




## ORIGINAL RESEARCH

## Personalised care packages for people with rheumatoid arthritis: a mixed-methods study

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**ABSTRACT**

**Objectives** Disease management in rheumatoid arthritis (RA) requires holistic assessment. We aimed to design personalised care packages suitable for people with RA.

**Methods** This study was conducted using a mixed-methods approach and exploratory sequential design. Consensus workshops were held, involving people with RA and healthcare professionals (HCPs) treating them. Subsequently, an online survey sought views on future care packages for people with RA at relevant disease progression/stages, based on (1) results from previous quantitative data analyses (eg, socioeconomic/clinical factors), and (2) themes identified during workshops.

**Results** Two conceptual care pathways were identified: (1) around the time of RA diagnosis, an early opportunity to influence the disease course; (2) for individuals with established RA, emphasising the importance of 'the right MDT member at the right time'.

Three care packages were suggested: (1) early care package (around RA diagnosis): introduction to MDT; (2) continuity of care package (established RA): primary/secondary providers; and (3) personalised holistic care package: integral to packages 1 and 2, implemented alongside allied health professionals.

The survey received 41 responses; 82.9% agreed that people with RA need a consistent 'early care package' at diagnosis. 85.4% approved of additional care packages tailored to individuals' clinical, psychological and social needs when moving to different stages of their long-term disease. Fleiss' Kappa calculations demonstrated fair level of agreement among respondents.

**Conclusion** Two care pathways, with three tailored care packages, were identified, with potential to improve management of people with RA. Future research will help to determine if such care packages can impact clinical (including patient-reported) outcomes.

**INTRODUCTION**

Advances in the understanding of the disease process and the management of rheumatoid arthritis (RA) over the last decade have enabled early diagnosis and treatments which have resulted in improved outcomes for people with RA.<sup>1,2</sup> Despite this progress, successful disease management in RA requires

**WHAT IS ALREADY KNOWN ON THIS TOPIC**

- ⇒ An increasing body of evidence supports the involvement of the multidisciplinary team in the care of people with rheumatoid arthritis (RA).
- ⇒ In addition, alongside the known benefits of tailored care for patients with RA, dedicated pathways to facilitate bespoke treatment (including appropriate multidisciplinary involvement) do not exist.

**WHAT THIS STUDY ADDS**

- ⇒ This study suggests a need for tailored care packages for early and established RA to improve disease management and patients' outcomes and experiences.

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

- ⇒ If implemented, these care packages may help to optimise and focus disease management for people with RA.
- ⇒ This study reiterates the benefits of a holistic and comprehensive approach which could explain links between the biopsychosocial factors influencing RA disease outcomes.

careful consideration and assessment of various biological, psychological and socio-economic (biopsychosocial) aspects of the patients and their condition. The development of a tailored approach to treatment was identified as a research priority in the most recent European Alliance of Associations for Rheumatology (EULAR) recommendations for the management of RA.<sup>3</sup>

Management of RA globally has subtle variations. In the UK, where this work was undertaken, it is recommended that people who present to primary care with suspected inflammatory arthritis need to be referred into secondary care for specialist treatment with disease-modifying therapies, if diagnosed with RA, using a treat-to-target approach to achieve remission.<sup>4,5</sup> Patients need to have regular reviews with either a specialist doctor

or nurse until remission is achieved, after which carefully structured annual reviews need to be undertaken, during which factors such as function, mental health and comorbidities can be assessed.<sup>5</sup> The National Institute for Clinical Excellence (NICE) specifies the role of the multidisciplinary team (MDT) in its guidance on the management of RA, stating: “Adults with RA should have ongoing access to a multidisciplinary team. This should provide the opportunity for periodic assessments of the effect of the disease on their lives (such as pain, fatigue, everyday activities, mobility, ability to work or take part in social or leisure activities, quality of life, mood, impact on sexual relationships) and help to manage the condition”.<sup>4</sup> However, as described in the findings from the National Early Inflammatory Arthritis Audit (NEIAA), access to the MDT, including adequate referral pathways, are variable across England and Wales, with lack of a tailored approach to an individual’s needs.<sup>6</sup>

Recent work from our group<sup>7, 8</sup> found that lower socioeconomic (SE) status and functional disability are associated with worse long-term RA disease activity, thus demonstrating the need to address SE factors to improve clinical and patient-reported outcomes. In line with this new evidence, the guidance from EULAR for the implementation of self-management strategies in patients with inflammatory arthritis<sup>9</sup> also emphasises the need to embrace physical, psychological and emotional well-being, personalised to an individual’s needs and circumstances.

