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Original article

Factors associated with patient activation in inflammatory arthritis: a multisite cross-sectional study

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CLINICAL SCIENCE

Abstract

Objectives Patient activation covers the skills, abilities and behaviour that impact how able and willing someone is to take an active role in self-managing their health. This study explored clinical and psychosocial factors associated with patient activation in rheumatology patients.

Methods This was a cross-sectional study using postal survey methods. Participants with inflammatory rheumatic conditions were from six rheumatology centres in England. Patient activation was captured using the Patient Activation Measure (PAM). Twenty-nine explanatory factors were tested for potential association with patient activation in univariable and multivariable analyses. In preliminary multivariable analyses, factors found to have an association with patient activation at a $P < 0.1$ level were entered into the final multivariable model. Those that remained significant at a $P < 0.05$ level were considered associated with patient activation.

Results The sample comprised 251 participants (74% female) with a mean age of 59.31 years (s.d. 12.69), disease duration of 14.48 years (s.d. 12.52) and a PAM score of 58.3 (s.d. 11.46). Of the 29 candidate factors, 25 were entered into a preliminary multivariable analysis. In the final multivariable analysis, four factors (self-efficacy, the illness belief that treatment will control participants' condition and two dimensions of health literacy) were significantly associated with patient activation. This final model accounted for 40.4% of the variance in PAM scores [$F(4, 246) = 41.66$, $P < 0.001$].

Conclusions Patient activation is important in managing rheumatic conditions. Our data confirm that self-efficacy and health literacy are particular targets for patient activation interventions.

Key words: survey, patient activation, self-management, self-efficacy, health literacy

Key messages

- Patients with inflammatory arthritis have a range of patient activation abilities and these should be considered when designing self-management support.
- This is the first study to investigate factors associated with patient activation in UK rheumatology patients.
- Self-efficacy and health literacy are significantly associated with patient activation and key to developing patient activation interventions.

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Introduction

Inflammatory arthritis (IA) is an umbrella term that includes several long-term conditions including RA, PsA and AS. Symptoms often include pain, fatigue, joint stiffness and swelling and issues such as psychological distress [1]. These are long-term conditions that require self-management to cope with the physical and psychosocial consequences of the conditions, as well as making treatment decisions and managing complex medication regimes.

IA is often managed in hospital settings with specialist rheumatology teams. However, research into long-term conditions in the UK suggests that patients spend approximately 5 hours ayear in consultations with healthcare professionals and remaining hours self-managing [2]. This leaves patients with a great deal of responsibility for their own condition.

A concept that is closely related to self-management is patient activation. Patient activation incorporates the skills, abilities and behaviours that contribute to how able and willing someone is to take an active role in managing his/her health [3]. Where patient activation is high, patients are confident and proactive in managing their health, seeking information when required to make decisions about their health and carrying out positive health-related behaviours [4]. Alternatively, when patient activation is low, people are passive, unable or unwilling to take responsibility for managing their health. They are often very dependent on healthcare professionals for information and direction. On a healthcare system level, higher levels of activation are associated with fewer emergency admissions, fewer days as an inpatient and lower healthcare costs [4]. On an individual level, increased activation is associated with better physical and psychosocial outcomes, including more frequent exercise, increased self-efficacy and lower rates of depression [5, 6]. Therefore there is value in understanding variables related to patient activation.

Patient activation is most commonly captured using the Patient Activation Measure (PAM), a commercially licenced measure that categorizes patients into one of four activation levels ranging from 1 (passive) to 4 (actively managing their health) [7, 8]. It also provides patients with a score up to 100, with higher scores indicating more skilled and active self-management. It has been used internationally and translated into more than 28 languages [9, 10]. It is intended for use in a range of environments and conditions to tailor and evaluate self-management support [7, 11].

