

RESEARCH ARTICLE

Rheumatology patients' perceptions of patient activation and the Patient Activation Measure: A qualitative interview study

Bethan Jones^{1,2}  | Andrew Hunt² | Sarah Hewlett¹ | Diana Harcourt¹ | Emma Dures^{1,2}

¹Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK

²Academic Rheumatology, Bristol Royal Infirmary, Bristol, UK

Correspondence

Bethan Jones, Faculty of Health and Applied Sciences, University of the West of England, Rheumatology Research, Bristol Royal Infirmary, Upper Maudlin Street, Bristol, BS2 8HW, UK.
Email: bethan15.jones@uwe.ac.uk

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Abstract

Introduction: An important aspect of self-management is patient activation (the skills, abilities and confidence someone uses to actively manage their health). The dominant method of capturing patient activation is the Patient Activation Measure (PAM) which has been integrated into many aspects of clinical practice in musculoskeletal care. However, limited research has investigated how rheumatology patients understand and perform patient activation, and how closely their perceptions align with the PAM.

Methods: Seventeen patients from two rheumatology departments in South West England participated in semi-structured interviews at two timepoints. They discussed how they actively managed their health and their views on the PAM. Data on activation were analysed using framework analysis and data on the PAM were analysed using content analysis.

Results: Participants self-managed with determination, finding ways to make small, sustainable behaviour changes and effectively navigate the healthcare system. They reported the value of knowing what self-management techniques suited them individually and reported benefitting from positive perceptions of their own health and good social support. Participants noted that the PAM did not always capture the fluctuating nature of their inflammatory arthritis and the collaborative nature of healthcare.

Conclusions: Patients' perceptions and experiences of patient activation covered a wide range of skills, behaviours and beliefs. However, these are not always captured by the PAM. Therefore, its use as a clinical tool is best accompanied by dialogue with patients to understand their self-management.

KEYWORDS

interview, qualitative research, self-management

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1 | INTRODUCTION

Patient activation describes someone's willingness and ability to take an active role in dealing with their health and covers the skills, abilities and confidence that people use to self-manage (Hibbard & Greene, 2013). Evidence shows that when patients are supported to become more activated, they benefit from better health outcomes, greater confidence and control over their condition, and fewer emergency admissions (Dixon et al., 2009; Rijken et al., 2014).

The dominant outcome measure for patient activation is the Patient Activation Measure (PAM) (Hibbard et al., 2004, 2005). The PAM was developed to support the design, targeting and evaluation of self-management support. It captures patients' knowledge, confidence and skills to take an active role in managing their health but does not report these domains separately. The PAM categorises patients into four developmental stages of patient activation with scores corresponding to levels (Greene et al., 2015). These are as follows:

1. Level 1 (score below 47), where patients are completely passive in health management.
2. Level 2 (score between 47.1 and 55), where patients are aware that they could take active responsibility for their health, but there is much they are unable or unwilling to do.
3. Level 3 (score between 55.1 and 72.4), where patients are taking active responsibility for their condition and continuing to develop skills and confidence.
4. Level 4 (score above 72.5), where patients are able to sustain active health management, including after a setback.

The measure was developed and refined using qualitative methods, literature reviewing and piloting (Hibbard, Stockard, et al., 2004). The algorithm that calculates scores and levels from the raw data is not publicly available. Rasch analysis has resulted in several versions of the measure as items are removed, but the most common version and the one used in this study is the 13-item PAM. The proposed meaningful clinically important difference for the PAM is 4 points on the scale of 0–100 (Anderson & Wallace, 2018).

Since the initial development of the PAM, both the measure and the concept of patient activation have increasingly become the focus of work to support patients to manage their health (Roberts et al., 2016). The measure has been implemented into health care in the NHS and internationally to tailor and evaluate self-management support (Armstrong et al., 2016). Consequently, studies have begun to explore the relevance of the PAM to patients with various health conditions, and to understand how they interpret the items and apply them to their specific conditions. This has raised critiques from patients around complexity of the language in some of the items of the PAM and vague phrasing meant that patients were concerned about misunderstanding in their responses (Ngooi et al., 2018). Interviews with patients with cardiac and respiratory conditions have also

identified an occasional mismatch between PAM-determined patient activation and patients' perceptions of how actively they managed their health (Gao et al., 2019).