Pathways for personalised care packages for people with RA are lacking. Early studies evaluating the utility of the MDT for patient outcomes in people with RA yielded inconclusive results, especially in relation to the impact on long-term disability.<sup>10</sup> However, an increasing body of evidence now supports the involvement of the MDT in the care of this patient cohort.<sup>11</sup> The ‘eumusc.net’ project within Europe, as well as more recent initiatives such as the NEIAA in the UK, has identified the importance of MDT involvement in optimising the management of RA, especially given the heterogeneity of the condition and how the disease may affect patients.<sup>6, 12</sup> The recommendation of annual reviews for patients with RA, often led by allied health professionals (AHPs) in the clinical setting is a testament to how MDT working can lead to streamlined and comprehensive reviews.<sup>5</sup> Yet, despite ample data and guidance from national and international organisations on the benefits of tailored care for patients with RA, dedicated pathways to facilitate bespoke treatment do not exist. Barriers to implementing such pathways include expense and frequent lack of coordination and communication between primary and secondary care services.<sup>13</sup>

Prior to this study, some of the authors (AB, EN) conducted a large-scale data analysis (quantitative phase, as per [figure 1](#)<sup>7, 14</sup>). Results from the previously published initial quantitative analyses informed the next step within the context of the ‘priority-sequence model’.<sup>7, 14, 15</sup> These quantitative phase findings were included in this

mixed-methods study, consisting of online consensus workshops and a survey.

The overarching aim of this work was to design tailored care packages which are acceptable, beneficial and relevant to the care of people with RA. The objectives were twofold: (1) determine the interventions that people with RA find beneficial to be included in future care packages, based on patients’ individual needs and disease characteristics, and (2) determine which aspects of care considered important by HCPs with experience of caring for people with RA are recommended for inclusion in the respective care packages.

## METHODS

This was a mixed-methods study, using an exploratory sequential design, comprising of phase I: three consensus workshops involving healthcare professionals (HCPs) caring for people with RA and people living with RA; and phase II: an online survey informed by the findings from the workshops, featuring responses from an expanded and different cohort of participants from the above two groups ([figure 1](#)).

