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Citation: McBain, H. B., Newman, S. P. and Shipley, M. (2018). Clinician and patients' views about self-management support in arthritis: a cross-sectional UK survey. *Arthritis Care and Research*, doi: 10.1002/acr.23540

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Link to published version: <http://dx.doi.org/10.1002/acr.23540>

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Clinician and patients' views about self-management support in arthritis: a cross-sectional UK survey.



Journal:	<i>Arthritis Care and Research</i>
Manuscript ID	ACR-17-0632.R3
Wiley - Manuscript type:	Original Article
Date Submitted by the Author:	n/a
Complete List of Authors:	McBain, Hayley; City, University of London Shiple, Michael; University College London Hospital, Centre for Rheumatology Newman, Stanton; City, University of London
Key Words: Please choose key words for your manuscript. Choosing the best match of the journal's keywords to your work will likely result in better match to reviewers with expertise in your interest area. It may also help to speed the review process.:	Access to Care, Education, Patient, Health Services Research, Quality of Care, Rheumatoid Arthritis
Optional Terms: You have the option to add additional key words that are not on the journal's list to more specifically categorize your submission.:	self-management

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Clinician and patients' views about self-management support in arthritis: a cross-sectional UK survey.

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Conflicts of interest: None

Word count: 3545

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ABSTRACT**Objective**

The overall aims of the study are to (a) establish receipt and provision of self-management support for patients with inflammatory arthritis in the UK; and (b) establish if receipt of self-management support is associated with patient's knowledge, skills and confidence to self-manage.

Methods

Questionnaire for patients and healthcare professionals were sent to members and associates of the National Rheumatoid Arthritis Society (NRAS). Patients completed the Patient Activation Measure (PAM), and questions about receipt of self-management support. Healthcare professionals completed the Clinician Support PAM and questions about provision of self-management support.

Results

A total of 886 patients and 117 healthcare professionals completed a questionnaire. Only 15% of patients had attended a structured self-management programme. Over half of patients reported having the skills, confidence and knowledge to self-manage and this was associated with receipt of self-management support embedded in routine care. All healthcare professionals felt that patients should be actively involved in their own care, however, 60% were unable to offer structured self-management support. Healthcare professionals reported engaging in more embedded self-management support than patients reported receiving in routine care.

Conclusions

Only a small proportion of patients with arthritis have attended a structured support programme. Although healthcare professionals report engaging in self-management support embedded in routine care, patients do not necessarily agree and these differences could impact on the experience of patients with arthritis. When embedded self-management support does occur this is a significant predictor of patients' knowledge, skills and confidence to self-manage, as opposed to attendance at a structured programme.

For Peer Review Only

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SIGNIFICANCE AND INNOVATIONS

- Only a small proportion of patients with arthritis have attended a structured self-management programme.
- Healthcare professionals report greater use of embedded self-management support as opposed to offering a structured self-management programme.
- There are significant disparities between what elements of self-management support patients feel are embedded in routine care and what healthcare professional believe they are delivering.
- Self-management support that is embedded into routine treatment is a stronger predictor of patients' knowledge, skills and confidence to self-manage than is attendance at structured self-management support programmes.

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3 Self-management support has been identified as one of a number of activities
4
5 recommended for people with inflammatory arthritis (1;2). This support aims to help
6
7 patients better manage their symptoms, treatment, physical and psychological
8
9 consequences and the lifestyle changes inherent in living with a chronic condition (3). This is
10
11 achieved by increasing patients' skills and confidence in their ability to manage their health
12
13 (4) and enabling them to take an active role in their own care. Self-management support is
14
15 thought to consist of eight components; education, goal setting, action planning, problem
16
17 solving, skills acquisition, self-monitoring, understanding illness and managing emotions (5).
18
19 This support can take the form of group or individually structured self-management support
20
21 programmes, such as those offered by arthritis charities or programmes delivered within
22
23 primary or secondary care but outside of outpatient clinics, or support that is embedded
24
25 within clinical teams and offered individually within routine consultations.
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32 The UK has a long history of structured arthritis self-management support programmes
33
34 many derived from the early work of Kate Lorig, which originally focussed on arthritis (6).
35
36 Although the content, delivery and intensity of the interventions in the UK differed, they
37
38 were frequently associated with some short-term benefits in terms of pain, disability,
39
40 knowledge, well-being and ability to cope (7-11), lasting up to 14 months post-intervention
41
42 and across a range of rheumatological conditions (9;11;12). At one time, a number of UK
43
44 arthritis charities offered these programmes throughout the country, alongside Primary
45
46 Care Trusts (PCTs) who were responsible for commissioning, organising and delivering
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48 community care at a local level. The PCTs tended to administer the Expert Patient
49
50 Programme, a chronic disease self-management programme where individuals with a range
51
52 of chronic conditions were recruited, including those with arthritis. During these times, large
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3 numbers of people with arthritis were served by structured self-management support.

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5 These efforts began to decline approximately 10 years ago when self-management support
6
7 was moved to a not-for-profit organisation set up by the UK Government to market and
8
9 deliver courses, while UK arthritis charities began to decrease the number of self-
10
11 management programmes they offered. As a result, these programmes then had to
12
13 compete with all other healthcare services for commissioning by NHS trusts, where as they
14
15 had been previously funded directly in one way or another by the NHS.
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21 Despite these organisational changes and limiting access it is clear that people with arthritis
22
23 remain eager for information (13) and access to self-management support (14). Recent
24
25 research indicates that only 27% of rheumatology units in the UK can provide access to self-
26
27 management education (15). The reasons for this are as yet unknown and even when
28
29 patients are referred and invited to attend, uptake rates in clinical practice are
30
31 undetermined and in clinical trials range between 2 and 28% (16). No published data
32
33 currently estimates the proportion of patients with arthritis who have attended a structured
34
35 self-management support programme in the UK, which would be one indicator of the
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37 impact of these organisational changes and the degree to which evidence has been
38
39 translated into practice.
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46 To address any potential barriers to providing and accessing structured self-management
47
48 support programmes, and provide an avenue for ongoing, sustainable provision recent
49
50 models are now seeking to embed self-management support within rheumatology clinical
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52 teams. This would involve clinicians offering self-management support during routine clinic
53
54 appointments. An RCT of brief skills-based training in communication and self-management
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3 skills, specifically for rheumatology healthcare professionals, found an increase in learning
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5 and integration of self-management support into standard care (17), and an increase in
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7 patient's self-efficacy and acceptance of their condition (18). What is unknown is the extent
8
9 to which rheumatology healthcare professionals are already embedding self-management
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11 support into standard care, or the extent to which patients feel they receive embedded self-
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13 management support within their rheumatology consultations.
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19 The overall aims of this study are therefore to (a) establish receipt and provision of both
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21 structured self-management support programmes and embedded self-management support
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23 for patients with arthritis in the UK; (b) establish if receipt of self-management support,
24
25 both structured and embedded, is considered to be associated with patient's knowledge,
26
27 skills and confidence in their ability to self-manage; and (c) determine healthcare
28
29 professional's attitudes to patient involvement in the care process and whether this predicts
30
31 provision of embedded self-management support.
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36 PATIENTS AND METHODS