There has currently been limited research into patient activation and rheumatic conditions. Understanding patient activation from a patient perspective can add context to the use of the PAM as a clinical tool in musculoskeletal care. This study aimed to explore patient perceptions of patient activation and the extent to which these aligned with, and were captured by, the PAM.

2 | AIM

To explore how patients with inflammatory arthritis perceive and understand patient activation.

3 | ETHICS

Ethics approval to carry out this research was granted by the West of Scotland 4 Research Ethics Committee (reference 17/WS/0143) and ratified by UWE Bristol (reference 17.08.007). The study was conducted in accordance with the Declaration of Helsinki.

4 | PATIENT INVOLVEMENT

A patient research partner (AH) contributed throughout. He reviewed study materials and piloted the interview schedules with (BJ) who conducted the interviews. He was also involved in discussing the results and implications of both interview datasets to ensure that they reflected patients' experiences. The first interview schedule (see Figure 1) was also shared with a local Patient Advisory Group to gather a range of perspectives.

5 | METHODS

The research was conducted as part of a wider project with a pragmatic epistemology. This allows the research question to be more of a consideration than the lens through which the phenomena are studied (Hanson et al., 2005). The study was conducted with an underpinning phenomenological qualitative orientation that looks to understand peoples' perceptions of their experiences and their world (Robson, 2011).

The study was longitudinal, with participants invited to take part in two face-to-face interviews approximately 12 months apart. This was to explore whether patients' perspectives on patient activation changed over time. These semi-structured interviews were conducted in non-clinical rooms at two hospital sites in the South West of England.

The intention was to interview patients who were experienced and skilled self-managers to understand how they had learned to actively self-manage. Therefore, while the participants were

Part A: People's experiences of actively managing their condition.

1. Tell me a little about your experience of having arthritis (symptoms, life impact)
2. Interested in the impact of arthritis on your life. What kind of things did you learn when you were beginning to manage your arthritis?
 - How did you find this out?
 - Did you try other things before then? What wasn't helpful?
 - Are there aspects of your arthritis that you find particularly challenging to deal with?
 - How do you manage your health now?
3. What kind of decisions do you make around your arthritis? These can be about broader things medications or treatments, or ways in which you've had to change your lifestyle. They can also be smaller ones, like how you manage your daily activities.
 - What prompts you to make these decisions?
 - How did the last decision go?

Part B: Identifying individual and contextual factors that contribute to active management

4. Interested in the kind of things you can do to help your arthritis, and the things that others also do to help your arthritis. What sort of things do you do to help your arthritis?
 - What other people are involved in helping with your arthritis? What do they do?
 - How does that factor impact your health? How do you manage that?
 - What things are most important for you to manage your arthritis?
5. What sort of relationship do you have with your health care team? How do they support you?
6. How do you know if you need more support, or information about your arthritis?
 - What do you tend to do then?
 - If you were talking to a new patient, what would be your top tip for dealing with arthritis?

Part C: Exploring perceptions of "Patient activation"

7. If I used the term "patient activation", what would that mean to you? You may not have heard it before, so what would you guess it means? (Clarify if necessary)
8. Can I tell you what some researchers think it means?
 - Give definition "skills, ability and likelihood that someone will take an active role in managing their health". What do you make of that?
 - How does that fit in with the experiences you described to me earlier?
 - Describe what active health management means to you, and what that would look like with your condition. How closely does what you do now fit that?
 - (If applicable) Do you think there is a better phrase? If so, what would it be?

Part D: Gathering opinions on the Patient Activation Measure:

9. Review question you completed earlier - does everything seem relevant for your experience of living with arthritis?
 - Does it make sense?
 - How does it fit with what you think about actively looking after your arthritis?

