

## Comparing reactions to written leaflets, online information and real-time Doppler images among South Asian patients with rheumatoid arthritis

Kumar, Kanta; Bradbury-Jones, Caroline; Armitage, Christopher J; Peters, Sarah; Raizada, Sabrina; Wong, Peter

DOI:

[10.1093/rap/rkaa009](https://doi.org/10.1093/rap/rkaa009)

License:

Creative Commons: Attribution-NonCommercial (CC BY-NC)

*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Kumar, K, Bradbury-Jones, C, Armitage, CJ, Peters, S, Raizada, S & Wong, P 2020, 'Comparing reactions to written leaflets, online information and real-time Doppler images among South Asian patients with rheumatoid arthritis', *Rheumatology Advances in Practice*, vol. 4, no. 1, rkaa009. <https://doi.org/10.1093/rap/rkaa009>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

## Original Article

# Comparing reactions to written leaflets, online information and real-time Doppler images among South Asian patients with rheumatoid arthritis

Kanta Kumar<sup>1</sup>, Caroline Bradbury-Jones<sup>1</sup>, Christopher J. Armitage<sup>2,3</sup>, Sarah Peters<sup>2</sup>, Sabrina Raizada<sup>4</sup> and Peter Wong<sup>5</sup>

## Abstract

**Objective.** There is poor adherence to medication in patients of South Asian origin with RA. There are limited numbers of interventions to improve patient engagement. The objective of this study was to explore how patients of South Asian origin make sense of their disease after receiving written leaflets compared with online information or visualizing real-time Doppler US images of their inflamed joints.

**Methods.** Patients of South Asian origin with RA were recruited from two National Health Service hospitals in the West Midlands, UK. In-depth semi-structured interviews were undertaken after exposure to vignettes designed to elicit patients' perspectives on: written leaflets; online information to complement face-to-face interaction with health-care professionals; and Doppler US during the early stages of the disease journey. Data were analysed thematically until data saturation was reached in 20 individuals.

**Results.** The responses to vignette scenarios were described by the patients. Overall, patients found real-time Doppler US more valuable in understanding RA and RA medications compared with other methods. Patients reported that Doppler US reduced anxiety and helped to address misconceptions about the long-term disease and its ability to be controlled.

**Conclusion.** We have developed new understanding regarding the educational utility of a Doppler US session in patients of South Asian origin and how these sessions can be optimized to increase patient engagement and adherence to medication.

**Key words:** rheumatoid arthritis, Doppler ultrasound scan, ethnicity, illness perceptions, medication adherence.

### Key messages

- This study proposes a novel intervention for improving clinical outcomes for RA patients of South Asian origin.
- The level of satisfaction with information received in a Doppler US session was linked with improved views about medicines and illness representations.
- The use of Doppler US as a means of providing biofeedback might prove superior to existing interventions, with potential relevance to a range of conditions.

<sup>1</sup>Institute of Clinical Sciences, University of Birmingham, Birmingham, <sup>2</sup>Division of Psychology and Mental Health, Manchester Centre for Health Psychology, School of Health Sciences, University of Manchester, <sup>3</sup>Manchester University NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, <sup>4</sup>Department of Rheumatology, Royal Wolverhampton

Hospitals NHS Trusts, Wolverhampton, UK and <sup>5</sup>Department of Rheumatology, Westmead Hospital, Westmead, NSW, Australia  
Submitted 28 October 2019; accepted 6 March 2020

Correspondence to: Kanta Kumar, University of Birmingham, Birmingham B15 2TT, UK. E-mail: k.kumar@bham.ac.uk

## Introduction

RA is a chronic systemic disease resulting in progressive joint damage, diminished quality of life, increased disability and premature mortality [1]. The treatment paradigm for RA has evolved over the past two decades to earlier, more aggressive treatment with conventional synthetic DMARDs (cDMARDs), biologic DMARDs (bDMARDs) and targeted synthetic DMARDs (tsDMARDs) [1]. Although improvements in disease activity and patient functional status mean that clinical remission is a realistic aim for most patients with RA, this is not necessarily true for all patient groups [2]. For example, South Asian patients originating from the Indian subcontinent, especially India and Pakistan, may have a disease framework centred on different perceptions of illness and beliefs about treatment [2]. We have previously shown this can have major implications for adherence to medication [2, 3]. Moreover, we have also reported that patients of South Asian origin showed significant delays in presenting to their primary care physician with RA symptoms, possibly owing to lack of knowledge about the disease and cultural influences [4]. Recent work published by us has shown that patients of South Asian origin attending early arthritis clinics demonstrated a disconnect with the treating health-care professional, mainly owing to lack of information about the disease and not having an opportunity to visualize their disease [5]. Yet, such clinics are major platforms for engaging patients in long-term disease management [6]. This may lead to poor adherence to medication [5].

