*Number of patient and healthcare providers completing the survey was 110 and 10, respectively.

Table IV. Healthcare providers perceived usefulness (20) of online form completion.

Items	Extremely likely	Quite likely	Slightly likely	Neither	Slightly unlikely	Quite unlikely	Extremely unlikely
Respondents % (n=11)							
Using an iPad, tablet or computer in my job to complete to patient medical forms would enable me to accomplish tasks more quickly	37	27	18	0	0	9	9
Using an iPad, tablet or computer to complete patient medical forms would improve my job performance	36	36	18	0	0	0	9
Using an iPad, tablet or computer to complete patient medical forms would improve my productivity	27	27	18	9	0	9	9
Using an iPad, tablet or computer to complete patient medical forms would improve my effectiveness on the job	27	45	9	0	0	9	9
Using an iPad, tablet or computer to complete patient medical forms would make it easier to do my job	27	45	0	9	0	9	9

lar acceptability of online entry of electronic entry of PROMs was found in other studies (23, 24), with high rates of willingness to complete the online version in the medical waiting room (96% compared with 73% at home) (23) with patients having a general preference to entering data electronically (23, 24).

Collecting and reviewing clinical data, including PROMs, are central to the T2T approach in aggressively treating RA disease activity (25). Additionally, visual feedback to clinicians and patients can help with patient education about disease status and trends (25). In a recent randomised trial of electronic PROMs (26), patient adherence to treatment was significantly higher in patients randomised to receiving a monthly electronic PROM questionnaire compared to those receiving monitoring only by physicians during clinical encounters.

Tracking PROMs electronically may also be associated with higher satisfaction of care for patients. In a multi-site randomised control trial with RA patients (n=1079) investigators evaluated the impact of electronic data capture on patient satisfaction and patient-physician interactions (27). Patients completed quarterly health questionnaires (including VAS scales, HAQ and Short Form-12 and a 57 joint self-assessment), and physicians completed a 28-joint assessment. The assessments were summarised in a “Health Tracker” report that was randomly generated for a subset of the cohort. Physicians reported significantly improved patient in-

teractions in both groups (health tracker viewers and non-viewers) but the magnitude was larger in the group viewing the summarised reports. After 1 year, the viewer group indicated they were more satisfied with their care compared to baseline ($p<0.001$), but the same was not observed in the non-viewing group ($p=0.131$) (27). A future direction of the Rheum4U platform is to develop dashboards for viewing data trends in clinic that are relevant to patients and clinicians, analogous to the “Health Tracker” platform. Additionally, we have incorporated a measure of patient experience and satisfaction with care into the platform since the pilot-testing.

The collection of PROMs is becoming increasingly important in healthcare, beyond the domain of research. Indeed, healthcare policy focuses on the effectiveness of healthcare, as measured by PROMs and patient experience (25). The advantages of computerised collection of PROMs include improved consistency, accuracy and completeness of data collection, immediate scoring, and ability to track key patient outcomes more easily over time. The PROMs that are collected in Rheum4U are important not only for day-to-day clinical monitoring, but in future will also be useful for clinical studies including health economic analyses, quality of care studies, phenotyping for genomics work and pragmatic clinical trials. The Rheum4U PROMs are similar to those collected in clinical research, as evidenced by a recent systematic review of PROMs (28). One exception is

health related quality of life. Since the completion of pilot testing, a standardised measure of health-related quality of life, the EQ-5D-5L (29), has been added to the platform using a validated and approved online version.

The challenges of collecting PROMs electronically have been highlighted in other studies and are summarised by El Miedany (25) and include time, resources for implementation, validity concerns, and interpretation. The physicians and healthcare providers were most concerned about their workload in either transferring some of the data (*e.g.* HAQ, DAS28) to their clinical record or adding additional data on medications to the platform. We hope to obviate this issue in future by integrating Rheum4U into standard care practices to eliminate duplicate entry for research. A future study is planned to examine how Rheum4U data are used in clinical decision-making at the point of care and how the use of the data impacts patient outcomes. One area that was identified to increase utility of the platform and healthcare provider platform use is the addition of a page to help facilitate renewal of insurance coverage for biologic agents. Additionally, as discussed above, developing clinical dashboards to track and trend PROMs and disease activity is anticipated to increase provider uptake.

An additional limitation of our study is that we did not assess the correlation between paper and electronic results. However, this has been evaluated in a number of studies for PROMs including

the HAQ and VAS pain and global assessment scales and strong correlations between the computer and paper-based versions have been found (24, 30-33). Ideally PROMs, disease activity, and comorbidities should be collected routinely on RA patients to guide T2T care; however, this is often inconsistently done in routine clinical practice. A major barrier in many centres to data collection is the electronic means to do so. While some EMRs contain rheumatology-specific tools such as homunculi and PROMs, unfortunately many still do not, including the EMR in our own academic tertiary care centre. This necessitated the development of Rheum4U. While the present study has shown that the collection of PROMs and clinical data using Rheum4U is feasible, acceptable and efficient to healthcare providers and patients, further work is ongoing to continuously improve the platform and develop tools to increase usability and day-to-day clinical utility.

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