

Research article

Physical activity in ankylosing spondylitis: evaluation and analysis of an eHealth tool

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ABSTRACT

Background Ankylosing spondylitis (AS) is a chronic inflammatory condition characterised by spinal arthritis and exercise is often recommended to reduce the symptoms and improve mobility. However, very little evidence exists for the value of exercise in AS.

Objectives Firstly, this pilot study aimed to evaluate an eHealth tool, the AS Observer, specifically designed to monitor symptoms, quality of life and physical activity in AS, in terms of patient experience and suitability in generating data for epidemiological studies. Secondly, it also investigated the collected data to determine if physical activity benefited individuals with AS.

Methods The AS Observer was designed to enable weekly monitoring of AS symptoms and exercise using a web based platform. Participants with AS ($n = 223$) were recruited to use the AS observer. They provided baseline data and completed online weekly data entry for 12 weeks (e.g. Bath Ankylosing Spondylitis Activity Index (BASDAI), howRu, International Physical Activity Questionnaire (IPAQ)). Panel data analysis with fixed effects models investigated associations between variables. Activity type data and exit questionnaires were subjected to qualitative thematic analysis.

Results In general, the AS Observer was well received and considered useful by participants, with 66% providing a positive response. The collected data suggested that IPAQ is inversely associated with total BASDAI, stiffness, tenderness and pain, but not fatigue. Stratified analysis demonstrated differential associations between BASDAI, IPAQ and howRU based on sex, HLA-B27 status and disease duration. Approximately half of the participants frequently did therapy and three-quarters undertook at least some vigorous activity ranging from formal exercise to recreation and (house) work. Despite some technical challenges, tool evaluation suggested that the AS Observer was a useful self-monitoring tool for participants.

Conclusions This pilot study demonstrated that increased exercise intensity and duration were associated with an improved BASDAI symptom score in a cohort of participants with AS. Furthermore, it provided further evidence of the value of using eHealth tools for clinical purposes and data collection for research, inclusive of the development of treatment pathways and disease management strategies.

Keywords: Ankylosing spondylitis, AS Observer, BASDAI, eHealth tool, physical activity

INTRODUCTION

Ankylosing spondylitis (AS), which is the prototype of the seronegative spondyloarthropies, is an inflammatory condition characterised by spinal arthritis and associated conditions such as uveitis and Crohn's disease.¹ The prevalence of AS is reported as 0.24% in Europe² and 0.27% in the UK. AS is a chronic inflammatory condition with a heavy burden of disease³ that includes sacroiliitis, spinal fusion, peripheral arthritis and a range of extra-articular manifestations,⁴ ultimately leading to impacts upon mobility, societal functioning, mental health and elevated mortality.⁵ Understanding of AS aetiology and pathogenesis is still limited. However, hereditary polygenic characteristics have been recognised, most notably the association with Human Leukocyte Antigen gene (*HLA-B27*),⁶ which is often used within diagnosis criteria.⁷

Exercise and physiotherapy are commonly used in managing AS to maintain spinal mobility, reduce pain and support mental health. Studies have shown a positive correlation between the amount of exercise and improvement of symptoms, spinal movement, flexibility and strength during individual and supervised exercise programmes (including physiotherapy) for a duration of between two and six months.^{8,9} However, a recent systematic review undertaken to support recommendations for the management of AS noted that despite these positive findings 'the small numbers of participants, the heterogeneity of the interventions and outcome measures, and deficiency in reporting data result in wide intervals and lack of strong evidence',¹⁰ eHealth, which is the use of information and communication technologies to investigate health, may provide solutions to address concerns raised by the systematic review. Mobile phone applications and websites are increasingly being utilised to allow patients to monitor their condition and other aspects of their lives on a daily basis, thus generating large longitudinal datasets for analysis and therefore improving our understanding of particular conditions. The availability of self-assessment technology is increasing and as eHealth accessibility is improving, prevention, treatment and health maintenance is becoming personalised and patient tailored.¹¹ Studies show that there has been an upward trend in using the internet for health-related purposes¹² and that small studies with a direct focus improve the efficacy and accuracy of clinical support for long-term conditions.¹³

This pilot study aimed to determine whether the AS Observer (<https://asobserver.wordpress.com/home/>), a specially developed online tool, was suitable to monitor the symptoms, health-related quality of life and physical activity of participants with AS. The study also utilised the data collected to investigate whether physical activity influenced the symptoms and quality of life of individuals with AS.

METHODS

The online AS Observer tool, a web-based participant engagement interface, was developed in collaboration with myClinicalOutcomes Ltd (mCO; <http://www.myclinicaloutcomes.com>).

The mCO system is designed to support real-life clinical workflows by collecting core clinical metrics at timely intervals along the diagnosis and treatment pathway, displaying this data on tailored patient and clinician interfaces.¹⁴ This was modified to produce the AS Observer module, with the clinician interface replaced with a researcher dashboard enabling the research team to login and investigate some basic summary statistics during the 12-week data collection phase.

Participants meeting the inclusion criteria (aged 18+, diagnosed with AS, U.K. resident and with computer access) were invited to participate via email (with assistance from the National Ankylosing Spondylitis Society; NASS) and social media (e.g. AS forums). They were directed to the project website (<https://asobserver.wordpress.com/home/>) where information on project goals, ethical information and how to participate was available.