The prevailing model of patient activation [12] suggests positive and negative affect (underlying internal feelings) contribute to patients' activation via their comfort and confidence to carry out small behaviour changes related to their health. This model was not developed with any specific long-term conditions as a focus. It was also not clear how many, if any, participants in this study had a rheumatic condition. Due to this lack of evidence regarding rheumatology patients in particular, this present study was needed.

Surveys in multiple sclerosis, diabetes and chronic obstructive pulmonary disease (COPD) have identified factors commonly associated with patient activation in those conditions, including illness perceptions, anxiety, participants' knowledge about their condition, engagement with routine check-ups and positive health behaviours [13–17]. In rheumatology, there was one study conducted in Brazil that included patient activation in a quest to assess factors associated with functional disability [18]. The same study found that high patient activation was negatively associated with functional disability as measured by the HAQ [19].

Initial qualitative research with a sample of UK patients with rheumatic conditions suggested concepts that might be associated with patient activation [20]. These included self-efficacy (the belief that one can achieve a desired outcome or goal), health literacy (skills related to comprehending and evaluating health-related information to make health-related decisions as well as the ability to navigate health services to obtain the support needed to self-manage) [21, 22] and illness beliefs (expectations about the nature and severity of one's condition and its treatment) [23].

The purpose of this study was to understand whether these psychosocial variables contribute to patient activation in UK rheumatology patients, as there is limited research on factors associated with patient activation in this population. This is important because it is possible there are rheumatology-specific variables that can inform theory-led patient activation interventions tailored to the needs of this group.

Methods

Design

This was a multisite cross-sectional study using survey methods. The survey pack was designed by B.J. (doctoral student with a psychology background) with input from multiple perspectives including patient perspectives (A.H.), a nurse researcher (M.N.) and academic psychologists (D.H. and E.D.). Candidate factors (explanatory variables) were identified based on their prominence in the patient activation literature, including qualitative research with skilled self-managers [20]. Measures used in the survey pack were chosen for their psychometric properties, prior use in research with rheumatology patients, and minimal participant burden.

Ethics approval

The research was conducted in compliance with the Declaration of Helsinki. Ethics approval to carry out this research was granted by the Yorkshire and Humber South Yorkshire Research Ethics Committees (reference 18/YH/0227) and ratified by the University of the West of England (reference HAS.18.06.191). Consent to participate in the research was presumed based on participants having completed and returned the anonymous questionnaire survey pack.

Study population

The opportunity sample of participants was recruited from six rheumatology departments in England between July and October 2018 and data collection took place until July 2019. Predetermined sample characteristics were not specifically sought but the intention was to capture a range of participants using multiple recruitment sites. The inclusion criteria were age $>$18 years, living with an inflammatory rheumatic condition (including RA, PsA and AS) or SLE because of the shared experiences between SLE and IA, a patient at a recruiting site and the ability to read and write in English.

Data collection and measures

Eligible patients were either approached in clinics and invited to participate in the research or they were invited to join via packs sent in the post with a cover letter and information sheet. There were no alternative versions of the survey with outcome measures in different orders to reduce order effects. To ensure anonymity, packs were coded and recruiting sites kept a record of which patient was given which code. Completed pseudo-anonymized packs were returned directly to B.J.

Patient activation (outcome variable) was measured using the short form Patient Activation Measure (PAM) [8]. The 13-item version of the measure was used and participants are able to respond to the items with ‘disagree strongly’, ‘disagree’, ‘agree’, ‘agree strongly’ or ‘N/A’. The PAM provides patients with the score (between 0 and 100), with higher scores indicating more skilled and active self-management. The items in this measure and further details about its development are discussed elsewhere [8].

The candidate factors tested for association with patient activation were physical disability, self-efficacy, health beliefs, health locus of control (HLOC), health literacy, affect, fatigue and pain.

Physical disability

Physical disability was measured using the HAQ [19]. The scores range between 0 and 3, with higher scores reflecting a high level of disability.