Part E: Close

10. Are there any issues that we have not talked about that you would like to raise?

FIGURE 1 Topic guide for first interviews

recruited via a convenience sample, there was an effort to purposefully recruit those who appeared to be self-managing well. This was determined through discussion with clinical staff or using medical notes with recruiting rheumatology teams. However, potential participants were not formally screened using the PAM.

Patients were eligible to take part if they were over 18 years old, diagnosed with a form of inflammatory arthritis by a rheumatologist,

able to provide informed consent to participate, and able to communicate, read and write in English. Patients were approached to participate either face to face when attending clinic or via a postal invitation. Data are not available on the number of patients approached in total or who declined to participate.

The interviews and analysis were conducted by a female doctoral researcher (BJ) who had prior experience in conducting research

TABLE 1 Individual participant demographics ($n = 17$)

Participant	Sex	Age (years) at time of the first interview	Diagnosis	Disease duration (years)	Highest level of education	HAQ score	PAM Level	PAM score
Mary	Female	48	RA	13	International diploma	0	N/A	N/A
Joanna	Female	54	RA	2	GCSEs	0.35	N/A	N/A
Lindsay	Female	57	RA	8.5	National diploma	0.4	N/A	N/A
Tony	Male	71	RA	26	National vocational qualification	1.05	4	100
Jim	Male	68	RA	28	English language certificate	0	4	90.7
Jackie	Female	69	RA	35	National vocational qualification	0.95	4	75
Avril	Female	73	PsA	15	Bachelor's degree	0.2	3	63.1
Mark	Male	46	RA	2	O-levels	0	2	51
Jan	Female	71	RA	12	No formal qualifications	0.25	2	51
Richard	Male	49	PsA	12	O-levels	0.6	2	48.9
Cheryl	Female	54	PsA	3	Certificate of secondary education	0.85	3	70.2
Greta	Female	65	RA	10	O-levels	0.25	4	77.7
Christine	Female	39	SLE	6	Postgraduate diploma	1	3	63.1
Patricia	Female	64	RA	21	Bachelor's degree	0.7	3	63.1
Stuart	Male	45	RA	15	GCSEs	0	2	53.2
Anne	Female	53	RA	30	O-levels	0.4	4	100
Meryl	Female	71	RA	38	No formal qualifications	0.8	4	80.9

Abbreviations: PsA, psoriatic arthritis; RA, rheumatoid arthritis; SLE, systemic lupus erythematosus.

'You do it because you have to': Determined independence

'You find ways to do different things': Making small changes

'If you have a problem just phone up': Navigating the system

- 'If I have that knowledge then it helps': How to seek and get help and information.
- 'If I feel there's a concern, I will raise it': Collaborating with healthcare professionals.

'I think I've recognised what works for me, and what I need': Knowing oneself

- 'I knew it was obviously something shook up in my body': When to seek help and information.
- 'It just helps me': Knowing what techniques work for individuals.
- 'I know what each tablet is for': Health-related knowledge.

'There are people far worse than me': Positive perspectives on health

'Just does a lot of fetching and carrying': Practical social support

TABLE 2 Summary of framework analysis categories and subcategories

interviews. The study was part of a wider, mixed-methods project conducted with a pragmatic epistemology.

Prior to starting the interview, BJ explained that the interviews formed part of her PhD looking at how people managed their health, explained the interview process and answered any questions. Participants signed a consent form and provided demographic information (including age, sex, diagnosis and disease duration). They also completed the following outcome measures:

- Health Assessment Questionnaire (HAQ) (Fries et al., 1980), a measure of physical function (Hewlett et al., 2002). This measure takes approximately 5 minutes to complete.
- PAM (Hibbard et al., 2005), a 13-item measure designed to capture patient activation that provides patients with a level (between 1 and 4) and a score (between 0 and 100). Higher scores and higher levels indicate more skilled active self-management. The measure typically takes between 2 and 4 min to complete.

