

# The Patient Activation Measure in Patients with Rheumatoid Arthritis: A Systematic Review and Cross-Sectional Interview-Based Survey

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**Introduction/Objective:** The patient activation measure (PAM) is considered a reliable tool for measuring patient activation. This study aimed to systematically review the scientific literature regarding the use of PAM –13 in rheumatology patients and to compare PAM scores in patients with rheumatoid arthritis (RA) following two different practices at a single institution with previously published studies.

**Methods:** The study consisted of a systematic review of articles reporting the PAM-13 in patients with RA, followed by a cross-sectional study evaluating PAM scores between standard rheumatology clinics and specialized rheumatology clinics (SRCs). The correlation between PAM levels and other variables, such as demographics, disease characteristics, and treatment, was assessed.

**Results:** Nineteen studies, published between 2012 and 2022, met the inclusion criteria. The studies in this review had inconsistent results and quality, with patient activation in RA ranging from 29 to 76. A total of 197 patients with confirmed RA diagnoses were interviewed (response rate, 88%). Most were female (n=173, 88%) and older than 40 years (n=150, 76%). The average patient activation score was 64.9 (standard deviation, 15.7). Most participants had level 3 and 4 patient activation measures (n=71 [36%] and n=72[37%], respectively). Patients who were attending SRCs also had borderline higher PAM levels. Patients with high PAM scores tended to be older, have active disease, and were taking corticosteroids.

**Conclusion:** Adequate activation of patients was observed from our center, which was higher than that reported in most published literature. The PAM of patients with RA was variable according to the systematic review. Longitudinal interventional studies should be considered to improve activation in patients with low scores.

**Keywords:** rheumatoid arthritis, patient activation measures, patient engagement, systematic review, cross-sectional study

## Introduction

Patient empowerment is an essential aspect of health condition management. This enables patients to become more active in managing themselves by understanding their roles. It is also critical for patients to be knowledgeable and have skills and motivation to be proactive in their management.<sup>1,2</sup> This approach involves patient activation, which is defined as patients' preparedness to manage their health based on their knowledge, skills, and confidence, and understanding their role in the care process to manage their health and health care.<sup>3</sup> The patient activation measure (PAM) is a tool that can be used to measure patient empowerment.<sup>4</sup>

Hibbard et al developed the PAM.<sup>4</sup> It was first developed as a 22-item PAM questionnaire, and a short version was later developed with 13 items.<sup>5</sup> The 13-item PAM questionnaire is a reliable and valid measure for different chronic illnesses.<sup>6</sup> In addition, it is now considered one of the most frequently used questionnaires, with published evidence of its construct validity.<sup>4</sup>

However, it is important to keep in mind that patients differ in their willingness and ability to take on this role in managing their health.<sup>7</sup> Understanding each patient's readiness to take an active part in managing their health can help in designing customized interventions for each patient based on patient activation level, which has been reported to improve patient outcome measures.<sup>7</sup> Studies have demonstrated that patients who are actively involved in their treatment tend to cooperate more effectively with healthcare providers and eventually experience better health outcomes.<sup>8</sup> Those with higher activation levels reported significantly better health outcomes, with significantly lower rates of doctor's office and emergency room visits.<sup>4</sup> PAM levels were also observed to be a predictor for new chronic disease; patients with lower PAM levels were more likely to have a new chronic disease.<sup>9</sup> In addition, studies have shown that higher PAM levels are associated with lower health costs.<sup>9-11</sup> Changes in the PAM levels of patient populations might be used as an indicator of the performance of providers or healthcare delivery systems.<sup>12</sup> In addition, the PAM could be used to segment large populations and target interventions for those who have insufficient self-management skills. The PAM can be tracked over time, used to assess individual patient progress, and monitor whole populations.<sup>5</sup>

It is also essential to consider that several factors may affect patient activation.<sup>13</sup> A study carried out in older people with long-term conditions and multimorbidity in the United Kingdom observed that patient activation was significantly lower in older patients, those with depression, and those with poor health literacy, while it was higher in those with good quality of life and with better social support.<sup>13</sup>

To date, the PAM has been used in patients with multiple types of diseases, including cardiac diseases,<sup>14</sup> diabetes mellitus,<sup>15</sup> chronic kidney disease,<sup>1</sup> depression,<sup>16</sup> and rheumatoid arthritis (RA).<sup>13</sup> RA affects physical activity, and may lead to disability and early mortality.<sup>17</sup> It also affects the quality of life of patients both socially and mentally and has direct and indirect costs, including hospital and treatment costs and absence from work.<sup>18</sup> Engaging patients in managing their RA has shown improvements in clinical, functional, and patient-reported outcomes.<sup>19</sup>

A limited number of studies have assessed the PAM in patients with RA worldwide; however, studies assessing patient engagement and activation in Saudi Arabia are lacking.<sup>20</sup> Moreover, to the best of our knowledge, no systematic review has been conducted on the PAM in patients with RA. The present study aimed to evaluate the PAM in patients with RA in a tertiary care center in Saudi Arabia and assess the impact of multidisciplinary team care on patient scores. Moreover, the current study aimed to systematically review the literature on the PAM in patients with RA.

## Materials and Methods

### Study Design and Setting

#### Systematic Review

A systematic review was conducted using a predesigned search strategy to include all related keywords, including the patient activation measure and rheumatoid arthritis. The research question was (What is the reported prevalence of patient activation measurements by patient activation measure-13 in observational or interventional studies of adult rheumatoid arthritis patients?). A full search strategy is available ([Supplementary Appendix 1](#)). The keywords were entered into the following databases (ProQuest, Science Direct, PubMed, Cochrane Central Register of Controlled Trials, American College of Rheumatology conference proceedings, and US National Library of Medicine ClinicalTrials.gov) searching from the inception of each database until June 2022. The protocol was not registered and no language restrictions or search limits were applied. For study selection, main outcome and inclusion/exclusion criteria for all studies (observational or interventional) that reported the use of the PAM-13 in adult patients with confirmed RA diagnosis were included. No limit for number of participants per study was applied. For exclusion, books or review articles, studies not reporting the PAM or not involving adult patients with RA were excluded. This review used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting the methodology.<sup>21</sup> Article titles were screened in duplicate, followed by abstract screening, and any discrepancies in study inclusion were resolved by consensus. Data were extracted in a predesigned and piloted form to include author, year, country, study design, study setting, population, intervention (if any), PAM level, limitations, and conclusion about the PAM. In addition, to search databases, the company website was reviewed for all publications using the PAM-13 to include published studies. A manual search of references to full-text studies was performed in duplicate. The authors were not contacted further. The included studies were assessed for quality and risk of bias using a specific quality assessment for each study design (Cochrane risk of bias tool for

randomised controlled trials, National Institute of Health Quality Assessment for Cohort and Cross-sectional Studies, and the British Medical Journal quality assessment tool for qualitative research).<sup>22–24</sup> No data synthesis or analysis was performed.