The fundamental question remains, how do we improve information delivery for patients of South Asian origin? [7, 8]. Educational interventions have shown promising results in improving adherence to medication [8]. However, a review on interventions in RA highlighted that different types of interventions were required to optimize patient adherence to medication and to encourage patient engagement. Interventional studies in RA have not included patients of South Asian origin. Moreover, written material not being in an appropriate language may be a barrier to delivery of effective health-related messages [5].

In 2016, we published a potential approach that might assist clinicians to correct misconceptions about RA among patients of South Asian origin [9]. In that study, some patients reported that real-time imaging potentially increased understanding of RA and the role of RA medications. Joplin *et al.* [10] also demonstrated that Doppler US (Fig. 1) might assist in improving adherence to medication.

We therefore sought to explore how patients of South Asian origin make sense of their disease after receiving leaflets or online information compared with visualizing real-time Doppler US images of their inflamed joints. An explorative qualitative vignette [11] was used. Vignettes are short case stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond [12]. The vignette technique

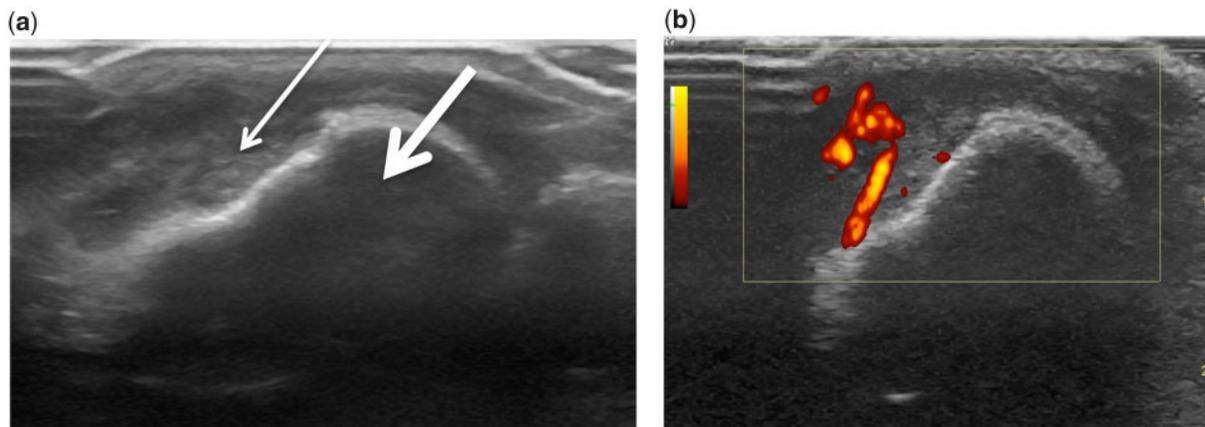
is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments on stories depicting scenarios and situations and has been used widely and effectively [13].

## Methods

Data have been reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [14]. Patients originating from the South Asian continent were invited to participate in individual face-to-face semi-structured interviews. The term South Asian is applied here to people from the Indian subcontinent; for example, India and Pakistan [15]. Participants were recruited from two health trusts in the West Midlands (central UK). Participants who had attended an initial clinic, had received a leaflet and had undergone a Doppler US (Fig. 1) within 6 months and who had clinician-diagnosed RA or other inflammatory arthritis were invited by clinical staff to participate in the study. Purposive sampling of participants was performed at early inflammatory arthritis clinics. Participants were recruited with a broad range of age, occupations and disease duration.

Written information outlining the study was sent to patients scheduled to attend a follow-up early inflammatory arthritis clinic appointment. A contact number for the researcher (K.K.) was provided if participants expressed interest in study participation. A mutually convenient interview time was arranged by the researcher with participants who agreed to participate. All participants provided written consent. K.K. has extensive experience in conducting qualitative research and is a female researcher of Indian background with fluency in English, Urdu and Punjabi. A pre-study questionnaire captured demographic data and disease activity score (Table 1). A vignette guide (Table 2) was developed based on discussions with the research team, including a patient research partner. It was suggested by our patient partner that it would be valuable to explore attitudes to other patient education material in addition to Doppler US to assess the impact of Doppler US better. Thus, the vignettes included the views of patients on other formats of information, such as leaflets and face-to-face consultations.

The patient research partner was female and diagnosed with RA 1 year earlier. Her experience of the early inflammatory arthritis clinics, Doppler US session and living with the condition were valuable in developing the topic guide. Interviews followed an iterative process, with new concepts that emerged during data analysis being explored in subsequent interviews. Each interview lasted approximately 1 h and was recorded digitally and transcribed verbatim. Transcripts were typed by an independent company familiar with translating material into different languages. Transcripts in Urdu and Punjabi were back translated into English by the company. The study was approved by the South Birmingham Research Ethics Committee (reference 251773).

