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Rheumatology Letters to the Editor (Other)

Capturing remote disease activity – results of a twelve-month clinical pilot of a smartphone app in NHS rheumatology clinics in Bristol

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Key Message:

Long-term smartphone-based remote disease activity reporting is feasible in routine practice without additional clinical resource

Dear Editor,

We read with interest the recently published work by Lynn Austin and colleagues reporting the results of the REMORA study (1). We agree with the findings of the work and the robust methodology of the work that they undertook. In their conclusions Austin et al state “Patient engagement was strong throughout the 3 months, but it is unknown to what extent patients would continue to enter daily data over longer periods of time”.

We have recently completed a twelve-month clinical pilot of a smartphone app in our rheumatology service in Bristol and report our experiences of offering a commercially available smartphone-based, cloud-enabled patient symptom diary to patients as part of a routine NHS rheumatology clinic over twelve-months. Our objectives were to: (i) examine the proportion of patients within the rheumatology clinic who have access to technology allowing access to the service, (ii) identify the level of interest in such a service; (iii) examine the persistence and frequency of app use over time in the normal clinical environment; (iv) observe if longitudinal trends in disease activity could be identified at a patient-level.

Patients with a clinical diagnosis of inflammatory arthritis attending routine rheumatology clinics were offered the opportunity to use a smartphone app (Living With Rheumatoid Arthritis™) to record their disease activity between hospital appointments. Patients who might be interested in using the app were identified by their treating clinician during their consultation. They had to have a smartphone (Android or iOS) and email address to be able to use the service and were given a verbal description of the download/installation process. Detailed download instructions and a hyperlink to the app were included in the invitation email. If requested, a postcard aide memoire with download/log in details was available. Patients were invited to complete a RAPID3 questionnaire on a weekly basis using their smartphone and received a pop-up reminder on their home-screen to submit their data. If no data was entered, a further reminder notification to their smartphone home screen was

issued. (2) Data was stored locally on the smartphone and transferred to a secure cloud database portal which authorised clinicians could access using a web browser. Data were not used to alter access to rheumatology services. Patients were told that their data would only be reviewed during their consultations unless the clinical team were specifically asked to review the data between appointments. Patients were advised to let their clinician know during their consultation if they were using the app. Clinicians then viewed the data during the consultation via the clinical portal and data were used to enrich and facilitate history taking in consultations. No formal data were collected regarding clinician access or use of the data in clinics. Patient-level data could be viewed in graphical and tabular format via the clinical portal (Figure 1).

To evaluate equity of access, we undertook a separate paper-based survey of patients attending routine rheumatology clinics which asked: “Do you have a smartphone or tablet device that can run ‘apps’?” and “Do you have an email address?”. Over a period of three weeks, unselected patients were given the survey in the waiting room and returned it to clinic support staff once completed.

Data were collected on the number of patients invited to use the service, downloaded the app, number who actively used the app to record their disease activity and the RAPID3 scores over a twelve-month period from July 2018 to July 2019. Patients were recruited at any time during this twelve-month period, and so each had a variable length of time during which they were able to record data.

Ethical approval was not required as this was not a research study. The smartphone app is NHS Data Security and Protection Toolkit compliant (ODS Code 8JP33), adheres to GDPR regulations and institutional information governance approval was granted.

54 patients were surveyed. The mean age was 54 years (range 17 - 86), 34 (70%) were female and 47 (87%) patients had a smartphone and email. Seven (13%) and three patients (6%) reported not having access to a smartphone or email respectively. The mean age of patients with a smartphone and email address was 55 years, compared with 64 years for those

patients who did not have a smartphone, and 66 years for those who did not have an email address.

141 patients were invited to use the app, 89 patients (63%) downloaded it, and 58 patients (41%) used it to record their disease activity. These patients had a mean age of 53 and were 76% female. 35 patients had rheumatoid arthritis, 15 patients had psoriatic arthritis and 8 had another inflammatory arthritis.

Of the 58 patients who used the app at least once, the median number of RAPID3 scores completed per patient was 8 (interquartile range 3 – 17) with a median of 1 RAPID3 scores submitted per patient month (interquartile range 1 – 3). 53 of 58 patients had been enrolled for more than three months, and of these 43 (81%) continued to submit data after three months. Granular data of long-term user engagement over the year is shown in Figure 2. A total of 706 RAPID3 scores were submitted over the 12 months. The mean RAPID3 score was 12 (range 0 – 27).

This pilot demonstrates the feasibility of remote reporting of disease activity in routine practice. Most patients have the technology to participate and individual profiles of disease activity could help improve and expedite clinical history taking within the outpatient clinic and facilitate non-face-to-face interactions (Figure 1). After initial high non-uptake (37%), most patients (65%) that downloaded the app used it.