## Cross-Sectional Study

The second part of this study was a cross-sectional survey assessing the level of activation of patients with RA in managing their health. The study was observational in nature and was guided using Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).<sup>25</sup> Patients were recruited from rheumatology clinics at King Saud University Medical City (KSUMC), Riyadh, Saudi Arabia.

## Ethical Approval and Consent

The study protocol and consent forms and methods were approved by the King Saud University Institutional Review Board (No. E-19-4363), and information was managed with confidentiality without any patient identifiers in the data collection form. Informed written consent was obtained from a group of participants before commencement of the study. However, due to COVID 19 pandemic the clinics were changed to virtual. The consent was changed to electronic (information sheet was sent via WhatsApp for participants able to read and write and they reply with consent before start of the study). If participant was not able to read or write they were asked if they agree to participate if yes, they were included. For documentation, in the data collection sheet, a check box of consent was marked by the researchers conducting the interview. The verbal consent was also approved by King Saud University Institutional Review Board (No. E-19-4363). The study complies to all Declaration of Helsinki ethical principles for medical research involving human subjects.

## Patients and Recruitment

Adult patients (>18 years of age) with a confirmed RA diagnosis according to the American College of Rheumatology/European League Against Rheumatism 2010 classification criteria<sup>26</sup> were included. Rheumatology care in KSUMC is provided through two different services:

1. General rheumatology clinics: Each clinic usually accommodates 15–20 patients in a standardized care facility.
2. Specialized rheumatology clinics (SRC): Each clinic usually accommodates 10–15 patients evaluated by a multidisciplinary team that includes a rheumatologist, clinical pharmacist, physiotherapist, clinical dietitian, and ultrasound technician. Patients rotate through these different specialties as required. During this multidisciplinary visit, each patient undergoes a complete evaluation of disease outcomes, monitoring of medical therapy safety and efficacy, comorbidity management and evaluation, patient education, and support. The clinics are divided according to commonly encountered illnesses, such as lupus, RA, vasculitis, spondylarthritis, and scleroderma spectrum disease. The SRC were launched in 2017, and approximately 80–90 patients with different rheumatological illnesses were examined and monitored each week. The SRC are novel specialized care and the first of their kind in Saudi Arabia.

Initially, all medical file numbers of patients attending clinics for appointment were reviewed to see those with a confirmed RA diagnosis. Candidate patients were approached, the study protocol was explained, and signed written informed consent was obtained if they agreed to participate. Following this, the patients who agreed to participate were interviewed to collect information using a previously designed form and answer all survey questions in person. However, owing to the coronavirus disease (COVID-19) pandemic and related restrictions, the recruitment methods and consent form process were modified as clinics were shifted to being virtual. Patients with a confirmed RA diagnosis and identified from the clinic electronic database (virtual appointment database). The patients were then contacted and interviewed via telephone and electronic consent was obtained prior to the interview. Patients were recruited for six months between November 2019 and April 2020.

## Variables, Data Source, and Measurements

An electronic data collection sheet was designed using Google Forms before conducting the study. The form included baseline patient sociodemographic data, including age, sex, education, economic status, current work status, and living situation alone or with a spouse or family member. The patients were then asked questions from the PAM survey. The Arabic version of the PAM-

13. was used to evaluate the patients' level of involvement in the self-management of their disease. Insignia Health provided permission to use the PAM-13 along with the Arabic version of the survey (license number:1570198456–1601820856). Insignia Health is the exclusive licencing body for the PAM survey on behalf of its creators and the University of Oregon. In the PAM, patients are asked to rate their statement level of agreement/disagreement using a five-point Likert scale, with the fifth option indicating "not applicable". The measure yields a total score ranging from 0 to 100, where a greater score indicates greater activation. The score is then computed by the company to divide the patients into four possible levels of 1–4; the higher the level, the greater the activation. Other measurements were completed by researchers using medical file reviews on the day of the patients' visit. These measurements included the disease activity score-erythrocyte sedimentation rate-28 (DAS-ESR-28). This involves examining 28 joints for 1) swelling and/or 2) tenderness by the attending physician when possible. The patient is then asked to rate their 3) global health from 0 to 10, where 0 indicates poor health status and 10 indicates excellent status. The three assessments are then fed to a mathematical formula adjusted to a fourth variable, which is either the erythrocyte sedimentation rate (ESR) or C-reactive protein level. Since the study was converted to a telephone interview, missing values in the DAS-ESR were managed by complete case analysis. Here, we used ESR, as the assessment is more prevalent in clinical settings. Other comorbidities and medications at the time of last visit were also collected from patient medical files.

## Bias, Study Size, and Statistical Methods

Patients were included as they presented for a clinic visit. When contacted via telephone, all patients who answered the call and agreed to participate were included. A sample size of more than 75 was recommended by the Insignia Health licencing body for survey validity. Data for the survey were entered into a statistical package and sent to Insignia Health for response analysis. Other information was coded and entered into Statistical Package for Social Sciences (SPSS) version 26.<sup>27</sup> The mean and standard deviation were obtained for normally distributed data; non-normally distributed data are presented as median and interquartile ranges (25th and 75th percentile values). Categorical data are presented as numbers and percentages. The baseline characteristics of patients with different levels of activation were compared using analysis of variance to compare the means of normally distributed data or the Kruskal–Wallis test for non-normally distributed data. For categorical variables, the chi-squared test was used. Multiple linear regression was performed to predict changes in PAM as a continuous variable and its interaction with different factors, considering the effects of common confounders, age, sex, and disease duration, regardless of significance.