37 Participants and recruitment

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39 Participants, both patients and healthcare professionals, were recruited through the
40
41 National Rheumatoid Arthritis Society (NRAS), UK. Members of NRAS were emailed a link to
42
43 the online survey via their electronic newsletter and the wider rheumatoid arthritis
44
45 community were contacted via NRAS's social media platform and website. The inclusion
46
47 criteria for patients were those over the age of 18, with a self-reported diagnosis of
48
49 inflammatory arthritis. For healthcare professionals, inclusion criteria were those involved in
50
51 the care of patients with inflammatory arthritis. All questionnaires were completed
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2
3 anonymously; completion and submission of the questionnaire was assumed as consent to
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5 participate. The study received full ethical approval from the School of Health Sciences
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7 Research Ethics Committee, City, University of London.
8
9

Measures

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11
12 Two online questionnaires were developed, one for patients and the other for healthcare
13
14 professionals. All data were collected online via Smart-Survey™ (19). All questions were
15
16 compulsory to ensure minimal missing data. NRAS provided input into the design of the
17
18 questionnaires, suggesting possible response options and rewording potentially confusing or
19
20 unclear questions. These were then amended prior to ethics approval and dissemination.
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22

Demographic and clinical variables

23
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25
26 Patient data were collected on self-reported age, gender, disease type/s (more than one
27
28 could be selected), use of methotrexate and disease duration. Healthcare professionals
29
30 reported their age, gender, profession and number of years in practice.
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32

Receipt of self-management support

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35 Patients were asked 'Have you ever taken part in a structured self-management support
36
37 programme?' (yes/no) and if so, where. To examine the extent to which patients were
38
39 receiving embedded self-management support from their rheumatology team eight
40
41 questions were designed, one for each of the eight components of self-management;
42
43 education, goal setting, action planning, problem solving, skills acquisition, self-monitoring,
44
45 understanding illness and managing emotions (5). For example, *"I work collaboratively with*
46
47 *members of my rheumatology team to develop actions plans about how I manage my*
48
49 *arthritis and its treatment"*. Responses for each item were on a 4-point Likert scale from
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51 'strongly disagree' (1) to 'strongly agree' (4). A Cronbach's alpha of 0.81 indicated good
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3 internal consistency for the scale. A sum score was therefore created, with greater scores
4
5 indicating greater receipt of embedded self-management support.
6

Provision of self-management support

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9 Healthcare professionals were asked if they offered a structured self-management support
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11 programme to their patients (yes/no), and if not the reasons why. To examine the extent to
12
13 which healthcare professionals engaged their patients with arthritis in embedded self-
14
15 management support eight questions were designed, one for each of the eight components
16
17 of self-management; education, goal setting, action planning, problem solving, skills
18
19 acquisition, self-monitoring, understanding illness and managing emotions (5). For example,
20
21 *"I work collaboratively with my patients to solve any problems they have about their arthritis*
22
23 *and its treatment"*. Responses for each item were on a 4-point Likert scale from 'strongly
24
25 disagree' (1) to 'strongly agree' (4). A Cronbach's alpha of 0.86 indicated good internal
26
27 consistency for the scale. A sum score was therefore created, with greater scores indicating
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29 greater provision of embedded self-management support.
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Self-managing

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36 Patients completed the Patient Activation Measure (PAM), which is a 13-item (20) measure
37
38 that assesses patient knowledge, skills, and confidence in their ability to self-manage. It is a
39
40 shortened version of the original 22-item scale (21), which has been found to possess
41
42 excellent internal validity and person reliability using Rasch models. Responses are on a 4-
43
44 point Likert scale from 'disagree strongly' (1) to 'agree strongly' (4), with a N/A option.
45
46
47 Scores can be categorised into one of four progressively higher levels of activation, level 1:
48
49 'may not yet believe that the patient role is important' (score ≤ 47.0), level 2: 'lacks
50
51 confidence and knowledge to take action' (score 47.1 - 55.1), level 3: 'beginning to take
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53 action' (score 55.2 - 67.0) and level 4: 'has difficulty maintaining behaviours over time'
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3 (score ≥ 67.1). Raw scores are a total for the scale, which are then converted into scores
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5 from 0-100 with higher scores suggesting a stronger belief in their ability to manage their
6
7 arthritis. This shortened version has been found to possess similar psychometric properties
8
9 to the original version (20).
10

Attitude to patient involvement in the care process

11
12 Healthcare professionals completed the Clinician Support Patient Activation Measure (CS-
13
14 PAM) (22) a 14-item measure that assesses a provider's attitude about the patient's role in
15
16 the care process. Responses are on a 4 point Likert scale from 'not important' (1) to
17
18 'extremely important' (4), with N/A an option. Raw scores are a total for the scale. This total
19
20 is then converted into a score ranging from 0-100, with higher scores indicating an increased
21
22 belief that patients with arthritis should be more involved in the care process. Scores can be
23
24 categorized into one of the 3 levels of activation. Level 1: 'patient should follow medical
25
26 advice' (score of ≤ 37.81), level 2: 'patient can make independent judgments and actions'
27
28 (score 39.23 - 58.44) and level 3: 'patient is able to function as a member of the care team'
29
30 (score ≥ 60.13). The authors report good internal validity and using Rasch models the person
31
32 reliability is also within acceptable limits (22).
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Analysis

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42 Descriptive statistics were used to summarise the characteristics of the sample. For patients,
43
44 a multiple regression was performed to predict patient knowledge, skills, and confidence in
45
46 their ability to self-manage (PAM) from disease type, age, gender, disease duration, use of
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48 methotrexate, attendance at structured self-management support programme and receipt
49
50 of embedded self-management support (8 items). For healthcare professionals, a multiple
51
52 regression was performed to predict engagement in embedded self-management support
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(total scores) from age, gender, profession, years in practice and attitude to patient involvement in the care process (CS-PAM).

RESULTS**Participant characteristics**

A total of 886 patients took part in the survey. One participant was removed from the study, as they did not identify themselves as having arthritis - 885 patients were included in the final analyses. Most participants were living with just one rheumatological condition (71.50%). A majority had been diagnosed with rheumatoid arthritis (Table 1). The average disease duration was 10.86 years (SD = 10.28 years). Eighty-three percent of the sample were female and age ranged from 21 to 88 years. A total of 117 healthcare professionals responded. Most of the sample were nurses followed by occupational therapists and rheumatologists (Table 2). Eighty-three per cent of the sample were female and age ranged from 21 to 64 years. The mean number of years in practice was 19.89 (SD = 10.93 years).