Self-efficacy

Self-efficacy was measured by the RA Self Efficacy Scale (RASE) [24], a 28-item measure developed to capture self-efficacy in British rheumatology patients. Final scores range from 28 to 140, with higher scores indicating higher self-efficacy.

Health beliefs

The Brief Illness Perceptions Questionnaire (BIPQ) [25] captures participants’ understanding of the timeline and nature of their condition in nine domains. These cover perceptions of consequences of their condition, perceived timeline, personal control over the condition, perceived treatment control over their condition, identity (covering experience of symptoms), illness concern, coherence (i.e., understanding) of illness and emotional impact of their condition. The personal control, treatment control and coherence domains are calculated so that lower scores indicate more threatening views of the condition and higher scores in the other domains represent more threatening perceptions of their condition [26].

Health locus of control (HLOC)

The HLOC [26] relates to what extent individuals feels that outcomes related to their health occur because of actions that they can take charge of (internal locus of control) or because of variables that are outside of their control (external locus of control). Form C of the multidimensional HLOC scale [27] includes 18 items and captures participants’ beliefs about how much of their condition is impacted by their personal actions or other determinants. The items’ phrasing allows for a specific condition to be named to personalize it for participant groups. The four subscales are internal (self), chance, doctors and powerful others. The higher the score on each subscale, the higher the participants’ type of locus of control. The subscales for doctors and powerful others have a range of 3–18. The internal and chance subscales have ranges from 6 to 36.

Health literacy

The Health Literacy Questionnaire [28] is a 44-item measure that captures participants’ abilities to navigate the healthcare system confidently, to gather and apply health-related information and to work with healthcare providers. There are nine total domains capturing various dimensions of health literacy:

1. Feeling understood and supported by my healthcare provider
2. Having sufficient information to manage my health
3. Actively managing my health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating the healthcare system
8. Ability to find good health information
9. Understanding health information enough to know what to do

Participants are presented with statements to respond to and scores for the first five domains range from 1 (strongly disagree) to 4 (strongly agree). For the last four domains the scores range from 1 (cannot do/always difficult) to 5 (always easy). Mean scores for each domain are calculated based on the participants’ responses to the items in the subscales. The higher the score, the higher the health literacy participants have.

Affect

The Positive and Negative Affect Scale (PANAS) is a 20-item measure (10 items each) that was selected because of its use in prior patient activation research [12, 29]. It provides a separate score for both positive and negative affect ranging between 0 and 50. The higher the score, the greater the positive or negative affect the participant has experienced recently.

Table 1 Characteristics of participants

Characteristics	Values
Sex, *n* (%)	Female, 185 (74) Male, 66 (26.3)
Ethnicity, *n* (%)	White British, 235 (94) Other white, 8 (3) Black, 1 (<1) Chinese, 1 (<1) Other Asian, 2 (<1) Other, 3 (1) Prefer not to say, 1(<1)
Diagnosis, *n* (%)	RA, 166 (66) SLE, 3 (1) Inflammatory polyarthritis, 1 (<1) AS, 31 (12) JIA, 2 (<1) PsA, 35 (14) Other, 10 (4) Don't know, 3 (1)
Age, years, mean (S.D.)	59.31 (12.69)
Disease duration, years, mean (S.D.)	14.48 (12.52)
Patient activation (PAM; range 0–100), mean (S.D.)	58.3 (11.46)
Physical disability (HAQ; range 0–3), mean (S.D.)	0.75 (0.65)
Self-efficacy (RASE; range 28–140), mean (S.D.)	101.61 (15.24)
Health beliefs (BIPQ), mean (S.D.)	
Consequences (range 0–10)	6.26 (2.30)
Timeline (range 0–10)	9.53 (1.13)
Personal control (range 0–10)	4.92 (2.26)
Treatment control (range 0–10)	7.41 (1.93)
Identity (range 0–10)	6.52 (2.12)
Coherence (range 0–10)	7.69 (1.99)
Emotional representation (range 0–10)	6.08 (2.65)
Illness concern (range 0–10)	6.91 (2.47)
HLOC, mean (S.D.)	
Internal (range 6–36)	16.98 (6.14)
Chance (range 6–36)	16.33 (6.47)
Doctors (range 3–18)	11.31 (3.23)
Powerful others (range 3–18)	8.71 (3.57)
Health literacy (HLQ), mean (S.D.)	
Feeling understood (range 1–4)	2.96 (0.71)
Sufficient information (range 1–4)	2.91 (0.48)
Actively managing (range 1–4)	2.89 (0.47)
Social support (range 1–4)	2.92 (0.57)
Appraisal (range 1–4)	2.68 (0.53)
Ability to engage (range 1–5)	3.78 (0.73)
Navigating healthcare (range 1–5)	3.59 (0.66)
Ability to find information (range 1–5)	3.83 (0.63)
Knowing what to do (range 1–5)	4.08 (0.55)
Positive affect (PANAS; range 0–50)	30.03 (8.85)
Negative affect (PANAS; range 0–50)	19.88 (7.73)
Fatigue severity (NRS; range 0–10)	6.43 (2.28)
Pain severity (NRS; range 0–10)	5.43 (2.51)