## Results

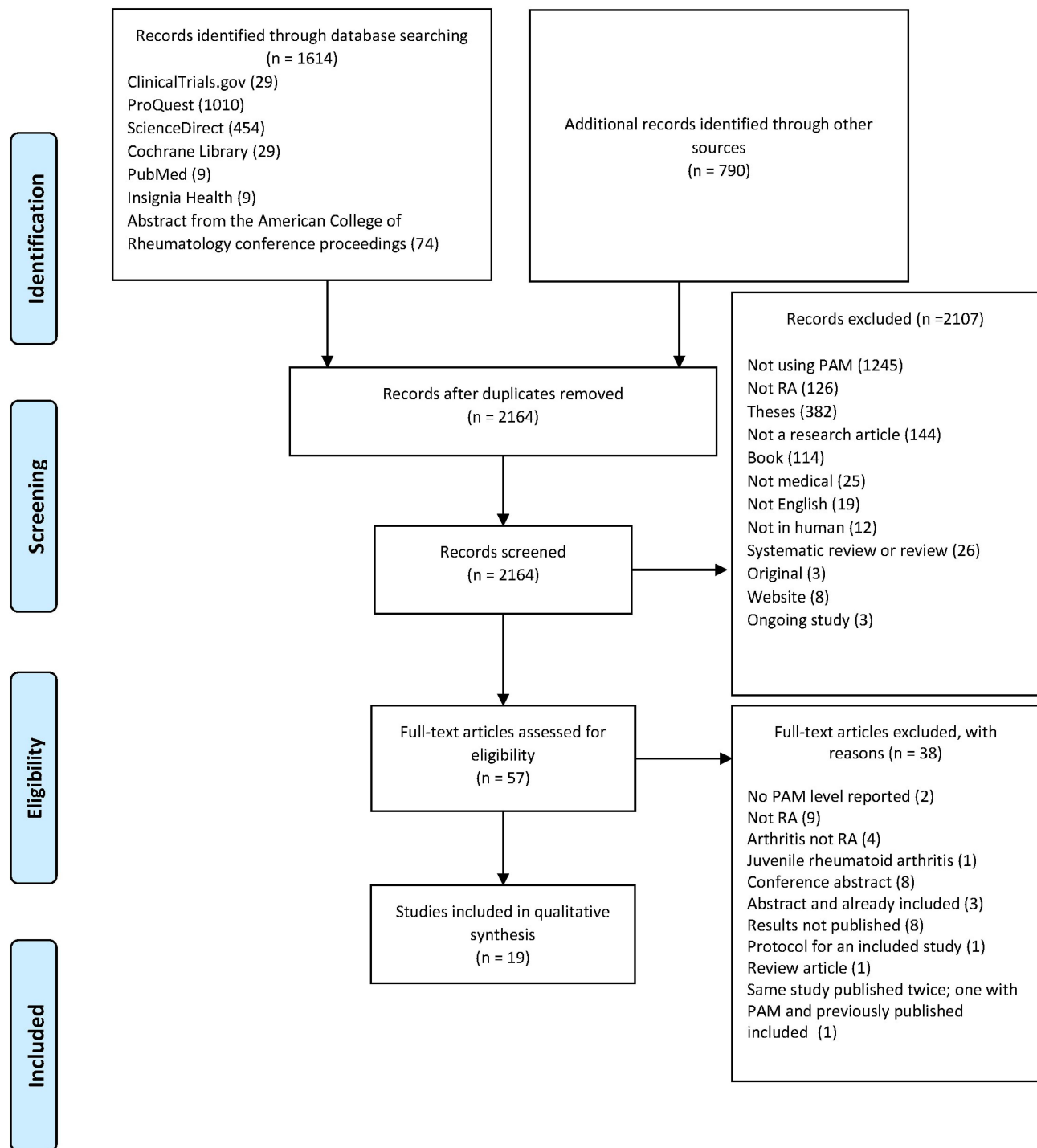
### Systematic Review

When searching the six databases, 2404 records were identified, and 2164 were screened after duplicates were removed. After removing multiple titles and abstracts, 57 titles and abstracts were eligible for full-text review. A total of 19 articles were eligible for qualitative analysis. Data on record screening and exclusion are available in the PRISMA flow diagram, as illustrated in [Figure 1](#). Detailed systematic review records are available ([Supplementary Appendix 2](#)). Owing to the inconsistency in study designs and differences in interventions, combining the results of data synthesis and meta-analysis was not possible. The study designs were different, starting from randomized control trials, cross-sectional, mixed methods, qualitative methods, and cohorts. Some studies had an intervention and thus reported the effect of the intervention on the PAM-13 level as one of the study outcomes, while others reported the PAM in patients with RA or with comorbid RA. Most studies reported patients with RA as part of a chronic illness with the PAM-13 as a continuous variable and did not compute it into levels. The PAM-13 of patients with RA in the 19 studies ranged from 28.8 to 75.8. Quality assessment of each study design ranged from moderate to good quality (50–100% of 14 assessment items). No low-quality studies were available. Information on the results, PAM-13 levels, and quality assessment is available in [Table 1](#). Details on quality assessment ([Supplementary Appendix 3](#)).

### Cross-Sectional Study

#### Demographics

A total of 223 patients visit the clinic and were contacted, 197 were invited, and 26 did not agree to continue the interview due to lack of time, generating a response rate of 88%. Of these, 124 (63.6%) were recruited from SRC. A total of 197 (N=173, 88%)



**Figure 1** PRISMA flow diagram.

**Notes:** Adapted from: Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. doi:10.1136/bmj.n71. Creative Commons Attribution (CC BY 4.0) license (<https://creativecommons.org/licenses/by/4.0/legalcode>).<sup>52</sup>

**Abbreviations:** PAM, patient activation measure; RA, rheumatoid arthritis.

were female and seropositive (69%), with a mean ( $\pm$ standard deviation [SD]) age and disease duration of 50.0 ( $\pm$ 12.2) and 13.5 ( $\pm$ 7.8) years, respectively. Background medications included conventional synthetic disease-modifying antirheumatic drugs (csDMARDs) (50.3%), biologics/small molecules (43.1%), and prednisolone (14.1%). The DAS28 median (interquartile range) was 1.14 (0.00–2.46) with 126 (69.6%) achieving either remission or low disease activity. A total of 119 (60%) patients had middle to high level of education. Additionally, 120 (91%) were unemployed and 109 (55%) had a low to intermediate