The interview schedule included participants' experiences of managing their health, the barriers and enablers to self-management, and how they made health-related decisions. In each participants' first interview, they were also asked if they had heard the term 'patient activation' previously, what it meant to them, and their definition of the term. They also reviewed the PAM, having completed it earlier in the interview. They considered how closely the items in the PAM captured their experiences of active self-management. As recruitment progressed, issues that arose in early interviews were explored in later interviews.

Participants were invited back a year later for follow-up interviews that focused on how they had managed their health in the meantime. These interviews were tailored to the individual participants to explore how they had managed their health over the prior year. They also discussed the overall findings from the first interviews with participants to understand how they felt the analysis captured their perceptions. This constituted a member checking exercise as well as an opportunity to further discuss the topic with participants.

The interviews were audio-recorded, and these were transcribed and anonymised by replacing potentially identifying details with placeholder words and phrases. The data were analysed using framework analysis and analysis was assisted by the NVivo software package (Ritchie & Spencer, 1994). Framework analysis allows the opportunity to develop a thematic framework to describe the data, and to compare between and within participants and both time points (Ritchie & Spencer, 2003). It is a flexible approach that is suitable for different epistemologies, accommodates both inductive and deductive data analysis methods, and offers a systematic process to analysing qualitative data (Leal et al., 2015; Gale et al., 2013). The process of analysing data using the framework analysis method is well documented (Parkinson et al., 2016; Ward et al., 2013). Reflective field notes made by BJ between interviews provided context on the data and contributed to the planning of follow-up interviews (Furber, 2010) SH and ED both also reviewed several transcripts to conduct initial coding to review with [Author 1] and compare perspectives.

Participants sometimes managed multiple conditions and it was occasionally unclear whether their self-management was around actively managing their rheumatic condition or another health issue and this is a challenge that has been identified in prior patient activation research. Where this was the case, BJ tried to explore this during interviews. The findings have been analysed and written to reflect the rheumatology-specific aspects of participants' self-management where possible.

6 | RESULTS

6.1 | Demographics

Seventeen participants (12 female) were recruited from two sites and attended interviews that lasted between 45 and 75 min. Recruitment

ended after the 17th interview because BJ was no longer identifying new themes and perceived that data had reached saturation. The majority were one-to-one interviews with BJ, but one participant brought a sibling to observe both interviews. Table 1 reports the individual participants' demographic information. Thirteen participants had rheumatoid arthritis (RA), 3 had psoriatic arthritis (PsA) and 1 had systemic lupus erythematosus (SLE). All participants had been diagnosed for at least 2 years at the time of the first interview. HAQ scores were between 0 and 1.05 with an average score of 0.45 (SD: 0.37) indicating mild disability. Overall, participants demonstrated high levels of patient activation according to the PAM. Four were at level 2, four at level 3 and six at level 4. An ethics amendment requesting consent to share de-identified PAM data with the licensing organisation was not in place for three participants, who therefore did not complete the PAM.

Nine participants returned for a second interview. Reasons for not returning for a second interview included beginning working full time, other life commitments or being too unwell to attend an interview. The second interviews lasted between 28 and 56 min.

It was identified during data collection that discussions around the contents of the PAM did not fit clearly into a framework analysis but were relevant to participants' experiences. Consequently, these data were reviewed as part of the framework analysis for any data appropriate for coding but the data from these questions were also separated and analysed using content analysis.

7 | FRAMEWORK ANALYSIS

The framework analysis categories report how participants understood and performed patient activation. The findings of the two phases of data collection are presented together as one, with a summary of the six framework categories identified in Table 2.

7.1 | 'You do it because you have to': Determined independence

Participants tried to avoid their rheumatic condition ruling their lives:

You can't just live life with your feet up, you've got to do things (Lindsay).

The cognitive dichotomy between 'giving in' and 'getting things done' did not always lead to the 'boom and bust' patterns that occur when someone perseveres until reaching exhaustion (Hewlett et al., 2011). Greta described trying to balance 'giving in' and taking the rest she needed to manage long-term. Sometimes this meant carrying on, in a more measured way.