Fatigue

A numerical rating scale (NRS) [30] from the Bristol RA Fatigue Scale (BRAF) captures average fatigue levels over the previous 24 h. Scores range from 0 to 10, with higher scores reflecting more debilitating fatigue.

Pain

The pain NRS captures average levels of pain over the last 24 h. Scores range from 0 to 10, with higher scores reflecting more debilitating pain.

Patient involvement

A patient research partner (A.H.) was part of the study team. He offered his perspective on the study design (including study documentation), the constructs being captured, the outcome measures included and the format of the survey pack. He piloted the survey pack to review it for clarity and length.

Sample size

A sample size estimation was based on the requirement for multiple regression analysis using the formula $50 + 8m$, where m is the number of explanatory variables [31]. The number of explanatory variables in this study was 29 (accounting for the continuous demographic data, all outcome measures and any relevant subscales used as factors), therefore the sample size estimate was 282.

Analysis

Exploring factors associated with patient activation in participants requires understanding what proportion of the variance in PAM scores can be explained by the variables included in the regression models. Incomplete responses (missing one full demographic factor or one full outcome measure) were excluded in the analysis. If one item in the measures was missing, it was imputed by using an average score of other items in the measure or subscale. If more than one item was missing in a measure, it was excluded. Descriptive statistics were calculated for all continuous variables. For categorical variables, the frequencies of responses were calculated.

To begin with, it was necessary to understand what variables were significantly associated with the PAM scores. For this reason, candidate variables for the multiple regression were identified using univariable analyses by testing the relationships between PAM scores and each of the candidate variables. Those variables without a significant correlation with PAM scores were removed from the candidate variables for the regression analysis. Once candidate variables were identified, a preliminary multiple regression analysis was conducted with the PAM scores as the outcome variable. Variables that were statistically significant with a *P*-value <0.1 were included in a final multiple regression model. The parameter estimates (*B*) are presented with the corresponding 95% CIs and *P*-values for variables that were

Table 2 Univariable analyses testing the association between patient activation and candidate factors (explanatory variables)