**Fig. 1** Illustration of what Doppler images display to patients

Representative longitudinal views of the right third metacarpophalangeal joint (GE Logiq E, hockey stick transducer, 8–18 MHz). **(a)** Metacarpal head (thick white arrow) and synovitis/effusion (thin white arrow) in greyscale. **(b)** Power Doppler signal (red), indicating increased vascularity in the area of synovitis.

**TABLE 1** Showing demographic details of patients who took part in the study

Patient no.	Sex	Level of education	Age (years)	Type of current employment	DAS28-CRP around the time of interview	Treatment
1	M	University level	59	Business	3.8	MTX
2	F	University level	30	Teacher	2.3	SSZ and Pred
3	M	University level	43	Civil servant	3.7	MTX, HCQ
4	M	University level	32	Electrician	3.0	MTX, HCQ, Pred
5	M	University level	42	Manger	4.5	MTX, HCQ
6	F	Secondary school	57	Bank clerk	2.7	MTX
7	F	Secondary school	45	Manager	4.3	MTX, HCQ, Pred
8	F	University level	38	Teacher	3.4	MTX
9	F	University level	34	Police officer	5.8	MTX, SSZ
10	M	University level	39	Gym instructor	3.3	MTX, HCQ
11	M	Secondary school	35	Construction officer	3.3	MTX, HCQ
12	F	Primary	43	Home maker	2.9	MTX, HCQ
13	F	Primary	46	Home maker	3.4	MTX, HCQ
14	F	University level	61	Retired	4.5	MTX, HCQ
15	M	Secondary school	37	Driver	4.7	MTX, HCQ
16	F	University level	59	Retired	2.2	MTX, HCQ
17	F	University level	46	Waitress	3.4	MTX, HCQ
18	M	Secondary school	43	Technician	5.6	MTX, LEF, HCQ
19	F	Secondary school	36	Shopkeeper	1.9	MTX
20	F	Secondary school	62	Home maker	2.1	MTX, HCQ

F: female; M: male; Pred: prednisolone.

### Data analysis

Study data were analysed using thematic analysis, a method for identifying, analysing and reporting patterns within data without trying to fit them into a pre-existing coding frame or the preconceptions of the research [16]. For example, the researcher focused on topics suggested by the patient partner, and concepts raised by patients during the interview were studied in detail. Each interview was analysed individually and compared with earlier or subsequent interviews to determine the perspectives of

participants on Doppler US and delivery of information in early inflammatory arthritis clinics. A multidisciplinary group with a range of expertise conducted data analysis. Two rheumatologists (P.W. and S.R.), a nurse researcher (C.B.-J.) two health psychologists (C.J.A. and S.P.) and a patient partner (B.R.) discussed the emerging analysis. This triangulation exercise allowed the team to view data from different perspectives. The patient research partner (B.R.) was able to reflect on the findings generated from this study and her past experiences of engaging with

TABLE 2 Vignette scenario

**Vignette 1 (receiving a patient information leaflet on your condition)**

You are invited to the first clinic at the rheumatology department. Once your doctor has confirmed your diagnosis, he/she provides a written leaflet on your condition. Would this leaflet be enough to provide you with an understanding of your condition compared with visualizing your joints?

**Vignette 2 (face-to-face discussion and online resource)**

You attended a rheumatology clinic and your doctor or nurse discussed your condition and suggested you visit online resources for further information. How useful would this be to you compared with visualizing your joints on screen during an US session?

**Vignette 3 (seeing the swelling in joints on screen)**

You are invited to have an US scan of your joints to see the amount of swelling in the joints. You have an opportunity to see the joints visually on the screen. What would be your thoughts? More questions around this during interview

Doppler US sessions. Summarized findings were sent to study participants to see whether they agreed with the conclusions. The first author (K.K.) analysed all the transcripts where data were subjected to line-by-line coding. The patient research partner independently coded three transcripts to develop reliable and inclusive patterns to each vignette informed by multiple perspectives. Step-by-step guidelines in qualitative data analysis were developed for the patient partner [17]. Discussion of the coding framework took place between the research team (K.K., P.W., S.R., C.B.-J. and S.P.) and the patient research partner (B.R.). Coding categories that lacked concordance were discussed and absorbed into the coding framework. The initial codes were then grouped into the most noteworthy and frequently occurring categories. The core themes extracted and presented here focus on interaction of patients with the Doppler US session and other mechanisms of information delivery (Table 3). Initially, the three predominant themes enhanced understanding of the experiences of patients with the Doppler US session.

## Results

Of the 32 patients approached to participate in the study, 12 declined owing to time constraints. Twenty patients (12 females and 8 males) agreed to participate in the study (age range 30–62 years). Mean disease duration ranged between 6 months and 1 year. Fifteen interviews were conducted in English, two in Urdu and three in Punjabi. Full quotes can be viewed in Table 4, and examples of representative quotes are presented at the end of each theme.