**Table 1** Summary of Included Articles on Patient Activation Measure and Rheumatoid Arthritis with Quality Assessment

No.	Author	Year	Country	Study Design	Study Settings	Population	Intervention	PAM Level	Limitations with Regards to PAM	Conclusion	Quality Assessment (Number and % out of 14 Checklist Items)
Interventional studies											
1	Zuidema et al <sup>38</sup>	2019	Netherlands	Randomized Control Trial	2 Dutch hospitals	157 patients with RA	Web-based self-management enhancing program	Control group mean 46.9 ( $\pm$ 4.9), intervention 47.2 ( $\pm$ 3.7)	PAM was reported as a continuous variable and was not computed to levels	No positive effects of the program were detected	9 (64%)
2	Mollard et al <sup>39</sup>	2018	US	Mixed methods	University hospital in Nebraska	63 patients with RA	Live With Arthritis app	Intervention 67.4, control 71.9	PAM was reported as a continuous variable and was not computed to levels	The PAM was negatively correlated with non-significant changes of HAQ-II (Pearson correlations: $-0.33$ , $p = 0.10$ )	11 (79%) For qualitative part 3 (21%)

3	Van Den Bosch et al <sup>19</sup>	2017	Europe, Israel, Mexico, Puerto Rico, and Australia	Observational study (cohort)	Australia, Belgium, Czech Republic, France, Germany, Greece, Israel, Mexico, Netherlands, Portugal, Puerto Rico, Slovakia, Switzerland, and the United Kingdom	1025 patients with RA	Patient support programs (PSP) and instructions on how to use adalimumab	PSP users mean score 60.7 ( $\pm 15.3$ ), non-users 58.9 ( $\pm 14.6$ )	Focusing on adalimumab treatment, PAM was reported as a continuous variable and was not computed to levels	The percentage of patients that demonstrated improvement in PAM-13 levels was significantly higher among PSP users vs PSP non-users (35.7 vs 28.1%, $p = 0.01$ ). Compared to PSP users, PSP non-users had a significantly higher percentage of patients that started at PAM-13 level 4 at baseline and remained at level 4 until week 78 of ADA treatment (64.5 vs 53.8%, $p = 0.028$ ).	12 (86%)
4	Gronning et al <sup>42</sup>	2016	Norway	Qualitative study within the published randomized control trial	University hospital	Adult RA patients last included in the randomized control trial	Nurse-led hospital-based patient education program	26 (intervention 15, control 11) PAM of intervention group 73, of control group 70	A small group of which had RA	The experiences from the Patients in the nurse-led patient education program were in concordance with the pathway of self-efficacy and patient activation, which many patient education programs are based on	10 (71%)

(Continued)



Table I (Continued).

No.	Author	Year	Country	Study Design	Study Settings	Population	Intervention	PAM Level	Limitations with Regards to PAM	Conclusion	Quality Assessment (Number and % out of 14 Checklist Items)
5	Joplin et al <sup>40</sup>	2014	Australia	Cohort	Mid-North Coast Arthritis Clinic (MNCAC), a community-based rheumatology practice in Coffs Harbour	18 patients with RA	Joint ultrasound	60.0 ( $\pm 15.5$ ) at baseline	Very small sample size, PAM was reported as a continuous variable and was not computed to levels	PAM-13 scores did not change during the study. The study, with levels of activation at T1, T2, and T3 of 60.0 ( $\pm 15.5$ ), 55.7 ( $\pm 12.0$ ) and 57.8 ( $\pm 14.8$ ) ( $p = 0.21$ ), respectively.	7 (50%)
6–8	Gronning et al <sup>41,49</sup> follow-up study after 5 years <sup>50</sup>	2012, 2013, 2019	Norway	Randomized control trial	University hospital	141 of which a group of patients had RA 101 follow-up 63 of which had RA	Nurse-led hospital-based patient education program	Reports of the first study include intervention PAM 65.7 ( $\pm 13.3$ ), control PAM 65.6 ( $\pm 16.4$ )	Not all patients had RA, the exact number of RA patients was not mentioned, PAM was reported as a continuous variable and was not computed to levels	Reported results at 4 and 12 months, then 5 years follow-up. A significant improvement of PAM scores among women with intervention at 12 months, mean change 4.2 (0.0, 8.3, $p = 0.048$ ).	11 (79%)



9	Sandhu et al <sup>43</sup>	2012	Canada	Qualitative Pilot before and after study	Patients were recruited either from the primary care clinic in Toronto or via email sent from the Arthritis Society in Canada	Mentors: Adult patients with IA for more than 2 years and receiving drug therapy Mentees: adult patients with early IA	In the mentor training program, the mentee was assessed before and after pairing with a mentor	17 (9 mentors, 8 mentees PAM of mentees mean 75.80 (SD 73.11) p= 11.75 effect size 0.22	A very small number of patients as it is mainly qualitative and IA was not clear if it was RA or not	No difference between groups with regards to PAM level	10 (71%)
Non-interventional studies											
10	Jones et al <sup>32</sup>	2021	UK	Qualitative Semi-structured interviews at two timepoints	Patient were recruited from two rheumatology departments in south west England	17 participants total, 13 of which had RA	None	Participants demonstrated high levels of patient activation Four were at level 2, four at level 3 and six at level 4	Did not mention the exact level and RA patient were not assessed separately	Patients' perceptions and experiences of patient activation covered are not always captured by the PAM	14 (100%)
11	Huang et al <sup>33</sup>	2021	Singapore	Cross-sectional	Specialist outpatient clinics of a tertiary hospital in Singapore	200 participants with chronic conditions 56 of which had other chronic conditions including RA	None	The mean activation score was 58.8 (SD = 15.0)	Small number of participants and RA patient were not assessed separately	Some factors as age, income, education and health literacy are factors contributing to change in patient activation	9 (64%)

(Continued)

Table 1 (Continued).