Explanatory variables	Spearman's rank correlation coefficient	*P*-value
Age (years)	−0.14	0.03
Disease duration (years)	0.03	0.59
Physical disability (HAQ)	−0.36	<0.01
Self-efficacy (RASE)	0.50	<0.01
HLOC		
Internal	0.25	<0.01
Chance	−0.07	0.26
Doctors	0.14	0.02
Powerful others	<−0.01	0.97
Health beliefs (BIPQ)		
Consequences	−0.39	<0.01
Timeline	−0.05	0.40
Personal control	0.29	<0.01
Treatment control	0.30	<0.01
Identity	−0.31	<0.01
Coherence	0.24	<0.01
Emotional representation	−0.30	<0.01
Illness concern	−0.36	<0.01
Health literacy (HLQ)		
Feeling understood	0.27	<0.01
Sufficient information	0.48	<0.01
Actively managing	0.41	<0.01
Social support	0.33	<0.01
Appraisal	0.38	<0.01
Ability to engage	0.33	<0.01
Navigating healthcare	0.30	<0.01
Ability to find information	0.41	<0.01
Knowing what to do	0.42	<0.01
Pain intensity (NRS)	−0.33	<0.01
Fatigue intensity (NRS)	−0.31	<0.01
Positive affect (PANAS)	0.41	<0.01
Negative affect (PANAS)	−0.33	<0.01

significant at $\alpha = 0.05$ are interpreted as factors significantly associated with patient activation. All analyses were conducted using SPSS 25 for Windows (IBM, Armonk, NY, USA).

Results

A total of 267 patients participated. Seven were excluded due to missing data on any outcome measures or demographic variables and nine were excluded due to completing outcome measures in ways that invalidated them (e.g., completing the PAM by giving the same response to all items, following guidance by Insignia Health who licences the measure). This left data for 251 patients to be analysed. Demographics data for these participants are presented in Table 1.

Of the 251 patients, 185 (74%) were female. Most participants [*n* = 235 (94%)] were white British. The most common diagnosis was RA (66% of participants). The mean age of participants was 59.3 years (S.D. 12.7) and mean disease duration was 14.5 years (S.D. 12.5). The mean PAM score was 58.3 (S.D. 11.46) and scores ranged between 33 and 90.7. Table 1 also provides information about the central tendency and spread of other variables.

Table 2 presents the results of the univariable analyses, testing potential associations between individual factors and patient activation. Of the 29 factors that were tested, 25 were found to have a significant association with PAM and these were tested in the subsequent multivariable analyses. Variables removed at this point were disease duration, the timeline domain of the BIPQ, the chance HLOC subscale and the powerful others HLOC subscale.

Factors associated with patient activation scores

The results of the two multivariable analyses (the preliminary regression and the final regression models) are reported in Tables 3 and 4, respectively. The factors included in the final regression model were self-efficacy (RASE), sense of control over treatment (BIPQ) and two domains of health literacy (HLQ subscales: 'having sufficient information to manage health' and 'understanding health information enough to know what to do').

Table 3 Factors associated with patient activation: preliminary multivariable model