### Patient perspectives on written leaflets during the early stages of the disease journey

In this study, only four patients reported finding information provided via written leaflets to be useful (Quotes 1, 2

and 3) during the early stages of the disease journey. Some patients struggled with reading, particularly non-English-speaking patients and those with low literacy (Quote 4). Some patients admitted not receiving adequate information for self-management (Quote 5). Others felt that information provided via written leaflets failed to convey the severity of RA and did not help them to come to terms with the condition (Quote 5). Some patients reported that written leaflets were less likely to provide them with an opportunity to engage with a chronic complex disease, such as RA (Quote 4). Leaflets were also felt less likely to present the whole picture of RA, especially the future consequences (Quotes 6 and 7).

Examples of patient quotes:

**Quote 1:** *I think leaflets are good but more to know about rheumatoid I guess leaflets can be useful as a starting point.* [Female, teacher, 30 years old, English speaking]

**Quote 2:** *I didn't mind having leaflets to remind me of the problem.* [Female, retired, 59 years old, English speaking]

**Quote 3:** *My leaflets had some information that I found useful on exercise but would prefer more to put things into perspective.* [Male, electrician, 32 years old, English speaking]

**Quote 4:** *I don't rate leaflets to understand long-term condition especially when you can't read English. Most of the time everything is in English. I didn't find mine useful.* [Female, home maker, 62 years old, non-English speaking]

**Quote 5:** *I read, but it only scratches the surface for me and, to be honest, it doesn't force me to self-manage nor did it help understand the severity.* [Male gym instructor, 39 years old, English speaking]

### Patient perspectives on online information to complement face-to-face interaction with health-care professionals

In this theme, patients expressed that additional verbal explanation about the condition together with online and leaflet information was beneficial (Quote 8). Many patients highlighted the personal approach of the clinician to be an important part of engagement (Quote 9). Patients expressed that not only was the explanation about the condition important, but also that the opportunity to change behaviour, which facilitated better self-management of symptoms, was important (Quote 10). All patients expressed that their expectations after having a long-term condition diagnosed needed to be explained, and sometimes this was not done, given the limited time for consultation (Quote 11). Patients highlighted the need for additional information to be provided along with verbal communication (Quotes 12 and 13).

Examples of patient quotes:

**Quote 8:** *You can really learn good lessons with the health-care team, and the online material is also good. What this does is that it leaves you to deal with and make decisions yourself.* [Female, retired, 59 years old, English speaking]

**Quote 9:** *The interaction that is half-hearted is really not good for understanding the disease and treatments. The approach of the*

**TABLE 3** Thematic pattern of Doppler US and delivery of other information

Leaflets	
<p><b>Strengths</b> Can take away and read in own time</p>	<p><b>Weaknesses</b> Some understanding disease what does this mean? Lack of ability to justify disease seriousness Not conveying the problem Reading things is different to seeing your joints in pain Autoimmune disease is not easy in a leaflet Problem for patients with literacy; language barrier family education cannot not get involved</p>
Face-to-face and online	
<p><b>Strengths</b> Communication face to face is good Relationship Rapport with doctor is important Approach is important</p>	<p><b>Weaknesses</b> Time factor Face to face is good communication, but the person might not tell you all that there is to be told</p>
Doppler US	
<p><b>Strengths</b> Knowledge, satisfaction, informed choice, fear, extended consultation time, level of anxiety reduced, adherence, communication, source of evidence on severity, emotions – belief in controlling symptoms and sense of personal self-efficacy increase, seriousness of medication and disease, behaviour change, activity increase, lower literacy, meaningfulness, journey perspective, enlightenment, comprehensive, positive engagement with service, beliefs validation of symptoms</p>	<p><b>Weaknesses</b> Nil reported</p>

doctor has to be right. I guess time is also a factor. [Female, waitress, 46 years old, English speaking]

**Quote 10:** My doctor does try to explain face to face, which is good, but that message has to get into my head to understand what is going on, and if there isn't enough to change my behaviour then something more is needed. [Female, bank clerk, 57 years old, English speaking]

### Patient perspectives on Doppler US scanning during the early stages of the disease journey

In this theme, there were detailed explanations about the use of Doppler US. All patients interviewed in this study were positive towards having had a different method of education that helped them engage in understanding the disease process. Most of the data in this theme were linked to how patients perceived RA and the available treatments. The psychological impact was also evident.