Patient's receipt of self-management support

Only 15% (n=133) of patients had attended a structured self-management support programme and this was primarily within the rheumatology service at their treating hospital (Table 3). Receipt of embedded self-management support was more common. Approximately 50% of participants agreed or strongly agreed that they worked collaboratively with members of their rheumatology team to set goals and develop action plans about how to manage their arthritis and had been taught the skills they needed to manage and monitor their condition, as well as understand any test results (online supplementary material A). Over 70% of patients strongly agreed or agreed that a member of their rheumatology team had provided them with information and education about their

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2
3 arthritis, or that patients had worked collaboratively with their rheumatology team to solve
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5 any problems relating to their condition. By contrast, only 20-30% of participants agreed or
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7 strongly agreed that they had been able to discuss their understanding of their arthritis and
8
9 its treatment with a member of their rheumatology team or that a member of the team had
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11 helped them manage the emotions or stresses associated with their condition and its
12
13 treatment.
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15

Patients self-managing

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18 Patients' mean score on the PAM was 57.82 (SD = 15.51). The sample were evenly split
19
20 across the four levels of activation, 251 (28.40%) participants were at activation level 1 (may
21
22 not yet believe that the patient role is important), 182 (20.60%) at level 2 (lacks confidence
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24 and knowledge to take action), 204 (23.10%) at level 3 (beginning to take action) and 248
25
26 (28.00%) at level 4 (has difficulty maintaining behaviours over time). The multiple regression
27
28 model explained 55% of the variance in PAM scores ($F(15, 868) = 25.59, p < 0.001$). Disease
29
30 duration ($\beta = 0.16, p < .001$), embedded goal setting ($\beta = 0.16, p = .01$), embedded self-
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32 monitoring ($\beta = 0.16, p = .03$) and embedded discussions about the patients understanding
33
34 of their condition ($\beta = -0.15, p < .001$) were the only statistically significant predictors in the
35
36 model (Table 4).
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Healthcare professionals attitudes to patient involvement in the care process

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44 Healthcare professionals' mean score on the CS-Pam was 77.13 (SD = 13.99). No healthcare
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46 professionals scored within activation level 1 (patient should follow medical advice), 11
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48 (9.40%) were within level 2 (patient can make independent judgments and actions) and 106
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50 (90.60%) were in level 3 (patient is able to function as a member of the care team).
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Healthcare professionals provision of self-management support

Almost 60% of the healthcare professionals were unable to offer a structured self-management support programme to their patients with arthritis. This was mainly due to a lack of staffing (n = 41, 35.00%) and funding (n = 20, 17.10%). Others reported not being aware of a suitable programme in their area (n = 14, 12%). Some had a preference to refer patients to other external agencies or organisations (n = 13, 11.1%) or to offer self-management support themselves on an individual basis (n = 3, 2.6%).

Whilst many healthcare professionals were unable to offer a structured approach to supporting their patients, self-management support was more likely to be embedded within standard care. All healthcare professionals surveyed agreed or strongly agreed that they provided information and education to their patients about their arthritis and its treatment (online supplementary material B). Over 90% agreed or strongly agreed that they worked collaboratively with their patients to set goals, develop plans of action, problem solve, help them acquire the necessary skills to manage their arthritis and, understand their arthritis and its treatment. Over 85% agreed or strongly agreed that they taught their patients how to monitor their arthritis and its treatment including the meaning of any blood tests and managing the emotional impact and stresses related to their arthritis. A multiple regression to explore whether CS-PAM scores, along with demographic characteristics could predict engagement in embedded self-management support was not statistically significant ($F(8, 108) = 1.69, p = 0.11$).

Differences between healthcare professionals and patients

Figure 1 demonstrates differences between healthcare professionals and patients on the degree to which the eight components of self-management support were felt to be

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2
3 embedded in standard care. Healthcare professionals on average agreed or strongly agreed
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5 that they worked with their patients to engage in all eight components of self-management
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7 support. Patients, on the other hand, disagreed that many of the eight components of self-
8
9 management support were being offered to them during their routine consultations.
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DISCUSSION

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15 Self-management support should be integral to the care of people with arthritis (1). The
16
17 mode in which this is implemented can differ from structured programmes delivered in
18
19 secondary and primary care but outside of the outpatients setting to approaches that are
20
21 embedded within routine care. There is limited data however, on the provision and uptake
22
23 of self-management support by patients with arthritis in the UK. This survey found that only
24
25 15% of patients with arthritis had attended a structured self-management support
26
27 programme. Possibly unsurprising given that 60% of rheumatology healthcare professionals
28
29 were unable to offer a structured self-management support programme to their patients.
30
31 Primarily because they were unable to staff or fund such services, which corresponds to the
32
33 barriers to providing psychological support in arthritis (15). Attendance is an important
34
35 indicator of reach (23), but despite evidence dating back to the 1980's (6) translation of
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37 evidence into UK practice appears to remain limited potentially due to the changes made to
38
39 the commissioning of self-management programmes over 10 years ago.
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47 One potential way of overcoming a lack of access to structured approaches is to embed self-
48
49 management support into standard care. A model which has received recent attention in
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51 the literature (17;18). In fact, although the current study found that many healthcare
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53 professionals were unable to offer structured self-management support, they reported
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3 embedding self-management support into their routine clinic appointments. This shift from
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5 the provision of structured self-management programmes, 10 years ago, to embedded
6
7 support may in part reflect the permeation of the self-management approach into clinical
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9 training and NHS priorities (24;25). This does however rely on the ability and preferences of
10
11 individual clinician.
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16 Although patients and healthcare professionals were not matched, data from this survey
17
18 indicated that patients do not perceive receiving much self-management support in their
19
20 clinical encounters, whilst healthcare professionals report providing high levels of support.
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22 This could indicate variation between clinicians on the self-management support offered
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24 within routine consultations, a lack of shared language between healthcare professionals
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26 and patients for self-management (26) and/or the inability of patients and/or healthcare
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28 professionals to accurately assess receipt or delivery of self-management support. When
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30 patients are able to engage with their healthcare team at a level of involvement consistent
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32 with their preferences they experience greater satisfaction with their care, are less
33
34 depressed and have better health outcomes (27) therefore further investigation into the
35
36 delivery and receipt of self-management support within the same clinical encounters is
37
38 required. Given that this study found that embedding goal setting and self-monitoring into
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40 routine consultations was associated with greater knowledge, skills and confidence in
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42 patients' ability to self-manage, as opposed to attendance at a structured self-management
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44 support programme. This provides further justification for embedding self-management
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46 support into routine care.
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3 Recruitment of participants to this survey via online methods yielded a significant response
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5 from patients, highlighting the advantages of this approach. One of the strengths of this
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7 study is the large, national sample, however concerns have been raised about the
8
9 representativeness of online research (28). It was however, not possible to estimate the
10
11 number of people who received or saw the invitation to participate to assess
12
13 representativeness, due to the online recruitment methods. There was a poorer response
14
15 from healthcare professionals, and data is bias towards nursing and the allied health
16
17 professions and those who are more interested in self-management support. The study was
18
19 limited by its recruitment strategy, as individuals who join societies such as NRAS, may be
20
21 those who actively seek information and support in relation to their condition. Other
22
23 potential limitations relate to the questions aimed to measure engagement in embedded
24
25 self-management support. We do not know how participants interpreted structured self-
26
27 management support programmes and there may be other components of self-
28
29 management that were not covered, particularly as we know that patients and healthcare
30
31 professionals often hold different models of self-management (26). The measure was also
32
33 developed specifically for this study, and although it contained good internal consistency we
34
35 did not assess test-retest reliability or other forms of validity. Generalisability of the study
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37 outside of the UK is also not possible, given that importance and funding of self-
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39 management support differs by country.
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49 Considering the emphasis placed on patient empowerment (24) and the integration of self-
50
51 management support into the guidelines for managing arthritis (1;2), there seems to be
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53 some way to go before evidence has been translated into practice. Despite its long history
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55 and evidence base this survey revealed that the organisational changes made to the delivery
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3 and funding of self-management support in the UK means that only a small proportion of
4
5 patients with inflammatory arthritis have attended a structured self-management support
6
7 programme. From the healthcare professional perspective, it appears that self-management
8
9 support is now more likely to be embedded within routine clinic appointments. When goal
10
11 setting and self-monitoring were embedded into routine care this was associated with
12
13 increased patient knowledge, skills and confidence to self-manage. Patients however, felt
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15 that this does not always occur, which raises concerns about the impact that this may have
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17 on their experience of care and the health outcomes of patients with arthritis.
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Table 1. Patient characteristics