Model	Explanatory variables	*B* (unstandardized)	95% CI	*P*-value
1	$R^2 = 0.128$ (R^2 change 128)			
	Age	−0.030	−0.139, 0.079	0.586
	Physical disability (HAQ)	−6.127	−8.251, −4.002	<0.001
2	$R^2 = 0.340$ (R^2 change 0.212)			
	Age	−0.069	−0.164, 0.027	0.158
	Physical disability (HAQ)	−4.349	−6.243, −2.455	0.000
	Self-efficacy (RASE)	0.354	0.275, 0.432	<0.001
3	$R^2 = 0.348$ (R^2 change 0.008)			
	Age	−0.072	−0.170, 0.026	0.147
	Physical disability (HAQ)	−4.040	−5.964, −2.115	<0.001
	Self-efficacy (RASE)	0.337	0.256, 0.418	<0.001
	Internal HLOC	0.110	−0.091, 0.311	0.282
	Doctors HLOC	0.242	−0.135, 0.619	0.208
4	$R^2 = 0.410$ (R^2 change 0.062)			
	Age	−0.111	−0.209, −0.013	0.026
	Physical disability (HAQ)	−2.674	−5.093, −0.254	0.030
	Self-efficacy (RASE)	0.269	0.184, 0.355	<0.001
	Internal HLOC	0.071	−0.128, 0.271	0.481
	Doctors HLOC	0.205	−0.180, 0.589	0.295
	BIPQ_1 Consequences	−0.575	−1.480, 0.331	0.212
	BIPQ_3 Personal control	0.276	−0.316, 0.867	0.360
	BIPQ_4 Treatment control	0.596	−0.088, 1.279	0.087
	BIPQ_5 Identity	0.344	−0.583, 1.272	0.465
	BIPQ_6 Illness concern	−0.370	−0.983, 0.243	0.235
	BIPQ_7 Coherence	0.773	0.165, 1.382	0.013
	BIPQ_8 Emotional response	−0.129	−0.718, 0.460	0.666
5	$R^2 = 0.493$ (R^2 change 0.084)			
	Age	−0.070	−0.165, 0.026	0.151
	Physical disability (HAQ)	−1.671	−4.093, 0.750	0.175
	Self-efficacy (RASE)	0.153	0.058, 0.248	0.002
	Internal HLOC	0.157	−0.042, 0.356	0.121
	Doctors HLOC	0.209	−0.170, 0.589	0.278
	BIPQ_1 Consequences	−0.546	−1.407, 0.316	0.213
	BIPQ_3 Personal control	0.135	−0.452, 0.721	0.651
	BIPQ_4 Treatment control	0.780	0.094, 1.465	0.026
	BIPQ_5 Identity	0.344	−0.552, 1.240	0.450
	BIPQ_6 Illness concern	−0.309	−0.898, 0.280	0.302
	BIPQ_7 Coherence	−0.008	−0.678, 0.661	0.981
	BIPQ_8 Emotional response	0.038	−0.557, 0.633	0.899
	HLQ Feeling understood	−0.874	−3.240, 1.491	0.467
	HLQ Sufficient information	4.113	0.638, 7.588	0.021
	HLQ Actively managing	1.649	−1.415, 4.712	0.290
	HLQ Social support	0.567	−2.082, 3.216	0.673
	HLQ Appraisal	1.980	−0.807, 4.767	0.163
	HLQ Ability to engage	0.075	−2.978, 3.128	0.961
	HLQ Navigating healthcare	−2.260	−5.672, 1.151	0.193
	HLQ Ability to find information	0.931	−2.401, 4.262	0.582
	HLQ Knowing what to do	4.908	1.776, 8.041	0.002
6	$R^2 = 0.498$ (R^2 change 0.004)			
	Age	−0.072	−0.167, 0.024	0.139
	Physical disability (HAQ)	−1.664	−4.147, 0.818	0.188
	Self-efficacy (RASE)	0.155	0.061, 0.250	0.001
	Internal HLOC	0.164	−0.035, 0.364	0.106
	Doctors HLOC	0.148	−0.241, 0.537	0.454
	BIPQ_1 Consequences	−0.607	−1.477, 0.262	0.170
	BIPQ_3 Personal control	0.123	−0.467, 0.712	0.682
	BIPQ_4 Treatment control	0.853	0.139, 1.566	0.019
	BIPQ_5 Identity	0.371	−0.609, 1.352	0.456
	BIPQ_6 Illness concern	−0.310	−0.899, 0.280	0.301

(continued)