No.	Author	Year	Country	Study Design	Study Settings	Population	Intervention	PAM Level	Limitations with Regards to PAM	Conclusion	Quality Assessment (Number and % out of 14 Checklist Items)
12	Zakeri et al <sup>35</sup>	2021	Iran	Cross-sectional	Chronic patients admitted to the Cardiac Care Unit and medical wards in Ali Ibn Abitaleb Hospital of Rafsanjan	293 patients with chronic conditions 33 had other conditions including RA	None	The mean score of PAM-13 was 56:99 ± 15:32	Small number of participants and RA patient were not assessed separately	The physical and psychological subscales of Quality Of Life (QOL) significantly predicted the levels of PAM	9 (64%)
13	Kosar et al <sup>30</sup>	2019	Turkey	Cross-sectional	University Hospital in Izmer	130 a group of which had RA	None	PAM scores of the patients ranged from 28.8% to 83.3%. Up to 28.7% of patients were in activation level 1, 44.9% were in activation level 2, 20.2% were in activation level 3 and 6.2% were in activation level 4.	130 patients of which patients with RA, did not mention the exact number	Validity study of PAM-13 in Turkish	9 (64%)

14	McBain et al <sup>31</sup>	2018	UK	Cross-sectional	National Rheumatoid Arthritis Society, UK	841 (95%) had RA	None	PAM was 57.8 ( $\pm 15.5$ ). The samples were evenly split across the 4 levels of activation, 251 (28.4%) level 1, 182 (20.6%) at level 2, 204 (23.1%) at level 3 and 248 (28.0%) at level 4.	Not all patients had RA	Only a small proportion of patients attended a self-management structure support program.	8 (57%)
15	Lofland et al <sup>37</sup>	2017	US	Cross-sectional survey and cost cohort	Claims database	Adult patients receiving biologics	None	453 responders to the cross-sectional survey to assess shared decision making. PAM scores SDM vs non-SDM: 66.9 vs 61.6; $P < 0.001$	RA patients were combined with PsA patients	Patient with SDM had a significantly greater PAM score	11 (79%)
16	Graffigna et al <sup>34</sup>	2017	Italy	Cross-sectional	Online panel provided by Research Now (secondary database)	Patients over 18 years of age and with chronic conditions	None	352 (11.1%) had RA meaning 39 patients Mean PAM of all patients was 65.3 (range 0–100)	Reported PAM was for the entire population and limited number with RA	Mean PAM of all patients was 65.3 (range 0–100)	10 (71%)

(Continued)

Table 1 (Continued).

No.	Author	Year	Country	Study Design	Study Settings	Population	Intervention	PAM Level	Limitations with Regards to PAM	Conclusion	Quality Assessment (Number and % out of 14 Checklist Items)
17	Blakemore et al <sup>13</sup>	2016	UK	Cohort	Cohort study database	Patients $\geq$ 65 years having at least one long-term condition	None	3390 PAM at baseline 60.8 (SD 15.4), at follow-up 60.3 (SD 20.0), no difference	Patients with RA were combined with all other illnesses and not clear as a separate group	No difference at baseline compared to follow-up with regards to PAM level	11 (79%)
18	Jones et al <sup>51</sup>	2021	UK	Cross-sectional	Six rheumatology clinics in England	Patients > 18 with an inflammatory rheumatic condition including RA, PsA and AS or SLE	None	166 (66%) patients had RA, PAM was 58.3 (SD 11.5)	Patients with RA were combined with all other illnesses and not clear as a separate group	Self-efficacy and health literacy are targets for patient activation interventions	9 (64%)
19	Oliveria et al <sup>36</sup>	2021	Brazil	Cross-sectional	Rheumatology outpatient facility at a high-complexity teaching hospital in Brazil	179 patients > 18 years with RA, having at least one year of formal education and being able to read and not having neurological or psychiatric disorders that affect cognition, and having enough visual acuity to read.	None	The average PAM-13 was 65.72, with 10.1% very low activation level, 15.6% having a low activation level, 39.1% moderate activation level and 35.2% having a high activation level.	None	Activation and health literacy are very important in RA patients and improving them could increase functional capacity	8 (57%)

average income. The patients lived with a minimum of one family member (187, 95%) and had other comorbidities (114, 58%; Table 2).