Characteristics	n(%)
Age, m(SD)	56.84(11.10)
Gender	
Female	735(83.10)
Male	150(16.90)
Condition†	
Rheumatoid arthritis	841(95.00)
Osteoarthritis	145(16.40)
Fibromyalgia	74(8.40)
Osteoporosis	57(6.40)
Psoriatic arthritis	33(3.70)
Lupus or Ankylosing Spondylitis	11(1.20)
Juvenile idiopathic arthritis	11(1.20)
Sjögren's	11(1.20)
Inflammatory arthritis	10(1.10)
Seronegative arthritis	8(0.90)
Gout	7(0.80)
Polymyalgia rheumatica	5(0.60)
Osteopenia	4(0.50)
Lumbar spinal stenosis	3(0.30)
Hypermobility syndrome	1(0.10)
Palindromic rheumatism	1(0.10)

Arthritis self-management support: a national survey

Characteristics	n(%)
Sciatica	1(0.10)
Degenerative disc disease	1(0.10)
Mixed connective tissue disease	1(0.10)
Marfan syndrome	1(0.10)

† Self-reported and more than 1 rheumatological condition could be selected

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Table 2. Healthcare professional characteristics

Profession	n(%)
Nurse Practitioner	55(47.00)
Occupational Therapist	19(16.20)
Rheumatologist	18(15.40)
Physiotherapist	12(10.30)
Podiatrist	6(5.10)
Clinical Nurse Specialist in Rheumatology	3(2.70)
Pharmacist	1(0.90)
Clinical Trials Coordinator	1(0.90)
Research Practitioner	1(0.90)
Practice Nurse	1(0.90)

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Table 3. Location of self-management programme attendance

Location	n(%)
Within rheumatology services at hospital	78(59.10)
Charity	27(20.45)
A local patient group	16(12.12)
GP service	9(6.82)
Expert patient programme (EPP)	9(6.82)
Self-taught	1(0.76)
COPERS [†] course	1(0.76)

[†] COPERS: coping with persistent pain, effectiveness research into self-management

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Table 4. Multiple regression model for patient PAM scores

	Standardized		
	β	t	p
	Coefficients		
(Constant)		7.70	0.00
Age	0.01	0.24	0.81
Gender	-0.01	-0.46	0.65
Disease duration (years)	0.16	5.54	0.00
Methotrexate use	-0.05	-1.78	0.08
Rheumatoid arthritis	0.00	0.04	0.97
Psoriatic arthritis	-0.02	-0.47	0.64
Attendance at a structured self-management programme	0.05	1.82	0.07
A member of the rheumatology team has provided me with information and education about my arthritis and its treatment	-0.02	-0.46	0.65
I work collaboratively with members of the rheumatology team to set goals about how I manage my arthritis and its treatment	0.15	2.65	0.01
I work collaboratively with members of the rheumatology team to develop actions plans about how I manage my arthritis and its treatment	-0.01	-0.17	0.86
I work collaboratively with members of the rheumatology team to solve any problems I have about my arthritis and its	0.09	1.86	0.06

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	Standardized		
	β	t	p
	Coefficients		
treatment			
A member of the rheumatology team has taught me the skills I need to manage my arthritis and its treatment	0.06	1.23	0.22
A member of the rheumatology team has taught me how to monitor my arthritis and its treatment, including the meaning of any tests I have	0.10	2.19	0.03
I have discussed what I understand about my arthritis and its treatment with a member of the rheumatology team	-0.15	-3.63	0.00
A member of the rheumatology team has helped me manage my emotions and any stress I have experienced in relation to my arthritis and its treatment	0.08	1.88	0.06

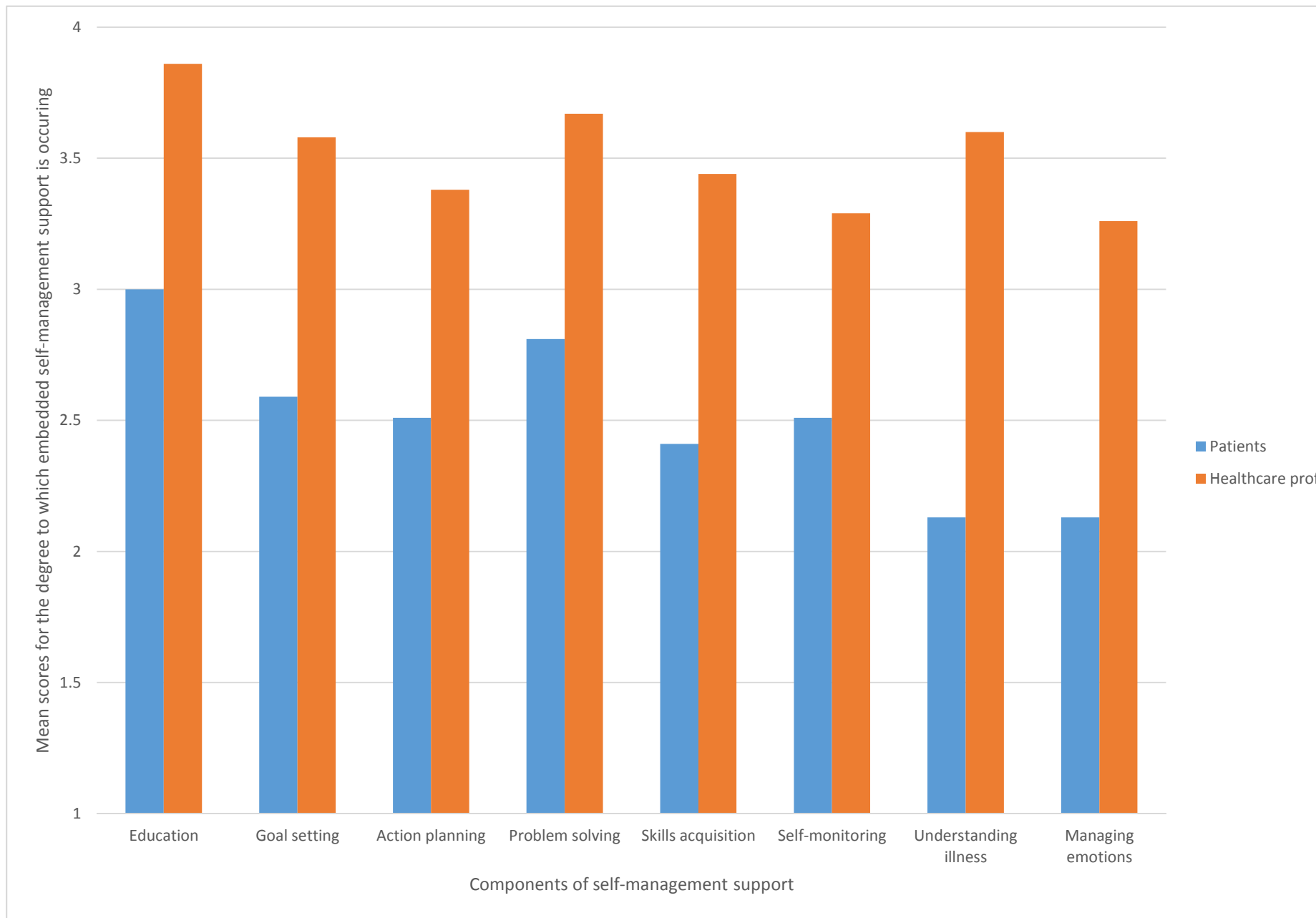
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Figure 1. Receipt and delivery of embedded self-management support (mean scores)