Registration and baseline data

At registration, consenting participants were allocated a unique identifier code and baseline data (e.g. sex, date of birth, year of diagnosis, body mass index (BMI), smoking status (never, former and current), disease severity proxies (i.e. HLA-B27 status, frequency of attendance at rheumatology clinic and current medications) and comorbidities (using Department of Health standardised question set) were collected¹⁵ using the patient interface of the mCO system (Figure 1).

Weekly question set

Data was collected for 12 weeks from 15 September to 7 December 2014. Weekly email reminders were sent to participants requesting them to fill out three assessments on the patient interface. These assessments included the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) as a measure of current disease activity (Figure 2),¹⁶ health-related quality of life was monitored via howRu (<http://www.r-outcomes.com>; four components: pain or discomfort, feeling low or worried, limited in what you can do and require help from others) and physical activity via the validated short form of the International Physical Activity Questionnaire (IPAQ; <http://www.ipaq.ki.se/ipaq.htm>), which assesses physical activity frequency, intensity and duration. The howRu questions have better readability statistics and a similar overall performance when based on a single point in time compared with the longer SF12¹⁷ and EQ-5D.¹⁸ Additionally, an open text question was added to the IPAQ to capture the different activity types patients were undertaking.

Total Metabolic Equivalent of Task (MET) minutes of exercise per week variable (which was subsequently log transformed) and IPAQ categories (low, moderate or high intensity exercise) were calculated following the IPAQ scoring protocols.¹⁹ A binary vigorous activity variable was also derived looking at participants who had done more than 1 hour of vigorous activity per week.²⁰

MY CLINICAL OUTCOMES

1 ABOUT YOU 2 HOSPITAL AND 3 ADDITIONAL 4 CHECK
DETAILS DETAILS

Where are you receiving treatment?

Hospital / clinic ?
Please select 'Not listed, don't have one OR not sure right now' if necessary

About your Ankylosing Spondylitis and treatment

Type -- Please select --

About your Main current treatment for AS

Main treatment -- Please select --

If you receive any other treatments for AS click 'Add another treatment' to tell us about them

ADD ANOTHER TREATMENT

< BACK NEXT >

ANKYLOSING SPONDYLITIS

OBSERVER

MY CLINICAL OUTCOMES

1 ABOUT YOU 2 HOSPITAL AND 3 ADDITIONAL 4 CHECK
TREATMENT DETAILS

These final questions will help risk-adjust the outcomes information you enter.

What year was your Ankylosing Spondylitis (AS) first diagnosed?

Who diagnosed your AS? -- Please select --

How frequently do you see a rheumatologist / attend a rheumatology clinic? -- Please select --

Do you smoke? -- Please select --

< BACK NEXT >

ANKYLOSING SPONDYLITIS

OBSERVER

Figure 1 Screenshots of the my clinical outcomes web-based tool for monitoring ankylosing spondylitis and physical activity

MY CLINICAL OUTCOMES

BATH ANKYLOSING SPONDYLITIS DISEASE ACTIVITY INDEX (BASDAI) IPAQ HOWRU SCORE CO-MORBIDITY QUESTIONS

ANKYLOSING SPONDYLITIS (HLA B27 UNKNOWN) ASSESSMENT

Check the area below when you log back in - further scores will be added to provide a more detailed picture of your overall health.

BATH ANKYLOSING SPONDYLITIS DISEASE ACTIVITY INDEX (BASDAI)

This question set assesses your recent levels of pain or discomfort and disease activity over the last 7 days

PLEASE INDICATE YOUR LEVEL OF ABILITY WITH EACH OF THE FOLLOWING ACTIVITIES DURING THE PAST WEEK.

How would you describe the overall level of fatigue/tiredness you have experienced?

↓

NONE 0 1 2 3 4 5 6 7 8 9 10 VERY SEVERE

ANKYLOSING SPONDYLITIS

OBSERVER

Figure 2 Screen shot of the patient interface for weekly reporting of the symptoms of AS (using the BASDAI score), health and wellbeing (using howRu) and physical activity (using IPAQ)

Tool evaluation

To facilitate evaluation of the eHealth tool any comments on the website or contact with the help desk were recorded. Additionally, all participants including those withdrawing before the end of the study received a set of exit questions to ascertain the validity and usability of the AS observer (Table S1). The answers to these questions were investigated using qualitative techniques. Coding frameworks were developed by utilising thematic analysis with an inductive content analysis approach on manifest content. This consisted of rounds of data familiarisation, open coding, theme construction, abstraction and interpretation²¹ and allowed identification of similarities in data and the development of thematic patterns.²² Where appropriate, counts were performed on the number of participants whose responses aligned with each code.

Statistical analysis – physical activity and AS

All statistical analysis utilised a panel data analysis approach and the 'xt' suite of functions in Stata V13.1. Descriptive statistics were generated for demographic characteristics of participants. Associations between categorical demographic characteristics and total mean BASDAI score (0–10) were ascertained using regression analyses. Fixed effect (FE) regression models investigated associations between BASDAI (and its individual components, i.e. fatigue, pain, stiffness and tenderness) and physical activity measures (IPAQ – continuous and categorical, 1 hour of vigorous activity). The FE models reduce bias by removing the effect of time invariant variables (e.g. demographics). Regression models were therefore only adjusted for confounding variables that altered weekly (e.g. howRu, physical activity or BASDAI). The association between howRu and total BASDAI or physical activity were assessed using FE regression models.