Table 3 Continued

Model	Explanatory variables	*B* (unstandardized)	95% CI	*P*-value
	BIPQ_7 Coherence	−0.096	−0.777, 0.585	0.782
	BIPQ_8 Emotional response	0.025	−0.592, 0.642	0.936
	HLQ Feeling understood	−0.592	−2.997, 1.813	0.628
	HLQ Sufficient information	3.880	0.373, 7.387	0.030
	HLQ Actively managing	1.602	−1.464, 4.668	0.304
	HLQ Social support	0.291	−2.395, 2.977	0.831
	HLQ Appraisal	2.059	−0.763, 4.880	0.152
	HLQ Ability to engage	−0.146	−3.248, 2.956	0.926
	HLQ Navigating healthcare	−2.232	−5.643, 1.180	0.199
	HLQ Ability to find information	1.334	−2.068, 4.737	0.440
	HLQ Knowing what to do	5.055	1.916, 8.194	0.002
	Fatigue severity NRS	−0.459	−1.181, 0.262	0.211
	Pain severity NRS	0.416	−0.379, 1.210	0.304
7	$R^2 = .499$ (R^2 change 0.001)			
	Age	−0.072	−0.170, 0.026	0.149
	Physical disability (HAQ)	−1.609	−4.119, 0.902	0.208
	Self-efficacy (RASE)	0.153	0.058, 0.249	0.002
	Internal HLOC	0.164	−0.036, 0.364	0.108
	Doctors HLOC	0.143	−0.248, 0.534	0.472
	BIPQ_1 Consequences	−0.605	−1.479, 0.268	0.173
	BIPQ_3 Personal control	0.128	−0.465, 0.720	0.671
	BIPQ_4 Treatment control	0.838	0.120, 1.557	0.022
	BIPQ_5 Identity	0.368	−0.618, 1.353	0.463
	BIPQ_6 Illness concern	−0.301	−0.894, 0.292	0.318
	BIPQ_7 Coherence	−0.105	−0.790, 0.580	0.763
	BIPQ_8 Emotional response	0.077	−0.585, 0.739	0.819
	HLQ Feeling understood	−0.515	−2.951, 1.921	0.677
	HLQ Sufficient information	3.931	0.405, 7.458	0.029
	HLQ Actively managing	1.262	−2.087, 4.610	0.459
	HLQ Social support	0.167	−2.574, 2.908	0.905
	HLQ Appraisal	2.117	−0.731, 4.965	0.144
	HLQ Ability to engage	−0.138	−3.253, 2.977	0.930
	HLQ Navigating healthcare	−2.273	−5.705, 1.159	0.193
	HLQ Ability to find information	1.335	−2.083, 4.752	0.442
	HLQ Knowing what to do	4.990	1.824, 8.156	0.002
	Fatigue severity NRS	−0.443	−1.171, 0.285	0.231
	Pain severity NRS	0.422	−0.388, 1.231	0.306
	Positive affect (PANAS)	0.043	−0.130, 0.215	0.627
	Negative affect (PANAS)	−0.014	−0.210, 0.181	0.885

The final regression model accounted for 40.4% ($R^2 = 0.404$) of the variance in patient activation within this sample [$F(4, 246) = 41.66$, $P < 0.001$]. Self-efficacy, perceptions of controlling the illness with treatment and HLQ domains 2 (having sufficient information to manage my health) and 9 (understanding health information enough to know what to do) were significantly associated with patient activation in participants.

Discussion

This study aimed to understand factors associated with patient activation in participants with IA. Factors that were significantly associated with patient activation were self-efficacy, illness perceptions related to treatment control and two dimensions of health literacy. Overall, patient activation (average PAM score) in this study was higher than published findings from participants with COPD [16] but lower than the scores of older adults with functional difficulties or employees recruited from two companies in the USA [32, 33]. Participants in our study had lower average PAM scores than those reported by Oliveira *et al*. [18] in a Brazilian study. While Oliveira *et al*. [18] observed the relationship between functional disability and patient activation, our study findings did not support this relationship.

The distribution of PAM scores across the sample demonstrates a range of experience and skills that participants have to manage their health. The lack of a statistically significant association between PAM scores and disease duration means that it is possible that some patients would benefit from support to self-manage, even after living with their condition for many years. This is particularly relevant with long-term rheumatic conditions, where people may experience fluctuations in their physical health as well as their ability and