Arthritis self-management support: a national survey

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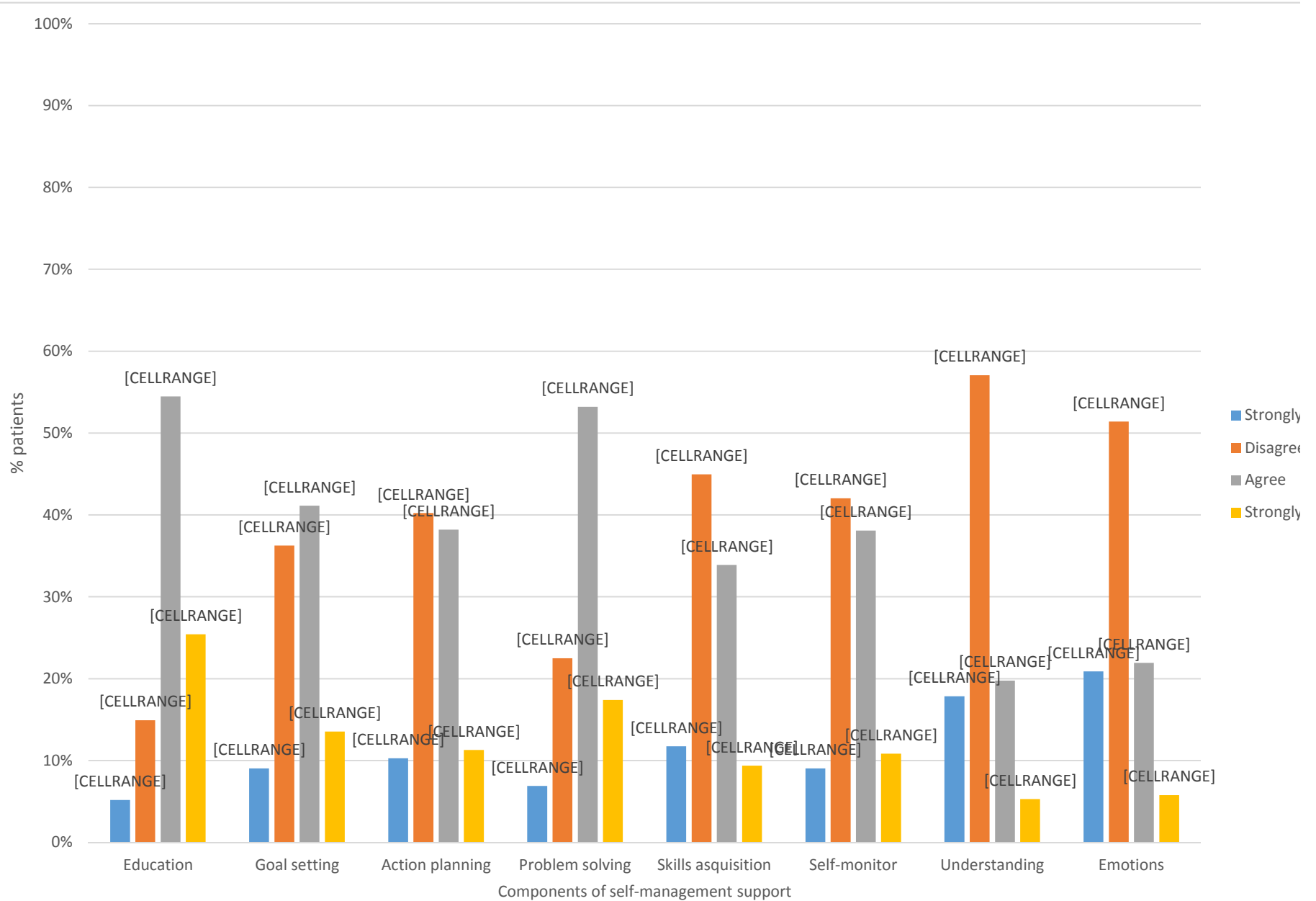
	Education	Goal setting	Action planning	Problem solving
Patients	3	2.59	2.51	2.81
Healthcare professionals	3.86	3.58	3.38	3.67

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Skills acquisition	Self-monitoring	Understanding illness	Managing emotions
2.41	2.51	2.13	2.13
3.44	3.29	3.6	3.26

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Clinician and patients' views about self-management support in arthritis: a cross-sectional UK survey.

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Conflicts of interest: None

Word count: 3545

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ABSTRACT**Objective**

The overall aims of the study are to (a) establish receipt and provision of self-management support for patients with inflammatory arthritis in the UK; and (b) establish if receipt of self-management support is associated with patient's knowledge, skills and confidence to self-manage.

Methods

Questionnaire for patients and healthcare professionals were sent to members and associates of the National Rheumatoid Arthritis Society (NRAS). Patients completed the Patient Activation Measure (PAM), and questions about receipt of self-management support. Healthcare professionals completed the Clinician Support PAM and questions about provision of self-management support.

Results

A total of 886 patients and 117 healthcare professionals completed a questionnaire. Only 15% of patients had attended a structured self-management programme. Over half of patients reported having the skills, confidence and knowledge to self-manage and this was associated with receipt of self-management support embedded in routine care. All healthcare professionals felt that patients should be actively involved in their own care, however, 60% were unable to offer structured self-management support. Healthcare professionals reported engaging in more embedded self-management support than patients reported receiving in routine care.

Conclusions

Only a small proportion of patients with arthritis have attended a structured support programme. Although healthcare professionals report engaging in self-management support embedded in routine care, patients do not necessarily agree and these differences could impact on the experience of patients with arthritis. When embedded self-management support does occur this is a significant predictor of patients' knowledge, skills and confidence to self-manage, as opposed to attendance at a structured programme.

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SIGNIFICANCE AND INNOVATIONS

- Only a small proportion of patients with arthritis have attended a structured self-management programme.
- Healthcare professionals report greater use of embedded self-management support as opposed to offering a structured self-management programme.
- There are significant disparities between what elements of self-management support patients feel are embedded in routine care and what healthcare professional believe they are delivering.
- Self-management support that is embedded into routine treatment is a stronger predictor of patients' knowledge, skills and confidence to self-manage than is attendance at structured self-management support programmes.