[Feeling] the need to do things, the need to get things done in the house, but also the need not to give in to the disease, which is very, very stupid and the opposite

of what you should be doing. I don't mean give in, but pace yourself, it's not giving in (Greta).

The balance between 'giving in' and 'persevering' could reflect some of the skill required to move from moderately skilled active self-management to the requirements of PAM level 4. Being able to step back and critically appraise self-management behaviours suggests skilled and dynamic self-management.

Many participants described themselves as determined people who persevered with doing what was important or valuable to them. This formed part of their identity:

I'm quite a determined, independent person. I just have to get on and do it, regardless (Mary).

There's nothing I can't do or won't do just because I won't let it get in the way (Richard).

This determination reflects an aspect of patient activation that is often central to its definition, that someone feels that for their own sake they must take responsibility for managing their health (Dwarswaard et al., 2016).

For some, taking responsibility for their health was often closely connected with independence. Some struggled to deal with the limitations their conditions caused:

Being very independent, quite fiercely independent, it was quite hard to have to accept I couldn't do certain things (Mary).

This reflects findings of prior rheumatology self-management research where patients have clarified that independence is a valuable treatment outcome (Carr et al., 2003; Yoshida & Stephens, 2004).

7.2 | 'You find ways to do different things': Making small changes

For many participants, actively taking responsibility for their health came in the form of smaller, day-to-day decisions that allowed them to continue with activities or roles that they valued. These changes required planning and thought to maintain:

Don't just pick up the [shopping] basket, even if it's only for a few items, take the smallest trolley in with you, because by the time you get round and you put even just a few items in, that really weighs down quite a lot (Lindsay).

Participants described how they made changes that allowed them to stay engaged with activities they valued:

I keep going, I go to darts, I go to skittles, I don't play because the balls are too heavy now, but I still go (Jan).

They also approached health behaviour maintenance in more manageable ways:

I've got a downstairs toilet, but if I want to go to the loo, I usually go upstairs, just to get a bit of exercise going up and down the stairs ... There's lots of things you can do within your own home without even leaving your own home (Cheryl).

As maintaining health-related behaviour changes can be difficult, making changes in small, manageable ways means that these behaviour changes are more likely to be successful (Hibbard & Mahoney, 2010; Kelly & Barker, 2016). This reflects the success in managing behaviour change that has contributed to participants being more confident and willing to further self-manage their conditions.

7.3 | 'If you have a problem just phone up': Navigating the system

When participants discussed how they managed their health, one skill they regularly used was the ability to navigate the NHS both in and out of appointments.

Something that shaped this category was that the two recruiting departments use a direct access system. This allows patients with stable conditions to have fewer unnecessary review appointments, but they can call a telephone line for advice, support and to arrange appointments if required. This process is described by Kirwan et al. (2003).

Within this category there are two subcategories.

7.3.1 | 'If I have that knowledge then it helps': How to seek and get help and information

This subcategory refers to participants' ability to select appropriate ways to get help and information about their condition. Participants reported using a variety of sources of help and information, particularly online resources. They considered credibility, trustworthiness and occasional scepticism about information gathered online unless from a clearly reputable source:

I know they say you shouldn't read everything, but there are some good sites on there. You have got the NHS one for a start ...so they are genuine sites (Joanna).

Participants demonstrated critical and communicative health literacy skills when identifying information and considering its

relevance to their own health (Ledford et al., 2015). Critical health literacy covers the ability to manage health based on the analysis of health-related information (Nutbeam et al., 2017). Communicative health literacy describes the ability to establish meaning from varying sources and types of information to apply it to self-management. This includes the ability to consider circumstances that have changed or make decisions after considering information (Nutbeam et al., 2017). These skills were fundamental to the process of gathering information for participants.