TABLE 4 Factors associated with patient activation: final multivariable model

Model	Explanatory variables	*B* (unstandardized)	95% CI	*P*-value
1	$R^2 = 0.266$ (R^2 change 0.266)			
	Self-efficacy (RASE)	0.388	0.307, 0.468	<0.001
2	$R^2 = 0.297$ (R^2 change 0.032)			
	Self-efficacy (RASE)	0.358	0.277, 0.439	<0.001
	BIPQ Treatment control	1.086	0.448, 1.725	0.001
3	$R^2 = 0.357$ (R^2 change 0.060)			
	Self-efficacy (RASE)	0.271	0.185, 0.356	<0.001
	BIPQ_4 Treatment control	0.662	0.025, 1.299	0.042
	HLQ Sufficient information	6.784	3.991, 9.577	<0.001
4	$R^2 = 0.404$ (R^2 change 0.047)			
	Self-efficacy (RASE)	0.226	0.141, 0.310	<0.001
	BIPQ_4 Treatment control	0.738	0.123, 1.354	0.019
	HLQ Sufficient information	5.111	2.315, 7.908	<0.001
	HLQ Knowing what to do	5.004	2.763, 7.244	<0.001

willingness to actively self-manage. This also has implications for services stratifying self-management support according to levels of patient activation, as measured using the PAM.

The contribution of self-efficacy to patient activation reflects the importance of the belief that participants could carry out behaviours relevant to their health. This is not surprising, given that self-efficacy is one of the most targeted concepts in self-management research and has been identified as amenable to intervention and a mechanism by which self-management interventions for long-term conditions can benefit patients [34, 35]. Self-efficacy is amenable to intervention through mastering experiences via the setting and achieving of goals or from vicarious experience [36]. It has previously been targeted in self-management rheumatology interventions [37]. This contributes to the argument that increasing patients' confidence and belief in their ability to carry out activities related to their health increases their willingness to do so as well as their perseverance when faced with a challenge. The relevance of health beliefs, specifically the sense that participants felt their condition could be controlled by treatment, suggests that developing this confidence and sense of control in clinics could have positive implications for self-management.

Research in other health conditions has confirmed the contribution that health literacy makes to patient activation [23]. Reviewing, assessing and helping patients to develop health literacy skills is clearly a key component of supporting them to actively manage their long-term condition. This requires further examination, and health literacy training at a broader, population level may be a direction for future research. Given that research has identified that health literacy is related to health inequalities (unfair and avoidable differences in the health of different sections of the population), it is a particularly valuable psychosocial concept to target in interventions [38, 39].

A notable finding in our data was that positive and negative affect (captured using the PANAS) was not associated with patient activation. Other personal factors were more important correlates of patient activation. This suggests that these other variables may be more important to patient activation in rheumatology than the prevailing model, which is not health condition specific [12].

Our findings add weight to the roles of self-efficacy and health literacy in patient activation. This indicates that patient activation interventions could usefully focus on training patients in determining how to seek out different types of support for long-term conditions, how to respond to flare-ups and setbacks and when and how to gather information and advice from trusted sources.

Strengths

This study is one of the first to investigate factors associated with patient activation in a UK rheumatology population. Another strength was the multidisciplinary input into the design of the survey, including the patient voice, as well as input from psychology, nursing and statistics.

Limitations

A challenge in this study was that outcome measures are often written in a way that renders them inaccessible to people with low health literacy [40]. This could mean that people with low levels of health literacy were more likely to decline participation. It is possible that only more activated patients participate in research in general. Therefore selection bias, and self-selection bias in particular, cannot be ruled out. Analysis of the BIPQ domains as separate variables alongside other candidate factors in the multivariable analyses meant that the statistical power in the preliminary multivariable analysis was somewhat reduced. However, the final model was appropriately powered.

Conclusion

Self-efficacy, health literacy and health beliefs related to treatment control are significantly associated with patient activation in IA. Positive and negative affect were not associated with patient activation and future research in rheumatology populations should investigate this further. Future studies should focus on identifying appropriate forms of intervention that target these variables and determine the acceptability of these interventions to patients and other stakeholders.

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Data availability statement

The data underlying this article cannot be shared publicly, as this was not covered by the participants' informed consent to take part in the study.

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