Stratified analyses were performed on sex, HLA-B27 status and disease duration (0–10; 11+ years). Following qualitative analysis of activity type, some stratified analyses were performed investigating a number of themes including gardening, team sports and housework.

A sensitivity analysis was also performed investigating associations only in participants that had completed at least 6 weeks of data.

RESULTS AND DISCUSSION

In this pilot study, 223 individuals were recruited and on average this cohort was 50 years old, which had been diagnosed 17 years ago, and of those who knew their HLA-B27 status 81% were positive (Table 1). At least half of participants could be considered to have active AS requiring management (52% attended a clinic at least twice a year and 38% were using anti-TNF α therapies). The majority of participants had comorbidities (75%), including chronic back pain, sciatica or osteoporosis (45%), cardiovascular problems (43%) and stomach or bowel problems (40%). The mean BASDAI, howRu score

and IPAQ MET minutes reported over the 12-week period are summarised in Table 1.

Associations between demographic characteristics and BASDAI (Table 2) were generally as expected, with significantly elevated BASDAI scores observed in those with higher BMIs and those with more frequent rheumatology clinic visits or high numbers of comorbidities.²³ Medication use did not correlate with levels of disease activity, except for patients using steroids who had the highest mean BASDAI (5.20 ± 2.15).

Physical activity, BASDAI and mental health

Higher physical activity levels were significantly associated with lower BASDAI even when adjusting for howRu (Table 3 and Figure 3). This supports previous studies where exercise or active lifestyles (even if formal exercise was minimal) have supported the management of AS.²⁴ At least 1 hour of vigorous activity per week also lowered disease activity to below the clinical cutoff BASDAI 4 indicating the need for treatment review (mean BASDAI = 3.31 ± 2.07 versus 4.3 ± 2.17). Analysis of the individual components of BASDAI suggested that physical activity benefited pain, stiffness and tenderness, but not fatigue (Table 3). This contrasts with previous reports,²⁵ where physical activity did improve fatigue levels. The association with peripheral and axial pain and activity was lost when adjusting the models for the howRu score, thus demonstrating the importance that mental health plays in the experience of pain.²⁶

Health-related quality of life scores were very strongly inversely associated with BASDAI (Figure 4). A one-unit increase in the total howRu score was associated with a 0.56 (95%CI 0.50, 0.62, $P < 0.001$) reduction in the BASDAI score. Increased physical activity was associated with improved overall quality of life (Figure 5) and less pain, even when adjusted for BASDAI (Table 4). This fits with previous research where quality of life was found to very strongly associate with self-reported disease activity,²⁷ and physical activity was noted to improve mental health.²⁶ These findings may indicate that undertaking physical activity even during periods of higher disease activity is beneficial especially for quality of life.

Interestingly, physical activity did not affect the feeling of dependency (Table 4). This may be due to the longer term effects of living with AS, including concerns around the future,²⁸ impacting an individual's perception of their independence regardless of whether their view of how capable they are changes.

Types of physical activity

Qualitative data analysis on activity types resulted in the generation of a coding framework consisting of five themes, which applied across all activity intensities: exercise, recreation / hobbies, household (or work) activities, care activities, none and an 'uncategorised' for unsuitable listings. For each activity, intensity-level codes were generated within each theme and the range of formal exercise listed was extensive. The most frequently noted categories across moderate and vigorous levels were biking = running/walking > therapy > water-based

sports > gym > land exercise classes > calisthenics > racquet games > ball games > contact sports (Table S2). Solo activities far outweighed team activities and this may reflect the variable nature of AS. Solo activities tend to require less planning

and prior commitment, and therefore individuals can choose to partake depending on their daily wellness. Additionally, it may reflect feelings of confidence in abilities due to the noncompetitive nature of solo activities.^{28,29}

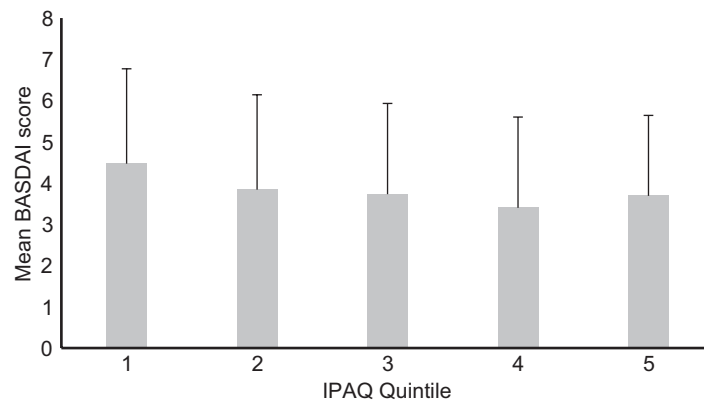


Figure 3 Bar chart showing the change in BASDAI score per quintile of IPAQ. There was an inverse relationship between the two with more exercise resulting in a lower BASDAI score. This was shown to be statistically significant in linear regression models (Table 3)