Examples of patient quotes:

**Quote 14:** The direction of treatment can become much more clear to me and gave me much more engagement to manage myself. [Female, shop keeper, 36 years old, English speaking]

**Quote 15:** I will exercise my joints more freely, because there was fear in my mind that if I move my joints I might make them worse. [Male, electrician, 32 years old, English speaking]

**Quote 16:** I am doing more work at home and making my chapatis. This scan reassured me that I am not doing any damage by moving my swollen joints. [Female, retired 61 years old, non-English speaking]

Patients of South Asian origin found that having seen the Doppler US images with relevant explanation resulted in higher engagement levels with treatment (Quote 14). In particular, patients expressed a readiness to change and adapt to self-management strategies after seeing the Doppler US images (Quotes 15, 16 and 17). Many views expressed by patients in the interviews related to increased motivation and a desire to be part of treatment

TABLE 4 Showing patient quotes

**Patient perspectives of leaflets during the early stages of the disease journey**

**Quote 1:** Leaflets are good way to know about RA. However to fully understand the impact of RA a scan could be better as a starting point. [Female, teacher, 30 years old]

**Quote 2:** I didn't mind having leaflets to remind me of the problem. [Female, retired, 59 years old, English speaking]

**Quote 3:** My leaflets had some information that I found useful on exercise but would prefer more to put things into perspective. [Male, electrician, 32 years old, English speaking]

**Quote 4:** I don't rate leaflets to understand long-term condition especially when you can't read English. Most of the time everything is in English. [Female, home maker, 62 years old]

**Quote 5:** I read, but it only scratches the surface for me and, to be honest, it doesn't force me to self-manage nor did it help me understand the severity. [Male gym instructor, 39 years old]

**Quote 6:** These don't do justice to get an understanding of this long-term disease. With leaflets you browse through and don't look at them again; therefore, you never really know the severity of the problem. Accepting the long term disease can take long time [Female, police officer, 34 years old]

**Quote 7:** I am slowly learning. There is more to know with my condition. If I had just been given a leaflet, I would say that that wouldn't be enough for me to fully engage with my condition. I feel more is needed to change the behaviour. [Male, driver, 37 years old]

**Patient perspectives of online information to complement face-to-face interaction with health-care professionals**

**Quote 8:** You can really learn good lessons with the health-care team, and the online material is also good. What this does is that it leaves you to deal with and make decisions yourself. [Female, retired, 59 years old]

**Quote 9:** The interaction that is half-hearted is really not good for understanding the disease and treatments. The approach of the doctor has to be right. I guess time is also a factor. [Female, waitress, 46 years old]

**Quote 10:** My doctor does try to explain face to face, which is good, but that message has to get into my head to understand what is going on, and if there isn't enough to change my behaviour then something more is needed. [Female, bank clerk, 57 years old]

**Quote 11:** Talking is good, but not all doctors have time to explain things to you. Therefore, less is spent on really meeting my expectations. The doctors need a new approach to educating patients. [Male, construction officer, 35 years old]

**Quote 12:** Talking face to face is good, but if you have something better to add, like these pictures, then why not? [Male, technician, 43 years old]

**Quote 13:** If the doctor is able to show me the problem then I would say that is much better. Can't do that in just communication face to face. [Male, manger, 42 years old]

**Patient perspectives of Doppler US scanning during the early stages of the disease journey**

**Quote 14:** The direction of treatment can become much more clear to me and give me much more engagement to manage myself. [Female, shop keeper, 36 years old]

**Quote 15:** I will exercise my joints more freely because there was fear in my mind that if I move my joints I might make them worse. [Male, electrician, 32 years old]

**Quote 16:** I am doing more work at home and making my chapatis. This scan reassured me that I am not doing any damage by moving my swollen joints. [Female, retired, 61 years old]

**Quote 17:** I am functioning on a daily basis. The last time I had the scan there wasn't much on my joints, so everything is going in the right direction. I am going for walks. [Male, own business, 59 years old]

**Quote 18:** My level of motivation to take medication has increased, and I will take my medication. [Female, teacher, 38 years old]

**Quote 19:** Time has changed now and there is a desire to know more about the disease. This has given me a good way to know more. I am feeling more confident at work. [Male, civil servant, 43 years old]

**Quote 20:** Seeing the scan makes you realize how difficult it is to control the problem if medication isn't taken. Asians it takes time to convince of the problem. Scan does this. [Male, driver, 37 years old]

**Quote 21:** My thinking was this was not a serious disease. I saw a lot swelling on the scan picture. I can take my medication now with an aim; I mean, more meaningfully. [Female, home maker, 43 years old]

**Quote 22:** I would be thinking that ginger and methi [herbs] will help and not take medication properly, but I am working with my doctor now to see there is a lot of swelling. [Female, retired, 61 years old]

**Quote 23:** The thought did cross my mind to try herbal stuff, but after seeing the pictures that may be not a good idea and to try the medications first. [Male, manager, 43 years old]

**Quote 24:** If this scan wasn't shown to me I would have gone on about whether to or not accept this condition. Everyone has this period where we presented, nothing is going on, but seeing the scan made me realize the problem and I guess I had to make myself understand. [Female, bank clear, 57 years old]

**Quote 25:** I would have been in denial about this, but I know now why I need to take physio as well. [Female, retired, 59 years old]