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3 Self-management support has been identified as one of a number of activities
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5 recommended for people with inflammatory arthritis (1;2). This support aims to help
6
7 patients better manage their symptoms, treatment, physical and psychological
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9 consequences and the lifestyle changes inherent in living with a chronic condition (3). This is
10
11 achieved by increasing patients' skills and confidence in their ability to manage their health
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13 (4) and enabling them to take an active role in their own care. Self-management support is
14
15 thought to consist of eight components; education, goal setting, action planning, problem
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17 solving, skills acquisition, self-monitoring, understanding illness and managing emotions (5).
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19 This support can take the form of group or individually structured self-management support
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21 programmes, such as those offered by arthritis charities or programmes delivered within
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23 primary or secondary care but outside of outpatient clinics, or support that is embedded
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25 within clinical teams and offered individually within routine consultations.
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33 The UK has a long history of structured arthritis self-management support programmes
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35 many derived from the early work of Kate Lorig, which originally focussed on arthritis (6).
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37 Although the content, delivery and intensity of the interventions in the UK differed, they
38
39 were frequently associated with some short-term benefits in terms of pain, disability,
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41 knowledge, well-being and ability to cope (7-11), lasting up to 14 months post-intervention
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43 and across a range of rheumatological conditions (9;11;12). At one time, a number of UK
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45 arthritis charities offered these programmes throughout the country, alongside Primary
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47 Care Trusts (PCTs) who were responsible for commissioning, organising and delivering
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49 community care at a local level. The PCTs tended to administer the Expert Patient
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51 Programme, a chronic disease self-management programme where individuals with a range
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53 of chronic conditions were recruited, including those with arthritis. During these times, large
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Arthritis self-management support: a national survey

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3 numbers of people with arthritis were served by structured self-management support.

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5 These efforts began to decline approximately 10 years ago when self-management support
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7 was moved to a not-for-profit organisation set up by the UK Government to market and
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9 deliver courses, while UK arthritis charities began to decrease the number of self-
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11 management programmes they offered. As a result, these programmes then had to
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13 compete with all other healthcare services for commissioning by NHS trusts, where as they
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15 had been previously funded directly in one way or another by the NHS.
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21 Despite these organisational changes and limiting access it is clear that people with arthritis
22
23 remain eager for information (13) and access to self-management support (14). Recent
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25 research indicates that only 27% of rheumatology units in the UK can provide access to self-
26
27 management education (15). The reasons for this are as yet unknown and even when
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29 patients are referred and invited to attend, uptake rates in clinical practice are
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31 undetermined and in clinical trials range between 2 and 28% (16). No published data
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33 currently estimates the proportion of patients with arthritis who have attended a structured
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35 self-management support programme in the UK, which would be one indicator of the
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37 impact of these organisational changes and the degree to which evidence has been
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39 translated into practice.
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46 To address any potential barriers to providing and accessing structured self-management
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48 support programmes, and provide an avenue for ongoing, sustainable provision recent
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50 models are now seeking to embed self-management support within rheumatology clinical
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52 teams. This would involve clinicians offering self-management support during routine clinic
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54 appointments. An RCT of brief skills-based training in communication and self-management
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Arthritis self-management support: a national survey

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3 skills, specifically for rheumatology healthcare professionals, found an increase in learning
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5 and integration of self-management support into standard care (17), and an increase in
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7 patient's self-efficacy and acceptance of their condition (18). What is unknown is the extent
8
9 to which rheumatology healthcare professionals are already embedding self-management
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11 support into standard care, or the extent to which patients feel they receive embedded self-
12
13 management support within their rheumatology consultations.
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19 The overall aims of this study are therefore to (a) establish receipt and provision of both
20
21 structured self-management support programmes and embedded self-management support
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23 for patients with arthritis in the UK; (b) establish if receipt of self-management support,
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25 both structured and embedded, is considered to be associated with patient's knowledge,
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27 skills and confidence in their ability to self-manage; and (c) determine healthcare
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29 professional's attitudes to patient involvement in the care process and whether this predicts
30
31 provision of embedded self-management support.
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36 PATIENTS AND METHODS

37 Participants and recruitment

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39 Participants, both patients and healthcare professionals, were recruited through the
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41 National Rheumatoid Arthritis Society (NRAS), UK. Members of NRAS were emailed a link to
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43 the online survey via their electronic newsletter and the wider rheumatoid arthritis
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45 community were contacted via NRAS's social media platform and website. The inclusion
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47 criteria for patients were those over the age of 18, with a self-reported diagnosis of
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49 inflammatory arthritis. For healthcare professionals, inclusion criteria were those involved in
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51 the care of patients with inflammatory arthritis. All questionnaires were completed
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Arthritis self-management support: a national survey

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3 anonymously; completion and submission of the questionnaire was assumed as consent to
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5 participate. The study received full ethical approval from the School of Health Sciences
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7 Research Ethics Committee, City, University of London.
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Measures

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12 Two online questionnaires were developed, one for patients and the other for healthcare
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14 professionals. All data were collected online via Smart-Survey™ (19). All questions were
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16 compulsory to ensure minimal missing data. NRAS provided input into the design of the
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18 questionnaires, suggesting possible response options and rewording potentially confusing or
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20 unclear questions. These were then amended prior to ethics approval and dissemination.
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Demographic and clinical variables

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26 Patient data were collected on self-reported age, gender, disease type/s (more than one
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28 could be selected), use of methotrexate and disease duration. Healthcare professionals
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30 reported their age, gender, profession and number of years in practice.
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Receipt of self-management support

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35 Patients were asked 'Have you ever taken part in a structured self-management support
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37 programme?' (yes/no) and if so, where. To examine the extent to which patients were
38
39 receiving embedded self-management support from their rheumatology team eight
40
41 questions were designed, one for each of the eight components of self-management;
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43 education, goal setting, action planning, problem solving, skills acquisition, self-monitoring,
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45 understanding illness and managing emotions (5). For example, *"I work collaboratively with*
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47 *members of my rheumatology team to develop actions plans about how I manage my*
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49 *arthritis and its treatment"*. Responses for each item were on a 4-point Likert scale from
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51 'strongly disagree' (1) to 'strongly agree' (4). A Cronbach's alpha of 0.81 indicated good
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Arthritis self-management support: a national survey

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3 internal consistency for the scale. A sum score was therefore created, with greater scores
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5 indicating greater receipt of embedded self-management support.
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Provision of self-management support

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9 Healthcare professionals were asked if they offered a structured self-management support
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11 programme to their patients (yes/no), and if not the reasons why. To examine the extent to
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13 which healthcare professionals engaged their patients with arthritis in embedded self-
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15 management support eight questions were designed, one for each of the eight components
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17 of self-management; education, goal setting, action planning, problem solving, skills
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19 acquisition, self-monitoring, understanding illness and managing emotions (5). For example,
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21 *"I work collaboratively with my patients to solve any problems they have about their arthritis*
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23 *and its treatment"*. Responses for each item were on a 4-point Likert scale from 'strongly
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25 disagree' (1) to 'strongly agree' (4). A Cronbach's alpha of 0.86 indicated good internal
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27 consistency for the scale. A sum score was therefore created, with greater scores indicating
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29 greater provision of embedded self-management support.
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Self-managing

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36 Patients completed the Patient Activation Measure (PAM), which is a 13-item (20) measure
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38 that assesses patient knowledge, skills, and confidence in their ability to self-manage. It is a
39
40 shortened version of the original 22-item scale (21), which has been found to possess
41
42 excellent internal validity and person reliability using Rasch models. Responses are on a 4-
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44 point Likert scale from 'disagree strongly' (1) to 'agree strongly' (4), with a N/A option.
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47 Scores can be categorised into one of four progressively higher levels of activation, level 1:
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49 'may not yet believe that the patient role is important' (score ≤ 47.0), level 2: 'lacks
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51 confidence and knowledge to take action' (score 47.1 - 55.1), level 3: 'beginning to take
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53 action' (score 55.2 - 67.0) and level 4: 'has difficulty maintaining behaviours over time'
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Arthritis self-management support: a national survey

(score ≥ 67.1). Raw scores are a total for the scale, which are then converted into scores from 0-100 with higher scores suggesting a stronger belief in their ability to manage their arthritis. This shortened version has been found to possess similar psychometric properties to the original version (20).