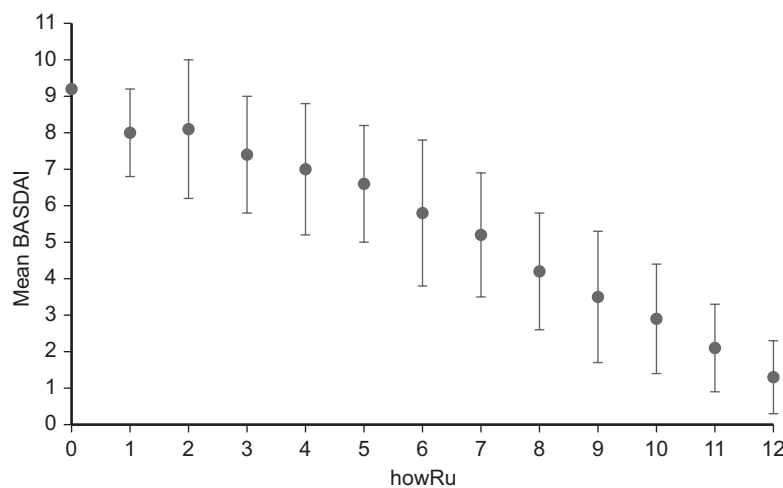


Figure 4 Dot plot of mean BASDAI score against howRu score. Error bars represent ± 1 standard deviation

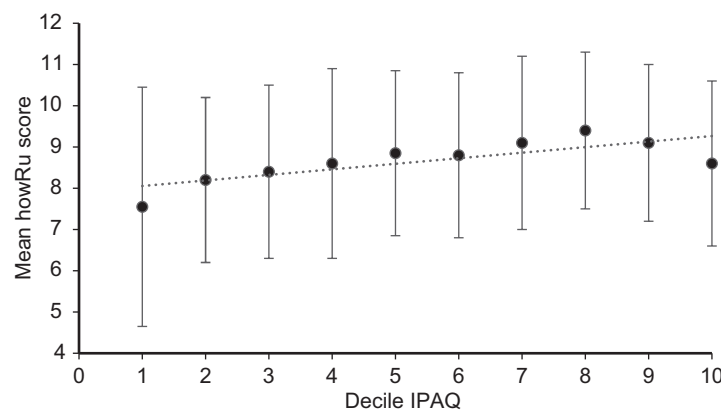


Figure 5 Dot plot representing mean howRu score per decile of the IPAQ physical activity measure. Error bars represent ± 1 standard deviation

Table 1 Demographic characteristics of AS observer participants

Total, n	223
Mean age at recruitment in years (SD)	50.2 (13.9)
Mean disease duration in years (SD)	16.9 (14.2)
Sex	
Male, n (%)	136 (61.0)
Female, n (%)	87 (39.0)
Mean BMI* (SD)	26.7 (5.4)
Smoking status	
Never, n (%)	126 (56.5)
Former, n (%)	78 (35.0)
Current, n (%)	19 (8.5)
HLA-B27 Status	
Positive, n (%)	120 (53.8)
Negative, n (%)	28 (12.6)
Unknown, n (%)	75 (33.6)
Diagnosed by	
Consultant, n (%)	194 (87.0)
GP, n (%)	29 (13.0)
Frequency of rheumatology visits	
Less than twice a year, n (%)	107 (48.0)
Twice a year, n (%)	73 (32.7)
More than twice a year, n (%)	43 (19.3)
Medications**	
Biologics (Anti-TNF), n (%)	84 (37.8)
Steroids, n (%)	15 (6.8)
DMARDs, n (%)	6 (2.7)
Painkillers, n (%)	117 (52.7)
Mean comorbidities, (SD)	2.1 (2.1)
Mean number of tool uses, (SD; range)	8 (3; 1–12)
Mean BASDAI, (SD; range)	3.9 (2.1; 0–9)
Mean IPAQ, (SD; range)***	4,117 (5,683; 0–62,582)
Mean howRu (SD; range)	8.5 (2.1; 1.8–12)

*BMI data was not available for 18 participants, and an additional two participants were excluded as the reported height and weight gave BMIs substantially outside of normal ranges, i.e. BMIs of 4 and 198

**indicates primary medication listed by participants from dropdown list; n = 222 for medications as one participant did not complete data entry. Medication options were as follows: simple oral pain killer tablets, e.g. aspirin or paracetamol; oral anti-inflammatory (NSAIDs) tablets, e.g. diclofenac, ibuprofen or naproxen; Opioid medication, e.g. morphine tablets or patches or tramadol; DMARDs (disease modifying anti-rheumatic drugs) Methotrexate and/or Sulphasalazine; Oral steroid tablets; Steroid injection; Biologic therapy – Adalimumab (Humira), Etanercept (Enbrel), Golimumab (Simponi) or Infliximab (Remicade)

***Analysed on the log scale but converted back to MET minutes per week here

Table 2 Associations between demographic characteristics and disease severity (total continuous BASDAI)