**Quote 26:** At the start of all this I was thinking how serious can this be, but after seeing the scan I know that this is all about control and no cure. [Female, home maker, 62 years old]

**Quote 27:** The doctor told me that there wasn't going to be any cure on this yet and to be honest after seeing the joints and swelling I can believe there wasn't going to be any miracle. [Female, home maker, 43 years old]

**Quote 28:** The fear of starting the problem, then we have the fear of starting treatment, then the fear of future and, for women, fear of coping with family life and disease. At least with seeing the pictures you can reduce some of that anxiety. [Female, teacher, 38 years old]

**Quote 29:** I look forward to coming back to the hospital appointment. This has given me a different feeling towards managing my condition. [Female, shop keeper, 36 years old]

**Quote 30:** I feel very positive towards my doctor, and my relationship is much better. If I only had leaflets then I wouldn't be so keen. [Male, manager, 42 years old]

**Quote 31:** I was really pleased that my daughter came with me to the scan and she saw my joints as well. It felt like my whole family would get an insight into this now, because it can be isolating to live with a long-term disease. [Female, home maker, 43 years old]

**Quote 32:** When I first started off with the problem, my mental state was really bad. I was getting upset. After seeing the scans of my joints, I thought I could balance my mental state and work with the doctors. My perception was altered. [Female, shop keeper, 36 years]

**Quote 33:** The awareness of the disease in our community is not that much. I realize this is a serious problem. I think new technology will help break that barrier. [Female, retired, 59 years old]

decisions (Quotes 18 and 19). Personal attainment (benefits) was associated with increased knowledge and self-efficacy (Quote 19). There was evidence highlighting how Doppler US assisted in informing their belief systems, allowing them to understand the necessity for medication, thereby enabling them to take these agents confidently (Quotes 18 and 19). Concerns decreased and were rationalized after the Doppler US session. Some patients felt that herbal remedies were sufficient to control RA symptoms. However, after Doppler US, that view changed (Quotes 20 and 21). For some, it helped them come to terms with the chronicity of the condition, where patients reported a sense of acceptance sooner (Quotes 22 and 23). Patients expressed that their views on seeking a cure had also been altered after visualizing their joints in the Doppler US session. Patients were more welcoming towards the control concept rather than expecting a 'miracle' (Quotes 24, 25 and 26).

Patients commented that visualizing their own joints via Doppler US helped to reduce anxiety, because it helped them to rationalize the problem. Many patients had a positive outlook towards the rheumatology service and looked forward to seeing their health-care professionals. Moreover, many reported an improved relationship with their health-care professionals after the Doppler US (Quotes 27, 28 and 29). There were positive views about Doppler US in helping them to involve family members. Patients expressed that convincing family members in the Asian community about the severity of their arthritis posed a challenge, but that having Doppler US images provoked interest from family members and often led to increasing support for the patient. There were data that Doppler US helped to balance the psychological impact of having a chronic condition in terms of managing fear and future consequences of RA (Quotes 30, 31 and 32). Furthermore, there were views about the lack of awareness of RA among the South Asian community; patients felt that this barrier could be broken by provision of copies of the Doppler US images (Quote 33).

## Discussion

This qualitative study explored the perspectives and experiences of receiving written leaflets vs online information compared with visualizing real-time Doppler US images of their inflamed joints in patients of South Asian origin with RA. It has demonstrated that symptom experience, illness perceptions (illness representation), perceived benefits/risks of treatment and the quality/quantity of information provided influenced levels of patient engagement and adherence to medication. We observed and documented clear evidence that provision of real-time Doppler US images has given patients of South Asian origin an additional and possibly more effective platform from which to engage than written leaflets or face-to-face consultation alone. This study highlights a potential platform for improving the willingness of patients to take long-term medication and an avenue for educating those with low health literacy.

We and others have previously reported that patient beliefs about treatment are grounded in necessity and concerns [18]. The notion of necessity in patients, who were informed of the need for therapy, derived from patient perceptions of illness; for example, the severity of symptoms stimulated use of medication [19]. Therefore, the consequences of the condition and its controllability matched their expectations, which outweighed their concerns. Similar concepts have been reported in other fields, such as cardiology [20]. The way in which individuals judged the necessity for treatment was related to their concerns and lack of knowledge about RA. Moreover, as predicted by Horne *et al.* [21], necessity beliefs were interlinked with perceptions of illness representations. Our study found that patients of South Asian origin did not initially view RA symptoms to be serious. However, a Doppler US session helped to change that view and brought many to an earlier recognition of the importance of symptom control than with leaflets alone. In contrast, the Doppler US session highlighted the importance and need for long-term therapy. There were also a few patients in this study who had high regard for traditional remedies and felt that these could help to improve RA symptoms. However, this perception altered after seeing Doppler US images. This would have been an unlikely outcome from leaflets and face-to-face discussion.