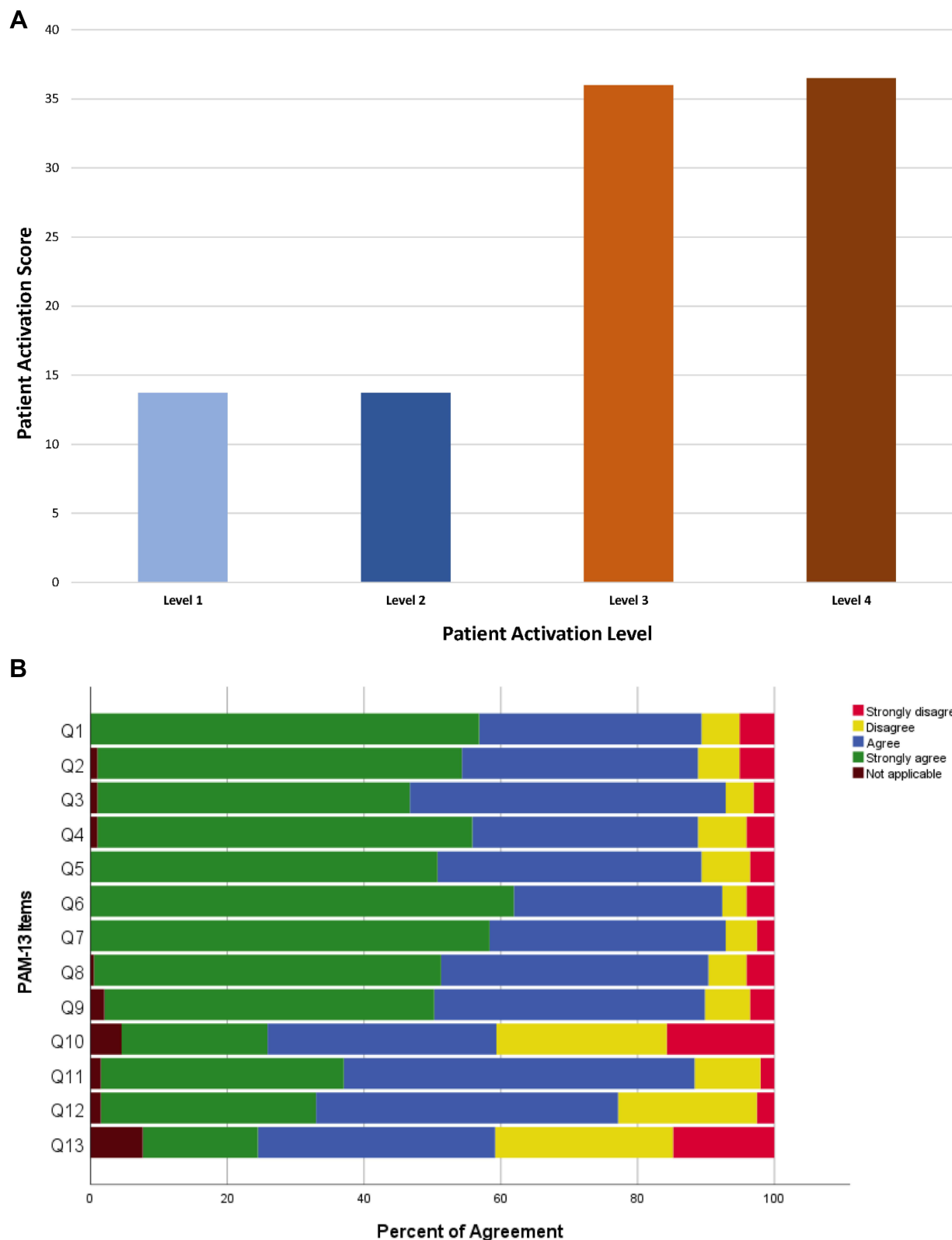
## Patient Activation Measure Scores

The mean PAM score was 64.9 ( $\pm 15.7$ ). Most patients were categorized as levels 3 and 4 PAM (71, 36%, 72, and 37%), with patients mostly agreeing on the 13 items of the PAM survey, as indicated in Figure 2A and B. Patients with levels 1 and 2 were in a minority, with the same number in both groups (27, 14%). The responses and level

**Table 2** Baseline demographics of Patients with Univariate Analysis of Difference Between Activation Levels

Patient Activation Level		Level 1 n=27	Level 2 n=27	Level 3 n=71	Level 4 n=72	Total n=197	p value
Sex, female (%)		24 (13.9)	27 (15.6)	60 (34.7)	62 (35.8)	173 (87.8)	0.195
Age, mean years, (SD)		53.1 (11.6)	49.6 (11.4)	52.4 (13.2)	46.9 (11.0)	50.0 (12.2)	0.024*
<b>Age (%)</b>							
≤40 years		3 (6.4)	6 (12.8)	15 (31.9)	23 (48.9)	47 (23.9)	0.149
>40 years		24 (16.0)	21 (14.0)	56 (37.3)	49 (32.7)	150 (76.1)	
<b>Type of clinic, (%)</b>							
Specialized multidisciplinary		17 (13.7)	14 (11.8)	46 (37.1)	47 (37.9)	124 (63.6)	0.594
Standard of care		9 (12.7)	13 (18.3)	25 (35.2)	24 (33.8)	71 (36.4)	
<b>Education (%)</b>							
<b>None to low</b>	Uneducated, primary, and middle school	15 (19.2)	9 (11.5)	30 (38.5)	24 (30.8)	78 (39.6)	0.194
<b>Intermediate to high</b>	High school, diploma, university and above	12 (10.1)	18 (15.1)	41 (34.5)	48 (40.3)	119 (60.4)	
<b>Income (%)</b>							
Low to intermediate		20 (13.4)	23 (15.4)	50 (33.6)	56 (37.6)	149 (75.6)	0.458
High		5 (12.2)	11 (26.8)	8 (19.5)	17 (41.5)	48 (24.4)	
<b>Working (%)</b>		5 (9.3)	9 (16.7)	15 (27.8)	25 (46.3)	54 (27.4)	0.180
<b>Living arrangements (%)</b>							
With family member		26 (13.9)	25 (13.4)	67 (35.8)	69 (36.9)	187 (94.9)	0.901
Alone		1 (10.0)	2 (20.0)	4 (40.0)	3 (30.0)	10 (5.1)	
<b>Other comorbidities (%)</b>							
One or less		16 (11.2)	22 (15.4)	50 (35.0)	55 (38.5)	143 (72.6)	0.243
More than one		11 (20.4)	5 (9.3)	21 (38.9)	17 (31.5)	54 (27.4)	
<b>Depression (%)</b>		3 (37.5)	0 (0.0)	1 (12.5)	4 (50.0)	8 (4.1)	0.099
<b>Other medication (%)</b>		1 (5.9)	3 (17.6)	7 (41.2)	6 (35.3)	17 (8.6)	0.756
<b>Supplements</b>		2 (5.9)	8 (23.5)	10 (29.4)	14 (41.2)	34 (17.3)	0.140

Note: \*Significance level at  $p < 0.05$ .



**Figure 2 (A)** Distribution of patients by PAM level. **(B)** Individual responses of patients using PAM survey (green indicates strongly agree).

distribution of patients are illustrated in Figure 2A and B. When conducting univariate analysis between different PAM groups, all were comparable except age, which was lower in the level group with a p-value of 0.024 (Tables 2 and 3).

**Table 3** Rheumatoid Arthritis-Related Information with Univariate Analysis and Resulting p values for Differences Between Activation Levels

Patient Activation Level	Level 1	Level 2	Level 3	Level 4	Total	p value
<b>Seropositivity (%)</b>						
Positive	9 (11.0)	15 (18.3)	32 (39.0)	26 (31.7)	82 (68.9)	0.399
<b>Erythrocyte sedimentation Rate (standard deviation)</b>						
	32 (28)	39 (30)	31 (30)	27 (23)	31 (28)	0.339
<b>Disease duration, years</b>						
	11.4 (6.6)	13.4 (8.8)	14.9 (7.1)	12.8 (8.3)	13.5 (7.8)	0.198
<b>Disease duration (%)</b>						
Early ( $\leq 2$ years)	2 (33.3)	1 (16.7)	1 (16.7)	2 (33.3)	6 (3.1)	0.466
Established ( $> 2$ years)	24 (12.7)	26 (13.8)	69 (36.5)	70 (37.0)	189 (96.9)	
<b>Disease activity score - erythrocyte sedimentation rate (%)</b>						
DAS28-ESR median (IQR)	1.21 (0.00–2.46)	2.41 (0.00–3.18)	0.68 (0.00–3.03)	0.87 (0.00–2.64)	1.14 (0.00–2.46)	0.822
Remission to mild	19 (15.1)	18 (14.3)	42 (33.3)	47 (37.3)	126 (69.6)	0.271
Moderate to severe	4 (7.3)	9 (16.4)	25 (45.5)	17 (30.9)	55 (30.4)	
<b>csDMARDs</b>						
	11 (11.1)	17 (17.2)	33 (33.3)	38 (38.4)	99 (50.3)	0.346
<b>TNFi, non-TNFi, small molecule agents</b>						
	8 (9.4)	16 (18.8)	33 (38.8)	28 (32.9)	85 (43.1)	0.126
<b>Corticosteroids (%)</b>						
	1 (3.4)	5 (17.2)	12 (41.4)	11 (37.9)	29 (14.7)	0.361
<b>NSAIDs (%)</b>						
	0 (0.0)	3 (27.3)	4 (36.4)	4 (36.4)	11 (5.6)	0.367

Note: \*Significance level according to  $p < 0.05$ .