This clinical pilot is important as it shows an appetite for such technology amongst rheumatology patients outside of the research setting. Research studies often have high user engagement, but are often of short duration and select a motivated group of patients, meaning translation of these data to the real-world clinical setting can be challenging.(1) Clinical pilots such as ours offer useful insights into the real-world use of these technologies. Use of the app in our pilot did not afford additional benefits for patients in terms of access to service, so our findings show that there is a genuine and persistent interest in using such technology without incentivisation. The next steps are to embed the technology to personalise outpatient experiences for patients and facilitate more efficient use of non-face-to-face follow-up approaches.(3)

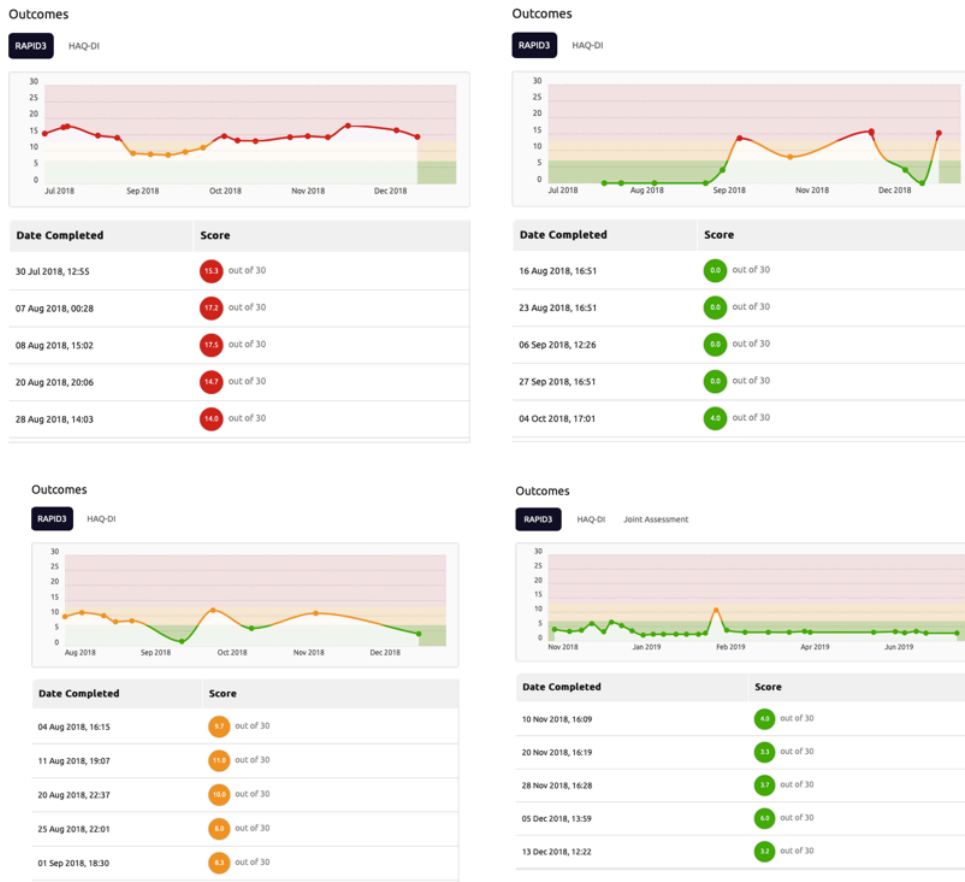


Figure 1. Example profiles of disease activity over time from patients using the app to record their disease activity

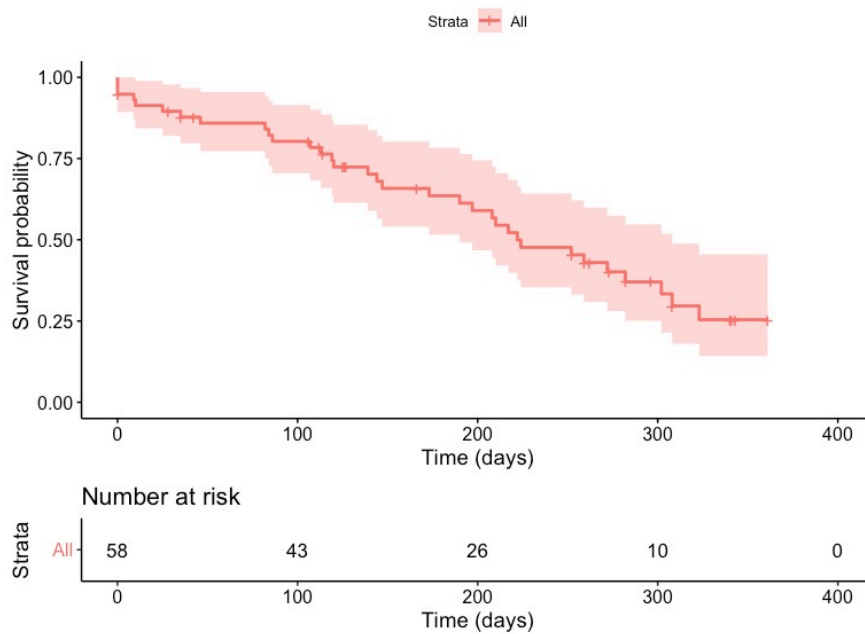


Figure 2. Kaplan-Meier curve demonstrating long term patient engagement with the app. Tick-marks represent censored data for patients who continued to use the app within one-month of the censor date of 27th July 2019. 95% confidence interval is represented by the shaded area. The number of patients and duration enrolled is shown in the “number at risk” insert.

Conflicts of interest

PH has provided consultancy for and has an options and limited royalty agreement with, Living With Ltd. software company for the development of the smartphone application described in this manuscript.

None of the other authors declare any conflict of interest.

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