Of note, our study showed that patient perceptions about the need for treatment and decisions to continue treatment were reinforced by receiving adequate information, particularly real-time visual aids (Doppler US), in contrast to leaflet information. In other chronic diseases, was reported that patients with stronger treatment control beliefs were more likely to have better health status and be more likely to engage in self-care behaviours [21, 22]. The results of our study demonstrated the ability of Doppler US to facilitate behavioural change. This might provide an opportunity to optimize clinical outcomes in patients of South Asian origin living with RA.

In non-RA diseases, interventions using real-time visual aids have been successful [10]. The utility of visualization tools to engage patients in understanding their disease and treatment and in reducing anxiety has been reported for other conditions, such as vascular disease [23]. Moreover, a study of 207 European women with ovarian cancer [24] reported less anxiety and improved confidence and well-being after an US scan where they were shown images. Another study reported that use of a moving three-dimensional heart in the context of an explanation of future risks of heart disease had more impact on patients than text-based information alone [25]. In that study, 23 smokers attending a cardiovascular outpatient clinic were randomly allocated to one of two groups: either to receive a print-out of an US image of their carotid artery showing atherosclerotic plaque alongside an image of a disease-free artery or to receive routine verbal feedback. That study reported the effectiveness of personalized biomarker feedback to increase the intention to stop smoking. The authors noted that

the three-dimensional images of the heart increased patient understanding of heart disease risk, causal beliefs and control beliefs. Moreover, patients made more behavioural lifestyle changes, such as eating a healthy diet and taking up physical exercise, in response to such images.

A Cochrane review of nine trials with a total of 1371 patients looked at whether showing patients the medical images of their problem would change behaviour towards external factors affecting disease outcome [26]. The review documented that visual feedback might help patients to understand some contexts of the problem, such as the importance of smoking cessation, diet and healthy living. Some lifestyle factors documented in the Cochrane review are also important in RA for example, smoking, which is an important poor prognostic factor in RA. Building similar interventions in rheumatology might benefit patients, particularly those from ethnic backgrounds with lower health literacy. Extensive work in those with low health literacy suggests that educational interventions including leaflets and other formats, such as online material, have resulted in only a small change in increasing the knowledge of patients and have not been successful in obtaining desired health outcomes [27]. Work around development of a handbook for patients recruited only non-South Asian patients, possibly limiting generalizability to those who could read [28]. The findings from our study are encouraging and suggest that use of Doppler US visual feedback within routine clinical practice might have a positive effect on adherence to treatment and on overall disease management [29].

### Strengths and weaknesses

Recruitment of South Asian patients was an important strength of this study, particularly the recruitment of male patients, because this patient group is often not included in studies. Although only 20 patients were enrolled, sufficient data were obtained for thematic saturation. Interviews were able to be performed in Urdu and Punjabi, ensuring that meaning was translated accurately and cultural nuances were preserved. Although the focus of the potential intervention was centred on South Asian patients, the opportunity for using visual or Doppler US representation in other ethnic populations could be considered, particularly among those with low literacy. A comparison between different minority ethnic populations requires further investigation.

### Conclusion

This study has extended the evidence relating to the use of real-time Doppler US as a novel intervention for improving patient engagement and adherence to medication in those of South Asian origin. Our results could be generalized to other ethnic minorities or even to those from a low-literacy background. Engagement and adherence to treatment views were highly reported in patients who underwent Doppler US. In contrast, the

more usual educative interventions using written leaflets or face-to-face consultations were not thought by patients to be as useful. The level of satisfaction with information received by a Doppler US session was linked with views about medicines and illness representations. Results from this study suggest that communication of information using Doppler US might be a novel and powerful intervention to improve adherence to medication and correct patient misconceptions about RA.

### Acknowledgements

We thank all patients for taking part in the study and staff at the participating organizations for their support for the study. We thank our patient research partner (Bhavana Rai) for assisting us with study design, development of interview guide and data analysis. Chris Armitage is supported by the NIHR Manchester Biomedical Research Centre and National Institute for Health and Research Greater Manchester Patient Safety Translational Research Grant.

*Funding:* This grant was funded by Health Education England, Royal College of Nursing and Mary Seacole. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

*Disclosure statement:* The authors have declared no conflicts of interest.