In multiple linear regression, all assumptions were met except for the normality of the dependent variable. However, since the significance of normality in regression is uncertain and  $N > 50$  in this study, we continued with the regression.<sup>28,29</sup> On applying simple regression to the possible confounding variables (age, sex, and disease duration), no prediction was statistically significant except for the type of clinic ( $p = 0.050$ ), which may be considered borderline significant. Although most models were not significant, also keeping in mind that confidence intervals were wide, some direction of higher PAM trended with younger patients, being male, established RA, higher education, lower income, working, living alone, having one comorbidity, no depression, seropositive, more disease activity, less use of other medications, more csDMARDs, more biologics, more prednisolone, and fewer NSAIDs. Patients recruited from SRC also had borderline significantly higher PAM levels (Table 4).

**Table 4** Multiple Linear Regression Predicting Factors That Influence Patient Activation Measurements Displayed as a Continuous Variable

Factor	PAM Mean (SD)	Beta	p value	95% Confidence Intervals
<b>Age</b>				
Age, years		-0.166	0.072	-0.347 to 0.015
$\leq 40$	67.8 (12.3)			
$> 40$	64.0 (16.4)	-3.823	0.147	-9.00 to 1.354

(Continued)



**Table 4** (Continued).

Factor		PAM Mean (SD)	Beta	p value	95% Confidence Intervals
<b>Sex</b>					
Female		64.3 (15.3)			
Male		69.1 (18.4)	4.824	0.160	-1.924 to 11.572
<b>Disease duration</b>					
Duration, years			0.030	0.833	-0.254 to 0.315
Early		58.8 (22.3)			
Established		65.3 (15.4)	6.924	0.287	-5.863 to 19.710
<b>Factors adjusted to age, sex, and disease duration regardless of significance</b>					
<b>Education Level</b>					
None to low	Uneducated, primary, and middle school	62.7 (17.5)			
Middle-High	High school, diploma, university, and above	66.3 (14.4)	1.587	0.532	-3.415 to 6.589
<b>Income</b>					
Low		65.1 (16.1)			
High		64.3 (14.6)	-1.171	0.657	-6.367 to 4.023
<b>Work status</b>					
No		64.0 (15.9)			
Yes		67.3 (15.3)	1.190	0.678	-4.449 to 6.830
<b>Living</b>					
With family		65.0 (15.8)			
Alone		63.0 (15.2)	0.304	0.953	-9.798 to 10.4.7
<b>Other comorbidities</b>					
One or more		65.8 (16.3)			
More than one		62.5 (16.8)	-0.942	0.736	-6.450 to 4.566
<b>Depression</b>					
No		65.0 (15.8)			
Yes		62.1 (13.8)	-2.028	0.716	-13.120 to 9.064
<b>Seropositivity (rheumatoid factor or anti-citrullinated peptide positive)</b>					
Negative		66.3 (16.0)			
Positive		63.8 (15.5)	-2.181	0.491	-8.442 to 4.079
<b>DAS-ESR</b>					
DAS28-ESR continuous			0.321	0.594	-0.866 to 1.507

(Continued)

Table 4 (Continued).

Factor	PAM Mean (SD)	Beta	p value	95% Confidence Intervals
Remission to mild	64.5 (16.5)			
Moderate to sever	65.6 (13.7)	1.781	0.486	-3.254 to 6.817
<b>Other medication</b>				
No	65.1 (15.9)			
Yes	62.9 (14.8)	-2.103	0.607	-10.145 to 5.939
<b>csDMARDs</b>				
No	63.9 (16.2)			
Yes	65.9 (15.3)	2.905	0.204	-1.594 to 7.404
<b>TNFi, non-TNFi, and small-molecule agents</b>				
No	65.1 (16.7)			
Yes	64.6 (14.5)	-1.800	0.437	-6.358 to 2.758
<b>CS</b>				
No	64.4 (16.4)			
Yes	67.6 (11.0)	3.868	0.228	-2.438 to 10.175
<b>NSAIDs</b>				
No	65.0 (16.0)			
Yes	63.5 (12.2)	-1.012	0.835	-10.576 to 8.551
<b>Type of clinic</b>				
Specialised multidisciplinary	66.5 (16.2)			
Standard of care	62.2 (14.6)	-4.570	0.050	-9.146 to 0.006

Notes: \*Significance level according to  $p < 0.05$ .<sup>52</sup>

**Abbreviations:** PAM, patient activation measure; SD, standard deviation; csDMARDs, conventional disease-modifying antirheumatic drugs, including methotrexate, sulfasalazine, hydroxychloroquine, leflunomide, or mycophenolate; TNFi biologics, tumor necrosis factor inhibitors, including adalimumab, etanercept, certolizumab, or infliximab; non-TNFi, non-tumor necrosis factor inhibitors, including abatacept, rituximab, or tocilizumab; NSAIDs, non-steroidal anti-inflammatory drugs; IQR, interquartile range.