Participants were able to select an efficient and appropriate route to contact healthcare professionals depending on the urgency of the issue. This was often their rheumatology team due to their specialist knowledge, and participants valued the consistency of seeing someone who knew them rather than a GP who would refer them onwards:

If you go to your doctor and yes the doctor is a GP, they don't specialise in rheumatoid, that's why you get sent to the hospital about it (Lindsay).

When you are under a consultant you trust them, and the nurse you see more often. You trust in what they are doing and the doctor [GP] doesn't know any of that. Alright, he might read reports when he gets back... (Jan).

Sometimes participants chose not to seek support out of fear of misusing resources:

I know you've got the nurse emergency number that you can ring but you don't like wasting her time (Cheryl).

This has the potential to contribute towards the self-management style that has been referred to as being a 'dangerous self-manager' (Náfrádi et al., 2017; Yadav et al., 2018). This occurs when somebody is confident and activated to manage their own health. However, their health literacy might not be sufficient to identify when they need additional support and their health is at risk. Therefore, health literacy is a valuable aspect of actively managing one's health safely.

Aspects of this subcategory reflect some of the ways that there may be a 'hidden curriculum' that does not reflect formal patient education or learning but captures knowledge and abilities that underpin patient' abilities to learn to self-manage (Kentli, 2009).

7.3.2 | 'If I feel there's a concern, I will raise it': Collaborating with healthcare professionals

This sub-category highlights the roles participants played in shared decision-making during appointments. While they all generally

implied that being more active in consultations demonstrated being more involved in managing one's health, the extent of individuals' involvement differed. Participants reported feeling able to ask clarifying questions, a general confidence in being able to disagree with the opinions of healthcare professionals, and a keenness to be involved in (but not always leading) decision-making:

I'll wait until he's finished waffling on and ask him at the end. Oh yeah, if there's something I want an answer to, I'll make sure he answers it (Tony).

They were also able to clearly raise the issue and outline problems they experienced:

If I feel there's a concern, I will raise it, and to I think it's only by being able to raise it and discuss it that I can get my own mind around it ... it is a case of being, I suppose open, being honest (Greta).

Participants also used practical strategies to communicate with healthcare professionals:

I take my folder with me everywhere of all my letters... I'd done a summary from my letters of all the things that I'd been sent for and what, and that's in the notes now (Mary).

The ability to disagree with healthcare professionals appeared important given often-present power imbalances between patient and healthcare professional (Becker & Roblin, 2008). Research indicates that people with higher patient activation are also more likely to rate their patient experience more positively (Mosen et al., 2007). This may be due to a greater ability to work collaboratively with healthcare professionals, as identified in this category.

7.4 | 'I think I've recognised what works for me, and what I need': Knowing oneself

This category describes the participants' sense of knowing their body, including demonstrating knowledge of the healthcare-related routines required to manage their health. Three subcategories contributed to this overall category.

7.4.1 | 'I knew it was obviously something shook up in my body': When to seek help and information

Participants were aware of their baseline, as well as a sense of their fluctuations and how their body felt during a flare. This allowed them to identify when something was out of the ordinary:

I am tuned in, I am. I do find, it's awful really, but I am very tuned in (Jackie).

Participants could not always describe how they developed the awareness to identify the onset of an issue:

I don't think I consciously do it either, I think sometimes it's just a case of I realise when I'm pushing my luck, so I draw back (Mary).

Participants also used this knowledge to anticipate if they were likely to be overly active, or more likely to contribute towards a 'boom and bust' pattern of over- and under-activity (Hewlett et al., 2011).

7.4.2 | 'It just helps me': Knowing what techniques work for individuals:

Participants used a range of techniques and products to manage their condition and a clear sense of what worked for them and the personal nature of these preferences:

I think I've recognised what works for me, and what I need (Mary).

What works for me might not work for someone else (Jim).

Participants did not always use analgesic medication as a part of their routine. However, they were a tool for flares:

I think to myself right, I need to stay in the warm today, might take a couple of paracetamols if it's really bad (Jackie).