### References

- Smolen JS, Landewé R, Bijlsma J *et al.* EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Ann Rheum Dis* 2017; 76:960–77.
- Kumar K, Raza K, Nightingale P *et al.* Determinants of adherence to disease modifying anti-rheumatic drugs in White British and South Asian patients with rheumatoid arthritis: a cross sectional study. *BMC Musculoskelet Disord* 2015;16:396.
- Kumar K, Gordon C, Toescu V *et al.* Beliefs about medicines in patients with rheumatoid arthritis and systemic lupus erythematosus: a comparison between patients of South Asian and White British origin. *Rheumatology* 2008;47:690–7.
- Kumar K, Daley E, Khattak F, Buckley CD, Raza K. The influence of ethnicity on the extent of, and reasons underlying, delay in general practitioner consultation in patients with RA. *Rheumatology* 2010;49:1005–12.
- Kumar KR, Stack RJ, Adebajo A, Adams J. Experiences of South Asian patients in early inflammatory arthritis clinic: a qualitative interview study. *Rheumatol Adv Pract* 2019;3:rkz017.
- Dures E, Almeida C, Caesley J *et al.* Patient preferences for psychological support in inflammatory arthritis: a multicentre survey. *Ann Rheum Dis* 2016;75:142–7.

- 7 Wong PKK. Medication adherence in patients with rheumatoid arthritis: why do patients not take what we prescribe? *Rheumatol Int* 2016;36:1535–42.
- 8 Lavielle M, Puyraimond-Zemmour D, Romand X *et al*. Methods to improve medication adherence in patients with chronic inflammatory rheumatic diseases: a systematic literature review. *RMD Open* 2018;4:e000684.
- 9 Kumar K, Raza K, Gill P, Greenfield S. The impact of using musculoskeletal ultrasound imaging and other influencing factors on medication adherence in patients with rheumatoid arthritis: a qualitative study. *Patient Prefer Adherence* 2016;10:1091–100.
- 10 Joplin SK, van der Zwan R, Bagga H, Joshua F, Wong PKK. Pilot study assessing the novel use of musculoskeletal ultrasound in patients with rheumatoid arthritis to improve patient attitudes and adherence to medication. *Int J Rheum Dis* 2016;19:658–64.
- 11 Thompson T, Barbour R, Schwartz L. Adherence to advance directives in critical care decision making: vignette study. *BMJ* 2003;327:1011–0.
- 12 Dresselhaus TR, Peabody JW, Luck J, Bertenthal D. An evaluation of vignettes for predicting variation in the quality of preventive care. *J Gen Intern Med* 2004;19:1013–8.
- 13 Peabody JW, Luck J, Glassman P *et al*. Measuring the quality of physician practice by using clinical vignettes: a prospective validation study. *Ann Intern Med* 2004;141:771–80.
- 14 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 15 Bhopal R. Medicine and public health in a multiethnic world. *J Public Health (Oxf)* 2009;31:315–21.
- 16 Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy* 2005;10:45–53.
- 17 Stack RJ, Stoffer M, Englbrecht M *et al*. Perceptions of risk and predictive testing held by the first-degree relatives of patients with rheumatoid arthritis in England, Austria and Germany: a qualitative study. *BMJ Open* 2016;6:e010555.
- 18 Horne R, Chapman SC, Parham R *et al*. Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the necessity-concerns framework. *PLoS One* 2013;8:e80633.
- 19 Petrie KJ, Weinman J. Why illness perceptions matter. *Clin Med* 2006;6:536–9.
- 20 Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosom Med* 2002;64:580–6.
- 21 Horne R, Weinman J. Self regulation and self management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventor medication. *Psychol Health* 2002;17:17–32.
- 22 Horne R, Buick D, Fisher M *et al*. Doubts about necessity and concerns about adverse effects: identifying the types of beliefs that are associated with non-adherence to HAART. *Int J STD AIDS* 2004;15:38–44.
- 23 Shahab L, Hall S, Marteau T. Showing smokers with vascular disease images of their arteries to motivate cessation: a pilot study. *Br J Health Psychol* 2007;12:275–83.
- 24 Tadmor OP, Zlotogorski Z, Galron-Duniec ML *et al*. The effect of feedback on anxiety levels during ultrasound scanning for ovarian cancer. *Ultrasound Obstet Gynecol* 1995;6:135–9.
- 25 Bovet P, Perret F, Cornuz J, Quilindo J, Paccaud F. Improved smoking cessation in smokers given ultrasound photographs of their own atherosclerotic plaques. *Prev Med* 2002;34:215–20.
- 26 Holland GJ, Hankins M, Marteau TM. Visual feedback of individuals' medical imaging results for changing health behaviour. *Cochrane Database Syst Rev* 2010;1:CD007434.
- 27 Lowe W, Ballinger C, Protheroe J *et al*. Effectiveness of musculoskeletal education interventions in people with low literacy levels: a systematic review. *Arthritis Care Res* 2013;65:1976–85.
- 28 Prothero L, Georgopoulou S, de Souza S *et al*. Patient involvement in the development of a handbook for moderate rheumatoid arthritis. *Health Expect* 2017;20:288–97.
- 29 Joshua F, Baily C, Marabani M, Romas E, White R, Wong P. Perceptions of Doppler ultrasound for rheumatoid arthritis disease activity assessment and education. *Int J Rheum Dis*. 2019;22:55–61.doi: 10.1111/1756-185X.13034. Epub 2017 Feb 16.