	Mean (SD) BASDAI	P
Disease duration		0.06
0–10 years	3.76 (1.94)	
11–20 years	4.17 (1.92)	
21+ years	3.94 (2.28)	
Sex		0.08
Male	3.70 (2.21)	
Female	4.22 (1.80)	
Smoking Status		0.66
Never	3.89 (2.15)	
Former	3.84 (2.00)	
Current	4.05 (1.84)	
BMI		<0.001
Normal	3.03 (1.77)	
Overweight	4.18 (2.12)	
Obese	5.0 (1.62)	
Severely obese	5.22 (1.95)	
HLA-B27 status		0.37
Positive	3.93 (2.13)	
Negative	3.54 (1.71)	
Rheumatology frequency		<0.001
Less than twice a year	3.35 (1.90)	
Twice a year	4.21 (2.19)	
More than twice a year	4.79 (1.90)	
Comorbidities		<0.001
0	2.98 (1.78)	
1–3	3.88 (1.92)	
4+	5.42 (2.44)	
Anti-TNF		0.07
Yes	3.54 (1.92)	
No	4.07 (2.16)	
Steroids		0.01
Yes	5.20 (2.15)	
No	3.79 (2.05)	
DMARDss		0.52
Yes	4.41 (2.71)	
No	3.86 (2.06)	
Painkillers		0.83
Yes	3.91 (2.37)	
No	3.85 (2.04)	

*Medication options were as listed in Table 1 footnote

Table 3 Associations between physical activity and disease severity measures

Association between BASDAI (outcome) and IPAQ (predictor)				
	FE model; crude	P	Adjusted*	P
Log IPAQ	-0.18 (-0.27, -0.09)	<0.001	-0.10 (-0.18, -0.02)	0.013
IPAQ category	-0.12 (-0.23, -0.00)	0.046	-0.04 (-0.14, 0.07)	0.49
Vigorous activity	-0.21 (-0.38, -0.04)	0.029	-0.16 (-0.31, -0.01)	0.037
Association between BASDAI Fatigue (outcome) and IPAQ (predictor)				
Log IPAQ	-0.11 (-0.23, 0.01)	0.07	-0.03 (-0.14, 0.08)	0.63
IPAQ category	-0.08 (-0.23, 0.07)	0.29	0.00 (-0.14, 0.14)	0.99
Vigorous activity	-0.13 (-0.35, 0.10)	0.26	-0.08 (-0.29, 0.14)	0.49
Association between BASDAI stiffness (outcome) and IPAQ (predictor)				
Log IPAQ	-0.19 (-0.28, -0.09)	<0.001	-0.11 (-0.20, -0.03)	0.01
IPAQ category	-0.19 (-0.32, -0.07)	0.002	-0.12 (-0.23, -0.01)	0.041
Vigorous activity	-0.16 (-0.34, 0.03)	0.091	-0.11 (-0.28, 0.06)	0.20
Association between BASDAI axial pain (outcome) and IPAQ (predictor)				
Log IPAQ	-0.17 (-0.29, -0.05)	0.005	-0.08 (-0.18, 0.03)	0.17
IPAQ category	-0.15 (-0.30, 0.01)	0.06	-0.05 (-0.19, 0.09)	0.46
Vigorous activity	-0.15 (-0.38, 0.07)	0.19	-0.09 (-0.30, 0.12)	0.38
Association between BASDAI other pain (outcome) and IPAQ (predictor)				
Log IPAQ	-0.12 (-0.24, -0.01)	0.032	-0.06 (-0.17, 0.05)	0.31
IPAQ category	-0.05 (-0.20, 0.10)	0.52	0.02 (-0.13, 0.16)	0.82
Vigorous activity	-0.17 (-0.39, 0.05)	0.12	-0.13 (-0.34, 0.08)	0.23
Association between BASDAI tenderness (outcome) and IPAQ (predictor)				
Log IPAQ	-0.23 (-0.34, -0.12)	<0.001	-0.15 (-0.26, -0.05)	0.004
IPAQ category	-0.15 (-0.30, -0.01)	0.034	-0.08 (-0.22, 0.05)	0.24
Vigorous activity	-0.17 (-0.38, 0.04)	0.12	-0.12 (-0.32, 0.08)	0.23

The log IPAQ scores given represent METs minutes per week; IPAQ categories consisted of low, medium and high as described in methods. Regression coefficients and the associated 95% confidence intervals are represented along with *P* values.

*Adjusted for howRU

Table 4 Associations between physical activity and health-related quality of life

Association between howRU (outcome) and IPAQ (predictor)				
	FE Model; Crude	P	Adjusted*	P
Log IPAQ	0.20 (0.10, 0.30)	<0.001	0.10 (0.01, 0.19)	0.029
IPAQ category	0.20 (0.07, 0.33)	0.003	0.14 (0.02, 0.26)	0.024
Vigorous activity	0.13 (-0.07, 0.33)	0.19	0.01 (-0.16, 0.19)	0.87
Association between howRU pain (outcome) and IPAQ (predictor)				
Log IPAQ	0.07 (0.03, 0.11)	<0.001	0.04 (0.01, 0.08)	0.025
IPAQ category	0.08 (0.03, 0.13)	0.002	0.06 (0.01, 0.11)	0.012
Vigorous activity	0.06 (-0.02, 0.14)	0.13	0.02 (-0.05, 0.09)	0.54
Association between howRU Dependent on Others (outcome) and IPAQ (predictor)				
Log IPAQ	0.03 (0.00, 0.06)	0.05	0.01 (-0.02, 0.04)	0.34
IPAQ category	0.03 (-0.01, 0.07)	0.12	0.02 (-0.02, 0.06)	0.28
Vigorous activity	0.05 (-0.01, 0.11)	0.13	0.03 (-0.03, 0.09)	0.36
Association between howRU Limited (outcome) and IPAQ (predictor)				
Log IPAQ	0.04 (0.01, 0.08)	0.026	0.01 (-0.02, 0.05)	0.52
IPAQ category	0.04 (-0.01, 0.09)	0.13	0.02 (-0.03, 0.06)	0.43
Vigorous activity	-0.02 (-0.09, 0.06)	0.65	-0.05 (-0.12, 0.01)	0.11
Association between howRU Feel Low (outcome) and IPAQ (predictor)				
Log IPAQ	0.05 (0.01, 0.10)	0.02	0.03 (-0.01, 0.08)	0.14
IPAQ category	0.05 (-0.01, 0.11)	0.1	0.04 (-0.02, 0.09)	0.22
Vigorous activity	0.04 (-0.04, 0.13)	0.34	0.02 (-0.07, 0.10)	0.66