Medication regimens prescribed by healthcare professionals as part of a toolkit to self-manage were rarely discussed, despite how this has previously been discussed in conjunction with patient activated behaviours (Mosen et al., 2007). Whether this was down to participants' assumption that adherence to medication was a given, or something else, was unclear.

7.4.3 | 'I know what each tablet is for': Health-related knowledge

Participants demonstrated knowledge of their condition, their responsibility for effectively managing their routine, and why certain behaviours, investigations and interventions needed to be performed. The knowledge and skills discussed in this category closely reflect functional health literacy (the basic ability to gather information related to one's health and successfully apply it to

prescribed activities) as an aspect of patient activation (Nutbeam et al., 2017):

[nurse] sent me for a bone scan last year and I am due another one at the moment (Joanna).

7.5 | 'There are people far worse than me': Positive illness beliefs

Participants often made sense of their health by comparing their experiences with those around them. The subjects of these comparisons included relatives with rheumatic conditions, friends, peers at support groups or patients they saw in waiting rooms:

There's an awful lot of people out there who are an awful lot worse off than I am (Cheryl).

[relative] only goes out a couple of times a week... [relative] has it worse than me (Jan).

The association between positive illness beliefs and patient activation has been documented in prior research (Rask et al., 2009).

7.6 | 'Just does a lot of fetching and carrying': Social support

Although participants were independent where possible, they received support from loved ones. This was often practical help such as housework, driving, lifting or carrying:

It is more the practical stuff of opening things, that I've needed help with (Mary).

Just does a lot of fetching and carrying for me. If I can't open something, she'll open it for me. If I can't lift something, she'll lift it for me (Richard).

Sometimes, this was flexible depending on participants' needs at that time:

We share the workload, really. If I'm doing well, I'll do more and if she's doing well, she'll do more (Stuart).

Social support is a valuable part of maintaining health-related behaviour change (Michie & Abraham, 2013). As rheumatology patients have identified a gap between their need for social and emotional support and current service provision (Dures et al., 2014), it is a potential target for intervention. Communication training may support people to build social networks, and interventions such as the GENIE intervention to identify valued activities and signpost patients to these can increase social support (Band et al., 2019).

8 | PATIENT ACTIVATION PERCEPTIONS AND OPINIONS ON THE PAM

Participants generally stated that they had not heard the term 'patient activation' prior to this study. Some participants suggested that how they self-managed reflected 'patient activation', others made references to 'perhaps getting more active, with what you're doing' (Cheryl).

Some definitions that participants offered were close to the understanding of the term used in literature to reflect patient activation and empowerment:

I suppose it's just about being proactive, just generally, it's about everybody being proactive (Greta).

Giving a bit more power to the patient... (Christine).

I would guess that it meant more patient input, I suppose, more patient-led (Stuart).

Anne had a very specific visual image when presented with the term, saying:

It makes me think of something chemical-like, [chuckling], there's going to be an alarm going off any minute.

Some participants referred to the idea of 'switching someone on' (Richard). This would imply that, to these participants, the responsibility for 'activating patients' lies with healthcare professionals rather than patients.

Participants' feedback on the PAM varied. Some participants felt that this measure captured things that they felt demonstrated how they actively self-managed:

No, I think the questions here are quite good, yeah ... I think they're really good, bold questions." (Jim)

I think most of them are relevant (Richard).

Others provided critiques on items of the PAM that did not reflect their experience of actively managing their health. Item one of the 13-item PAM ('I am the person who is responsible for taking care of my health') (Hibbard et al., 2005) was critiqued by several participants who made reference to the necessity of working collaboratively with healthcare professionals:

You've got to do your bit at helping. [Healthcare professionals] are there to sort of instruct and do what they can to help but you've got to do your bit as well I feel. You know, sort of go half-way to meet them sort of half-way (Meryl).

There's only so much I can do and therefore the health service have a degree of responsibility as well (Mark).