Attitude to patient involvement in the care process

Healthcare professionals completed the Clinician Support Patient Activation Measure (CS-PAM) (22) a 14-item measure that assesses a provider's attitude about the patient's role in the care process. Responses are on a 4 point Likert scale from 'not important' (1) to 'extremely important' (4), with N/A an option. Raw scores are a total for the scale. This total is then converted into a score ranging from 0-100, with higher scores indicating an increased belief that patients with arthritis should be more involved in the care process. Scores can be categorized into one of the 3 levels of activation. Level 1: 'patient should follow medical advice' (score of ≤ 37.81), level 2: 'patient can make independent judgments and actions' (score 39.23 - 58.44) and level 3: 'patient is able to function as a member of the care team' (score ≥ 60.13). The authors report good internal validity and using Rasch models the person reliability is also within acceptable limits (22).

Analysis

Descriptive statistics were used to summarise the characteristics of the sample. For patients, a multiple regression was performed to predict patient knowledge, skills, and confidence in their ability to self-manage (PAM) from disease type, age, gender, disease duration, use of methotrexate, attendance at structured self-management support programme and receipt of embedded self-management support (8 items). For healthcare professionals, a multiple regression was performed to predict engagement in embedded self-management support

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(total scores) from age, gender, profession, years in practice and attitude to patient involvement in the care process (CS-PAM).

RESULTS**Participant characteristics**

A total of 886 patients took part in the survey. One participant was removed from the study, as they did not identify themselves as having arthritis - 885 patients were included in the final analyses. Most participants were living with just one rheumatological condition (71.50%). A majority had been diagnosed with rheumatoid arthritis (Table 1). The average disease duration was 10.86 years (SD = 10.28 years). Eighty-three percent of the sample were female and age ranged from 21 to 88 years. A total of 117 healthcare professionals responded. Most of the sample were nurses followed by occupational therapists and rheumatologists (Table 2). Eighty-three per cent of the sample were female and age ranged from 21 to 64 years. The mean number of years in practice was 19.89 (SD = 10.93 years).

Patient's receipt of self-management support

Only 15% (n=133) of patients had attended a structured self-management support programme and this was primarily within the rheumatology service at their treating hospital (Table 3). Receipt of embedded self-management support was more common. Approximately 50% of participants agreed or strongly agreed that they worked collaboratively with members of their rheumatology team to set goals and develop action plans about how to manage their arthritis and had been taught the skills they needed to manage and monitor their condition, as well as understand any test results (online supplementary material A). Over 70% of patients strongly agreed or agreed that a member of their rheumatology team had provided them with information and education about their

Arthritis self-management support: a national survey

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3 arthritis, or that patients had worked collaboratively with their rheumatology team to solve
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5 any problems relating to their condition. By contrast, only 20-30% of participants agreed or
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7 strongly agreed that they had been able to discuss their understanding of their arthritis and
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9 its treatment with a member of their rheumatology team or that a member of the team had
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11 helped them manage the emotions or stresses associated with their condition and its
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13 treatment.
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Patients self-managing

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18 Patients' mean score on the PAM was 57.82 (SD = 15.51). The sample were evenly split
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20 across the four levels of activation, 251 (28.40%) participants were at activation level 1 (may
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22 not yet believe that the patient role is important), 182 (20.60%) at level 2 (lacks confidence
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24 and knowledge to take action), 204 (23.10%) at level 3 (beginning to take action) and 248
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26 (28.00%) at level 4 (has difficulty maintaining behaviours over time). The multiple regression
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28 model explained 55% of the variance in PAM scores ($F(15, 868) = 25.59, p < 0.001$). Disease
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30 duration ($\beta = 0.16, p < .001$), embedded goal setting ($\beta = 0.16, p = .01$), embedded self-
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32 monitoring ($\beta = 0.16, p = .03$) and embedded discussions about the patients understanding
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34 of their condition ($\beta = -0.15, p < .001$) were the only statistically significant predictors in the
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36 model (Table 4).
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Healthcare professionals attitudes to patient involvement in the care process

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44 Healthcare professionals' mean score on the CS-Pam was 77.13 (SD = 13.99). No healthcare
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46 professionals scored within activation level 1 (patient should follow medical advice), 11
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48 (9.40%) were within level 2 (patient can make independent judgments and actions) and 106
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50 (90.60%) were in level 3 (patient is able to function as a member of the care team).
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Healthcare professionals provision of self-management support

Almost 60% of the healthcare professionals were unable to offer a structured self-management support programme to their patients with arthritis. This was mainly due to a lack of staffing (n = 41, 35.00%) and funding (n = 20, 17.10%). Others reported not being aware of a suitable programme in their area (n = 14, 12%). Some had a preference to refer patients to other external agencies or organisations (n = 13, 11.1%) or to offer self-management support themselves on an individual basis (n = 3, 2.6%).

Whilst many healthcare professionals were unable to offer a structured approach to supporting their patients, self-management support was more likely to be embedded within standard care. All healthcare professionals surveyed agreed or strongly agreed that they provided information and education to their patients about their arthritis and its treatment (online supplementary material B). Over 90% agreed or strongly agreed that they worked collaboratively with their patients to set goals, develop plans of action, problem solve, help them acquire the necessary skills to manage their arthritis and, understand their arthritis and its treatment. Over 85% agreed or strongly agreed that they taught their patients how to monitor their arthritis and its treatment including the meaning of any blood tests and managing the emotional impact and stresses related to their arthritis. A multiple regression to explore whether CS-PAM scores, along with demographic characteristics could predict engagement in embedded self-management support was not statistically significant ($F(8, 108) = 1.69, p = 0.11$).

Differences between healthcare professionals and patients

Figure 1 demonstrates differences between healthcare professionals and patients on the degree to which the eight components of self-management support were felt to be

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2
3 embedded in standard care. Healthcare professionals on average agreed or strongly agreed
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5 that they worked with their patients to engage in all eight components of self-management
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7 support. Patients, on the other hand, disagreed that many of the eight components of self-
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9 management support were being offered to them during their routine consultations.
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DISCUSSION

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15 Self-management support should be integral to the care of people with arthritis (1). The
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17 mode in which this is implemented can differ from structured programmes delivered in
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19 secondary and primary care but outside of the outpatients setting to approaches that are
20
21 embedded within routine care. There is limited data however, on the provision and uptake
22
23 of self-management support by patients with arthritis in the UK. This survey found that only
24
25 15% of patients with arthritis had attended a structured self-management support
26
27 programme. Possibly unsurprising given that 60% of rheumatology healthcare professionals
28
29 were unable to offer a structured self-management support programme to their patients.
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31 Primarily because they were unable to staff or fund such services, which corresponds to the
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33 barriers to providing psychological support in arthritis (15). Attendance is an important
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35 indicator of reach (23), but despite evidence dating back to the 1980's (6) translation of
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37 evidence into UK practice appears to remain limited potentially due to the changes made to
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39 the commissioning of self-management programmes over 10 years ago.
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47 One potential way of overcoming a lack of access to structured approaches is to embed self-
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49 management support into standard care. A model which has received recent attention in
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51 the literature (17;18). In fact, although the current study found that many healthcare
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53 professionals were unable to offer structured self-management support, they reported
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Arthritis self-management support: a national survey