The log IPAQ scores given represent METs minutes per week; IPAQ categories consisted of low, medium and high as described in methods. Regression coefficients and the associated 95% confidence intervals are represented along with P values.

*Adjusted for BASDAI

Stratified analysis

Stratification of data by sex (Table 5) demonstrated that BASDAI in women was inversely associated with continuous IPAQ scores. However, this was not seen in men where more vigorous activity was required to see improvements in BASDAI. This may be partially explained by physical activity reducing symptoms that are more common in women, i.e. neck, knees and hip pain and tenderness.³⁰ Physical activity benefitted health-related quality of life for men, with higher levels of physical activity improving howRu scores, but this association was not seen in women. This may be due to differences in the profile of AS symptoms typically seen in men and women.³⁰

Associations between physical activity levels, BASDAI and quality of life were significant for individuals who were HLA-B27 positive (Table 5). No relationship was observed for HLA-B27 negative; however, numbers were low (28 participants). Additionally, in individuals with a disease duration

of >10 years, physical activity significantly benefited quality of life, but not BASDAI. More recently, diagnosed participants doing an hour or more of vigorous activity per week associated with improved BASDAI, but negatively associated with quality of life. This may suggest that at early stages of the disease, physical activity negatively impacts the individual, possibly via the interaction of pain and mental health. Furthermore, individuals recording vigorous or moderated gardening ($n = 98$ versus no vigorous or moderate gardening $n = 125$) as one of their more frequent activities had higher average log IPAQ scores (7.91 ± 0.93 versus 7.59 ± 0.99) and lower disease activity (BASDAI = 3.59 ± 2.1 versus 4.18 ± 2.0).

Tool evaluation

Participant experience of using the AS Observer tool was generally positive, with the large majority (66 %) expressing intent to continue using it, either for the purposes of self-monitoring tool, active disease management (e.g. identifying triggers), to

raise awareness of their own condition or as a motivator to undertake physical activity.

Withdrawal and completion rates

Only three participants chose to withdraw from the study before completion and these were all due to technical issues (including only having access to a phone, not a computer and failure of the site to load on particular browsers). The large majority of participants did not complete data entry every week with an average completion rate of 67%, i.e. 8 of 12 weeks (42% completed \leq half, 55% completed 7–9 of 12 data entries, and only 3% completed 11 or 12). This fits with previous eHealth studies of web-based monitoring, with adherence rates ranging between 30% and 75%.³¹ All participants who answered exit questions appreciated the use of reminder emails; however, technical problems prevented some reminder emails being delivered in the last few weeks (reported by 20% of participants) and likely contributed to a drop in compliance. Not receiving reminder emails (including delivery to spam folders) was the main reason given by participants for skipping reporting (44%, Table 6) and this illustrates how important the inclusion of the reminder or prompt mechanism is for effective data collection in eHealth tools.

Participant experience

Exit questionnaires obtained from those withdrawing early ($n = 1$) and participants at the end of study ($n = 92$; 41%) were tabulated and coded for each question. Aside from participants who declined to answer ($n = 33$), the majority intended to continuing using the tool (yes/maybe = 66%). Participants generally found the historical score function useful, enabling monitoring of their condition overtime and helping with self-management approaches.

Usability

Analysis of participant views on ease of tool use, likes and dislikes resulted in the generation of eight codes (Table 7). Participants liked the ability to see plots of their BASDAI scores and would have liked more information graphics (e.g. physical activity and averages for other users) to assist in monitoring their condition. There were split opinions among the participants regarding the tool layout, reflecting personal preference. A number of participants found recording physical activity difficult (Table 7). The use of an activity list as a memory prompt or a smartphone version allowing activity recording to occur at the time was proposed by participants. Additionally, participants would have liked a mechanism to record other influencing factors such as medication changes or periodic medicine use, weather, diet, reasons for no/low activity (e.g. injury/flare up), non-AS ill health, AS associated conditions (e.g. iritis/Crohns), alternative therapies (e.g. massage) and holidays.

Some participants reported technical problems with the website (e.g. compatibility issues and screen freezing during data input), with 28 enquiries to the technical support team. It was possible to resolve 11 of these enquiries, which predominantly related to problems caused when using certain browsers.

Further specific information was needed and not obtained for seven enquiries, thus preventing resolution. Further seven enquiries could not be resolved, despite the use of browser mimic software, and due to the lack of an email address, it was not possible to follow up on three enquiries.