## Discussion

The present study is the first systematic review reporting the PAM in patients with RA. In the systematic review total of 19 studies on the PAM-13 in RA were identified. Ten studies measured the level of activation without any intervention, such as the Turkish study by Kosar et al which reported a small number of patients (26.4%) achieving a level of 3 or 4.<sup>30</sup> However, Bain et al reported higher activation in more than half of the patients at levels 3 and 4.<sup>31</sup> Jones et al also reported high levels of patient activation in their study sample (n=17), four of which were at level 2, four at level 3, and six at level 4.<sup>32</sup> Four other studies from the United Kingdom, Italy, Singapore, Brazil and Iran only reported mean PAM without categorization.<sup>13,32-36</sup> Lofland et al assessed the PAM in patients who initiated biologics and the impact of adequate shared decision-making.<sup>37</sup> A higher mean PAM was observed in patients who had adequate shared decision-making ( $p < 0.001$ ). The remaining nine studies applied different interventions with variable reporting. Zuidema et al randomized 157 patients to usual care and usual care plus access to a comprehensive unguided web-based program containing nine modules with 13 objectives.<sup>38</sup> The study showed a significant improvement, which could be partly

explained by the dropout level and incomplete responses.<sup>38</sup> Mollard and Michaud evaluated the impact of using a mobile application called LiveWith Arthritis (eTreatMD, Vancouver, BC) on self-management behaviors in a small sample of patients. The Patient-Reported Outcomes Measurement Information System Self-Efficacy Managing Symptoms score was significantly better in the intervention group ( $p=0.04$ ); however, the PAM changes were not significant ( $p = 0.48$ ). Similarly, the main challenge was the large dropout rate, which could have affected the study results.<sup>39</sup> The PASSION study was a post-marketing study sponsored by ABBVIE that compared the introduction of patients to a patient support program (PSP) vs usual care. PAM levels were measured at baseline and 78 weeks. All outcome measures improved in the PSP group, including the PAM score (35.7 vs 28.1%,  $p=0.01$ ).<sup>19</sup> Joplin et al conducted a pilot study on the effect of ultrasound on patients' perception of the need for medication change. The primary outcome was met with an improved decision; however, it did not impact the mean PAM.<sup>40</sup> Grønning et al conducted a long-term nurse-led program on a mixed Norwegian population that included patients with RA. The intervention included group sessions moderated by two nurses, followed by individual educational sessions. After the randomization period, all patients were invited to participate in the program. At 12 months, a trend toward improved PAM was confirmed at the 5-year follow-up ( $p = 0.024$ ).<sup>41</sup> This was followed by a qualitative study of patients who participated in the trial.<sup>42</sup> Sandhu et al paired patients with inflammatory arthritis and a disease duration of >2 years (mentors) with patients with early inflammatory arthritis and a disease duration of <1 year (mentees). Nine pairs interacted for 12 weeks with mentees experiencing improvements in the overall impact of arthritis on life, coping efficacy, and social support, with no impact on PAM scores.<sup>43</sup>

The findings of the cross-sectional study and in comparison, with reviewed literature showed that patients with RA had high activation scores in our center, with additional and possible positive impact of the multidisciplinary team on engagement. We also found that all patients were engaged equally and that no demographic, disease, and drug factors measured in this study differed statistically from these high scores except age and were adjusted for in the analysis. Patients participating in this study were provided with specialized healthcare experiences that may explain these high level scores. High activation levels were also observed in patients with atrial fibrillation treated at an academic medical center specialist clinic.<sup>44</sup>

In the general rheumatology clinic standard of care, patients visited rheumatology consultants every 3–6 months as per international guidelines, where laboratory tests for drug safety and efficacy and monitoring disease progression were performed. In addition, patients visit drug monitoring clinics to refill important medications and determine if the patient needs more frequent monitoring. However, the only team that patients encountered was medical rheumatology. The provision of specialized information tailored to patient needs has been associated with high activation levels in multidisciplinary clinic practice.<sup>45</sup> In addition, care provided by a multidisciplinary team has been associated with high activation levels, as observed in this study and another study of patients with metabolic syndrome.<sup>46,47</sup> In a systematic review published by Bearne et al multidisciplinary team care was not associated with improved outcomes in terms of disease activity, disability, or quality of life.<sup>48</sup> With the acknowledgment that the  $p$  value of specialized clinics was borderline significant, no published study has evaluated the impact of multidisciplinary team care on patient activation, and we believe that our study is the first to possibly indicate a positive impact of multidisciplinary care on health outcomes. This could be explained by the design of the SRC and staff providing care. We could not precisely determine which intervention in this model played a major role in improving patient activation.

To the best of our knowledge, this is the first published study in Saudi Arabia to identify patient activation scores for chronic diseases. Although it provides important insights into the patient activation level in Saudi Arabia, there are limitations to the generalization of the results. This study was conducted analyzing a clinical setting that provided specialized, centered patient care with no representation of patients attending primary clinics. This study emphasized the impact of specialized patient-centered care on patient activation as an intermediate outcome of care, which is linked to improved clinical outcomes.<sup>3</sup> Different patient settings are required to understand the impact of clinical services on patient activation in Saudi Arabia. Another important limitation is that this is a cross-sectional study with no longitudinal analysis to follow the changes in activation level; it only provides a snapshot of the level of patient activation in certain settings.

For future recommendations, more studies using different quantitative and qualitative methods are needed. A replicate of this study is required using multiple centers and different clinical settings to compare the impact of specialized clinics

to standard care and identify this as a factor in improving patient engagement in treating patients with RA. Qualitative studies exploring the patient's point of view are needed to gain a deeper understanding of cultural, religious, and social factors, which may affect patient activation levels. Further research should be conducted to compare patients with RA in primary care centers and other general RA clinics in Saudi Arabia. A deeper investigation should be carried out in patients who participated in this study to understand the way patients with high activation scores communicate with healthcare professionals involved in the provision of their care, identify alarming signs and report them, monitor their disease, improve medication adherence, and their involvement in appropriate health behaviors including exercise, diet, check-ups, and avoiding smoking and other unhealthy behaviors.

The limitations of the present study include the cross-sectional design and unmatched sample owing to the impact of the COVID-19 pandemic on the recruitment process. In addition, we did not assess other characteristics that might be important, such as disability and quality of life measures, which are potential subjects for future studies. The study findings cannot be generalized, as most patients were women and had established RA. Finally, the SRC model requires specific settings and cannot be easily applied to other institutions.

From the studies mentioned above, we noticed that there are limited studies that have evaluated patient activation in patients with RA. In interventional studies, small sample size, short study duration, and large dropout rate were the most important factors affecting study results. Our study provides promising results on the impact of multidisciplinary care patient activation and may be used as a model for national health transformation in Saudi Arabia.

## Conclusion

In conclusion, we observed adequate activation of patients from our center compared to the published literature, with borderline higher levels in the SRC group. Longitudinal interventional studies should be considered to improve activation in patients with low scores.

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## Disclosure

The authors report no conflicts of interest in this work.

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