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3 embedding self-management support into their routine clinic appointments. This shift from
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5 the provision of structured self-management programmes, 10 years ago, to embedded
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7 support may in part reflect the permeation of the self-management approach into clinical
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9 training and NHS priorities (24;25). This does however rely on the ability and preferences of
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11 individual clinician.
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16 Although patients and healthcare professionals were not matched, data from this survey
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18 indicated that patients do not perceive receiving much self-management support in their
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20 clinical encounters, whilst healthcare professionals report providing high levels of support.
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22 This could indicate variation between clinicians on the self-management support offered
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24 within routine consultations, a lack of shared language between healthcare professionals
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26 and patients for self-management (26) and/or the inability of patients and/or healthcare
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28 professionals to accurately assess receipt or delivery of self-management support. When
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30 patients are able to engage with their healthcare team at a level of involvement consistent
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32 with their preferences they experience greater satisfaction with their care, are less
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34 depressed and have better health outcomes (27) therefore further investigation into the
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36 delivery and receipt of self-management support within the same clinical encounters is
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38 required. Given that this study found that embedding goal setting and self-monitoring into
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40 routine consultations was associated with greater knowledge, skills and confidence in
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42 patients' ability to self-manage, as opposed to attendance at a structured self-management
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44 support programme. This provides further justification for embedding self-management
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46 support into routine care.
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Arthritis self-management support: a national survey

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3 Recruitment of participants to this survey via online methods yielded a significant response
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5 from patients, highlighting the advantages of this approach. One of the strengths of this
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7 study is the large, national sample, however concerns have been raised about the
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9 representativeness of online research (28). It was however, not possible to estimate the
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11 number of people who received or saw the invitation to participate to assess
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13 representativeness, due to the online recruitment methods. There was a poorer response
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15 from healthcare professionals, and data is bias towards nursing and the allied health
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17 professions and those who are more interested in self-management support. The study was
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19 limited by its recruitment strategy, as individuals who join societies such as NRAS, may be
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21 those who actively seek information and support in relation to their condition. Other
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23 potential limitations relate to the questions aimed to measure engagement in embedded
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25 self-management support. We do not know how participants interpreted structured self-
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27 management support programmes and there may be other components of self-
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29 management that were not covered, particularly as we know that patients and healthcare
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31 professionals often hold different models of self-management (26). The measure was also
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33 developed specifically for this study, and although it contained good internal consistency we
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35 did not assess test-retest reliability or other forms of validity. Generalisability of the study
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37 outside of the UK is also not possible, given that importance and funding of self-
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39 management support differs by country.
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49 Considering the emphasis placed on patient empowerment (24) and the integration of self-
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51 management support into the guidelines for managing arthritis (1;2), there seems to be
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53 some way to go before evidence has been translated into practice. Despite its long history
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55 and evidence base this survey revealed that the organisational changes made to the delivery
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Arthritis self-management support: a national survey

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3 and funding of self-management support in the UK means that only a small proportion of
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5 patients with inflammatory arthritis have attended a structured self-management support
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7 programme. From the healthcare professional perspective, it appears that self-management
8
9 support is now more likely to be embedded within routine clinic appointments. When goal
10
11 setting and self-monitoring were embedded into routine care this was associated with
12
13 increased patient knowledge, skills and confidence to self-manage. Patients however, felt
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15 that this does not always occur, which raises concerns about the impact that this may have
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17 on their experience of care and the health outcomes of patients with arthritis.
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Table 1. Patient characteristics

Characteristics	n(%)
Age, m(SD)	56.84(11.10)
Gender	
Female	735(83.10)
Male	150(16.90)
Condition†	
Rheumatoid arthritis	841(95.00)
Osteoarthritis	145(16.40)
Fibromyalgia	74(8.40)
Osteoporosis	57(6.40)
Psoriatic arthritis	33(3.70)
Lupus or Ankylosing Spondylitis	11(1.20)
Juvenile idiopathic arthritis	11(1.20)
Sjögren's	11(1.20)
Inflammatory arthritis	10(1.10)
Seronegative arthritis	8(0.90)
Gout	7(0.80)
Polymyalgia rheumatica	5(0.60)
Osteopenia	4(0.50)
Lumbar spinal stenosis	3(0.30)
Hypermobility syndrome	1(0.10)
Palindromic rheumatism	1(0.10)

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Characteristics	n(%)
Sciatica	1(0.10)
Degenerative disc disease	1(0.10)
Mixed connective tissue disease	1(0.10)
Marfan syndrome	1(0.10)

† Self-reported and more than 1 rheumatological condition could be selected

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Table 2. Healthcare professional characteristics

Profession	n(%)
Nurse Practitioner	55(47.00)
Occupational Therapist	19(16.20)
Rheumatologist	18(15.40)
Physiotherapist	12(10.30)
Podiatrist	6(5.10)
Clinical Nurse Specialist in Rheumatology	3(2.70)
Pharmacist	1(0.90)
Clinical Trials Coordinator	1(0.90)
Research Practitioner	1(0.90)
Practice Nurse	1(0.90)

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Table 3. Location of self-management programme attendance

Location	n(%)
Within rheumatology services at hospital	78(59.10)
Charity	27(20.45)
A local patient group	16(12.12)
GP service	9(6.82)
Expert patient programme (EPP)	9(6.82)
Self-taught	1(0.76)
COPERS [†] course	1(0.76)

[†] COPERS: coping with persistent pain, effectiveness research into self-management

Arthritis self-management support: a national survey

Table 4. Multiple regression model for patient PAM scores

	Standardized		
	β	t	p
	Coefficients		
(Constant)		7.70	0.00
Age	0.01	0.24	0.81
Gender	-0.01	-0.46	0.65
Disease duration (years)	0.16	5.54	0.00
Methotrexate use	-0.05	-1.78	0.08
Rheumatoid arthritis	0.00	0.04	0.97
Psoriatic arthritis	-0.02	-0.47	0.64
Attendance at a structured self-management programme	0.05	1.82	0.07
A member of the rheumatology team has provided me with information and education about my arthritis and its treatment	-0.02	-0.46	0.65
I work collaboratively with members of the rheumatology team to set goals about how I manage my arthritis and its treatment	0.15	2.65	0.01
I work collaboratively with members of the rheumatology team to develop actions plans about how I manage my arthritis and its treatment	-0.01	-0.17	0.86
I work collaboratively with members of the rheumatology team to solve any problems I have about my arthritis and its	0.09	1.86	0.06

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	Standardized		
	β	t	p
	Coefficients		
treatment			
A member of the rheumatology team has taught me the skills I need to manage my arthritis and its treatment	0.06	1.23	0.22
A member of the rheumatology team has taught me how to monitor my arthritis and its treatment, including the meaning of any tests I have	0.10	2.19	0.03
I have discussed what I understand about my arthritis and its treatment with a member of the rheumatology team	-0.15	-3.63	0.00
A member of the rheumatology team has helped me manage my emotions and any stress I have experienced in relation to my arthritis and its treatment	0.08	1.88	0.06

Figure legend

Figure 1. Receipt and delivery of embedded self-management support (mean scores)

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