Items on the PAM referring to preventing or reducing problems with patients' health were also discussed by participants. When discussing problems with health, participants often referred to setbacks or flares that they were often unable to prevent or predict:

I know how to prevent further problems with my health condition, again, I've put agree, because again, there's always the unknown, that we don't have control about, so again, so rather than strongly agree, I've put agree (Greta).

I know how to manage physically but I can't control what my body does in terms of flare (Christine).

This is an issue with the PAM that was raised by patients with cardiac conditions who felt that they would never be able to prevent all problems, and that there would always be an issue that they could not anticipate (Ngooi et al., 2018).

One participant suggested including an item in the PAM about how patients carried out their own research to find information. Some participants were particularly proud of the work they had done in order to gather information of their own:

So even though I agree and everything seems wonderful, actually a lot of the questions I agree with simply because of my own research rather than what information I maybe should have been given (Mark).

Similarly, participants with other health conditions have raised the need to distinguish between information that has been provided by professionals and information people have proactively gathered and evaluated (Ngooi et al., 2018).

9 | DISCUSSION

This study identified that self-managers defined actively managing their conditions as having a determined attitude to managing their health, finding ways to make small, sustainable behaviour change and effectively navigating the NHS. Participants also reported that knowing what techniques suited them individually, having positive perceptions about their health and good social support was part of managing their health well. They felt that while aspects of the PAM reflected how they performed patient activation, it was not suitable for capturing the fluctuating nature of their conditions and the collaborative nature of care. This adds to findings covering patients' perceptions of the PAM in other health conditions (Gao et al., 2019; Ngooi et al., 2018). This study also supports prior research into how

patients adjust to living with long-term conditions and health-related behaviour change. It also closely matches the sense that participants report of needing to take responsibility for their condition and living well (Dixon et al., 2009).

The PAM is intended to be a generic measure suitable for all kinds of health conditions. However, patients with long-term conditions have reported it is not always suitable for conditions that fluctuate (Roberts et al., 2016). Prior critiques of the PAM include complexity of the language within the measure, and ethnographic research identifying that many patients require support to complete the measure (Chew et al., 2017; Gao et al., 2019; Ngooi et al., 2018). This suggests flexibility in the use of the measure in practice and that in the context of rheumatology the PAM may capture aspects of patient activation but is not a comprehensive measure. Its use in clinic would ideally be supplemented with clinical judgement and discussion with patients about they feel they are actively self-managing. Interventions to develop skills that active self-managers make use of, such as health literacy, can also help to support those who are less confident and skilled at self-management.

10 | STRENGTHS

This study was strengthened by the patient and public involvement contributing to an interview schedule that was piloted to be accessible and easily understood by participants. The member checking exercise and opportunity for participants to clarify the findings, contributed additional detail and added credibility.

11 | LIMITATIONS

The attrition rate for the second interviews limited the opportunity to investigate the temporal aspect of patient activation with all participants. This also limited the helpfulness of member checking, as the participants who did not return did not discuss the findings with the interviewer.

12 | CONCLUSIONS

Patients' perceptions of patient activation covered a wide range of skills, behaviours and beliefs and these are not always captured by the PAM. This includes the prevention and prediction of flares and fluctuations. Therefore, its use as a clinical tool is best accompanied by dialogue with patients to understand their self-management.

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CONFLICTS OF INTEREST

Bethan Jones has received a speakers fee for presenting a webinar on patient activation for the British Society of Rheumatology in conjunction with. The other authors have no conflicts of interests to report.

AUTHOR CONTRIBUTIONS

Bethan Jones devised the study design and the methods as part of a PhD project with support and input from Andrew Hunt, Diana Harcourt, Sarah Hewlett and Emma Dures to refine the design. Bethan Jones collected the data and carried out the data analysis and interpretation with discussion and support from the other authors to interpret the findings. Emma Dures and Sarah Hewlett also reviewed transcripts as part of the analysis. Bethan Jones wrote the manuscript which was reviewed and revised by all authors. All authors gave approval for the final manuscript to be published.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

ORCID

Bethan Jones  <https://orcid.org/0000-0002-7253-0751>

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