Comments received

Comments received via the project website fell into six main themes: statements of support ($n = 17$), eligibility enquiries ($n = 8$), comments regarding periodic unavailability ($n = 3$), technical problems ($n = 4$) and participation queries regarding confidentiality and time to complete ($n = 2$). Several comments were also received regarding the module content, which reflected the complex nature of AS and feedback received in the exit questionnaire, namely regarding recording of additional information, e.g. medication and diet, or that data recording did not reflect the complexity of AS (e.g. no functional measurements) or the detailed nuances of exercise ($n = 3$).

In this pilot study, participants were not asked to modify their physical activity levels; however, participants noted that tool use (including historical scores) helped them to engage with the role of physical activity in their condition. However, there was no evidence of an overall increase of physical activity during the study duration. Therefore, tool use may have enabled participants to engage with their activity and condition, but did not necessarily serve as an effective motivator for the majority.

Strengths and weaknesses

This study was successful in collecting research data of 223 participants, who were representative of AS populations, using an eHealth tool. Whilst not all individuals responded weekly over the 12-week-period sensitivity, analyses including only participants that had completed at least 6 weeks revealed generally similar findings (Table S3).

However, user-orientated platforms present a number of challenges to data collection. The challenges include self-assessment, which is subjective by nature and can therefore lack precision and allows for a range of interpretation and therefore no standardised approach to comprehending or responding to questions or inputting data,³² even when standardised collection tools (e.g. IPAQ) are utilised. Furthermore, there is always a risk of recruitment bias. In this pilot study, NASS was instrumental in recruitment and although other recruitment approaches were used, it is likely that this cohort was dominated by NASS members, who are likely to be of middle to high socioeconomic status (who are more likely to engage in e-health/technology-based research³³), consist of potentially more severe AS cases and be particularly engaged with their condition. In this pilot study, we were unable to account for potential biases due to the socioeconomic status of the participants; however, socioeconomic status should not influence the observed associations between AS severity and exercise observed here, which utilised FE models to eliminate omitted variable bias. It should also be noted that due to study duration, it was not possible to account for seasonal impacts on physical activity or symptoms and that due

Table 5 Stratified analysis: by sex, HLA-B27 status and disease duration

No Adjustment for other time variable measures										
Outcome	Predictor	Males	P	Females	P	HLA B27+	P	HLA B27-	P	> 10yrs
BASDAI	Log IPAQ	-0.13 (-0.24, -0.02)	0.016	-0.25 (-0.41, -0.10)	0.001	-0.29 (-0.41, -0.17)	<0.001	0.12 (-0.07, 0.31)	0.2	-0.19 (-0.33, -0.05)
	IPAQ category	-0.03 (-0.17, 0.11)	0.69	-0.26 (-0.46, -0.06)	0.012	-0.21 (-0.37, -0.05)	0.012	0.08 (-0.20, 0.36)	0.58	-0.11 (-0.28, 0.06)
	Vigorous activity ≥ 1 hr/week	-0.26 (-0.46, -0.07)	0.007	-0.10 (-0.43, 0.24)	0.57	-0.26 (-0.50, -0.02)	0.037	-0.04 (-0.46, 0.38)	0.84	-0.19 (-0.44, 0.07)
howRU	Log IPAQ	0.23 (0.11, 0.35)	<0.001	0.15 (-0.04, 0.34)	0.13	0.34 (0.20, 0.48)	<0.001	0.01 (-0.21, 0.22)	0.96	0.20 (0.03, 0.36)
	IPAQ category	0.19 (0.04, 0.35)	0.014	0.21 (-0.04, 0.47)	0.1	0.39 (0.20, 0.57)	<0.001	0.09 (-0.24, 0.42)	0.60	0.14 (-0.07, 0.34)
	Vigorous activity ≥ 1 hr/week	0.20 (-0.02, 0.42)	0.07	-0.02 (-0.43, 0.40)	0.94	0.13 (-0.16, 0.41)	0.38	-0.10 (-0.59, 0.40)	0.70	-0.18 (-0.48, 0.12)
Adjusted for other time variable measures										
BASDAI	Log IPAQ	-0.04 (-0.14, 0.05)	0.39	-0.19 (-0.32, -0.06)	0.004	-0.14 (-0.25, -0.04)	0.008	0.12 (-0.05, 0.29)	0.16	-0.11 (-0.23, 0.01)
	IPAQ category	0.04 (-0.08, 0.17)	0.48	-0.17 (-0.34, 0.00)	0.05	-0.04 (-0.18, 0.10)	0.56	0.11 (-0.14, 0.36)	0.38	-0.06 (-0.21, 0.10)
	Vigorous activity ≥ 1 hr/week	-0.19 (-0.36, -0.01)	0.034	-0.10 (-0.38, 0.18)	0.47	-0.20 (-0.41, 0.00)	0.06	-0.08 (-0.45, 0.30)	0.68	-0.26 (-0.48, -0.03)
howRU	Log IPAQ	0.17 (0.06, 0.28)	0.002	-0.02 (-0.19, 0.14)	0.78	0.17 (0.04, 0.29)	0.008	0.06 (-0.13, 0.26)	0.53	0.09 (-0.05, 0.24)
	IPAQ category	0.18 (0.04, 0.32)	0.012	0.04 (-0.18, 0.25)	0.73	0.26 (0.10, 0.43)	0.002	0.13 (-0.17, 0.43)	0.39	0.08 (-0.11, 0.26)
	Vigorous activity ≥ 1 hr/week	0.07 (-0.13, 0.27)	0.47	-0.08 (-0.43, 0.27)	0.65	-0.03 (-0.27, 0.22)	0.82	-0.12 (-0.57, 0.33)	0.59	-0.28 (-0.55, -0.01)

The Log IPAQ scores given represent METs minutes per week; IPAQ categories consisted of low, medium and high as described in methods. Regression coefficients and the associated 95% confidence intervals are represented along with *P* values. Time variable measures for adjusted module included howRU or BASDAI as appropriate. Males *n* = 136 and females *n* = 87. HLA-B27 positive individuals for Log IPAQ *n* = 119, and for all other physical activity variables = 120 and HLA negative = 28. Disease duration ≤ 10 years *n* = 111 and > 10 years *n* = 112.

Table 6 Reasons for not reporting/completing data entry

	N
Not receiving reminder emails (including delivery to spam folders)	26
Unavailability due to holidays, ill health (including fatigue) or just being too busy	21
Forgetting	9
Technical, computer and internet problems	6
Actively choosing not complete data entry due to non-AS ill health and not wishing to skew results	1

Note: In total, n = 93 (includes findings from one early withdrawal participant); however, not all participants provided free-text comments (applicable for 34 of 93) and hence were excluded from the above list. Additionally, participants had the option to select more than one reason.

Table 7 Themes, codes, counts and excerpts from usability exit question

Question: Did you find the tool easy to use, and what did or didn't you like about the tool?				
Response	N (%)	Codes on detail	N	Illustrative Example Quotes
n/a or no clear answer	20 (22)			
Easy	67 (72)	Liked format e.g. standardisation, layout	5	'Yes easy, good to have standardised pro forms every week' 'its good how the page keeps moving up automatically'
		Liked monitoring scores	2	'Yes it is very easy and I liked the graphical representation of the data'
		Liked effect of awareness raising / thought provoking	2	'Yes - just made me think carefully about my condition' 'Very easy, didn't take much time, really useful for making me think about my own behaviours and pain'
Had difficulties	3 (3.5)	Disliked format e.g. standardisation, layout	6	'yes. I don't like the fact it scrolls down automatically - on the marker sections' 'Found it relatively easy to use sometimes hard to use the markers though' 'yes, although sometimes the answer is between stated levels' 'Sometimes the questions were too generic but on the whole helpful' 'didn't like all of the save and continue buttons'
		Technical problems	6	'Programme did not always respond' 'It was fantastic, until the links stopped coming' 'It's difficult to select a score of zero' 'Yes it was easy to use, however things not so good is the that the tool crashes and logs out if you press return' 't could not be used on a phone by those like me who are unable to sit'
No	3 (3.5)	Difficult to record physical activity	5	'Easy, but difficult to categorise some activities, e.g. moderate exercise doubles tennis for me would be vigorous' 'It is not easy to state how much time I spend each day doing various exercises because I swim on 2 days a week I take a long walk one day a week and so on' 'I would have preferred a table to complete, as each week and day was different in terms of activity'
		Disliked time / frequency of use	3	'yes if a bit long' 'fortnightly would be better' 'Should be done on a monthly basis'
		Felt it was too simplistic	6	'easy to use but bit of a blunt instrument in providing details of daily activities' 'sometimes other medical factors effect the spondy scores, no scoring mechanism allows for this effect' 'easy to use, but not linked other factors, e.g. weather, different location, change in medication, or diet change' 'I would have liked to be able to expand some of the answers'

Note: n = 93 (includes findings from 1 early withdrawal participant); however, not all participants provided free-text comments.

to the nature of the data, the direction of associations, i.e. cause and effect, could not be established.

CONCLUDING REMARKS

This pilot study was successful in its aim to develop an eHealth tool that was user friendly, participant engaging and was able to generate data suitable for epidemiological studies. The AS Observer was generally considered useful by participants, as evidenced by two-thirds of users intending to continue monitoring their condition. The pilot study highlighted the importance of using reminder/prompt systems, providing access to personal data stores for monitoring purposes, and that self-reporting physical activity was challenging. Future studies should where possible include participant tailored elements to provide the opportunity to record the impact of other influencing factors for chronic, variable conditions like AS.

Statistical analysis supported the use of physical activity in AS management to benefit overall disease activity, stiffness, tenderness and pain, but not fatigue. However, adjustment for the howRu data attenuated the associations between physical activity and both peripheral and axial pain, highlighting the importance of quality of life in this relationship. Increased BASDAI was associated with the mental health dimension of the howRu tool (Table 4) and therefore increasing physical activity may have multiple

benefits either directly via reduced disease activity and/or improved quality of life. This study suggests guidance around physical activity needs to consider patient specific factors including gender, disease duration and mental health status.

Ultimately, eHealth tools such as the AS Observer, which may have a key role to play in clinical settings in the future (e.g. self-management of chronic conditions and clinician remote monitoring of patients), also serve as a potential data source for research purposes. Although this pilot study only had a relatively small cohort ($n = 223$), scaling up participation in AS disease monitoring tools could provide a valuable means to collect data and facilitate research, which will ultimately benefit patients and clinicians alike by providing real-time monitoring and indicating potential treatment pathways.

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