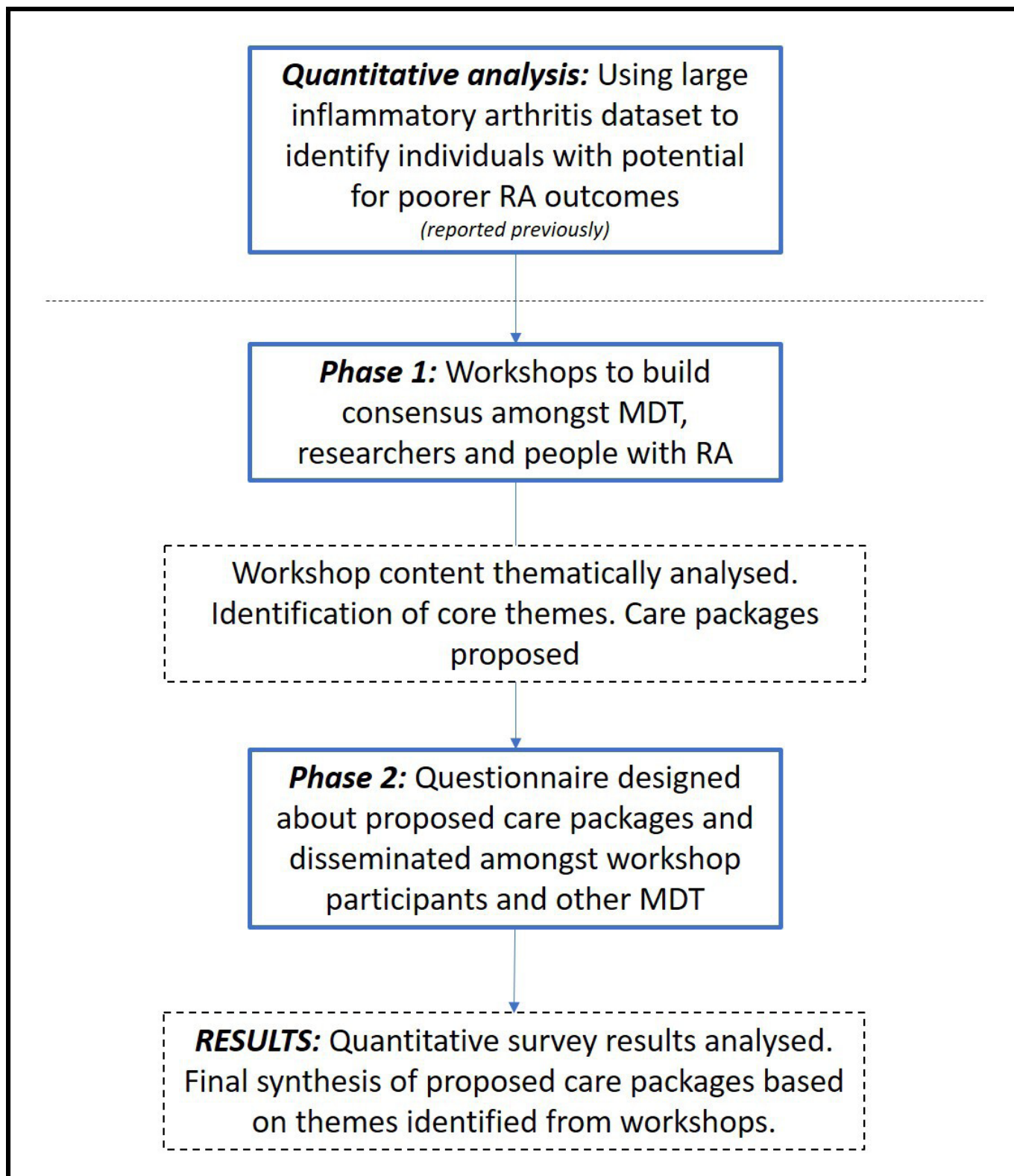
This work built on the previous quantitative analyses of two historical UK-based RA cohorts, the Early Rheumatoid Arthritis Study (ERAS, 1986–2001) and the Early Rheumatoid Arthritis Network (ERAN, 2002–2012), to determine baseline factors associated with poorer clinical disease outcomes. These results have been previously published.<sup>7, 14</sup>

### Phase I: workshops Participants

A purposive sampling strategy<sup>16</sup> was employed to identify potential participants, including people living with RA, rheumatology HCPs, members of national rheumatology charities and academics with RA-specific research experiences, from the UK. Each workshop comprised a different mix of participants, for example, patients and HCPs from across the MDT. The groups were kept small, with every member considered an equal partner, given the space and opportunity to voice their experiences and opinions. HCPs and AHPs included consultant and trainee rheumatologists, specialist nurses, occupational therapists, dieticians and podiatrists. All individuals were provided with a Participant Information Sheet and their written consent was received by MD prior to attending. All participants received a £30 Amazon Gift Card.

### Data collection

The core research team (EN, MD, AB, HL) arranged and conducted three workshops to build consensus in February/March 2022. Diverse experiences and expertise were obtained from a range of direct healthcare team members, patients and academics as to how best to improve personalised care for people with early RA. These consensus workshops were held online for convenience and to ensure accessibility.



**Figure 1** Timeline of methodology and study phases. MDT, multidisciplinary team; RA, rheumatoid arthritis.

Consensus workshops are an established form of data collection and synthesis used across areas of clinical research including rheumatology.<sup>17</sup> Participants received the information sheet and been consented prior to the workshops taking place. Participants were aware that taking part was voluntary, and withdrawal from the

workshop would not affect their ongoing clinical care. They were also informed that the workshop was being transcribed anonymously and would later be transcribed and analysed for the purpose of this research. Each of the three workshops were held virtually due to ongoing COVID-19 restrictions at the time, and led by the four

lead members of the research team. Each workshop lasted for 2 hours. One author (AB/EN) presented results from the quantitative phase, followed by reiterating the purpose of the workshop and providing ‘prompt’ questions to facilitate the discussion and for participants to consider the factors which they thought, from personal and professional experience, lead to poor clinical outcomes in RA. Participants were then prompted to draw on these discussion points to consider core and wider members of the MDT who may be involved in a person’s care, early and throughout the disease process. Key discussion points were noted by another member of the research team (MD/EN/AB). The audio recording was transcribed verbatim by a professional transcribing agency with the lead authors checking for errors prior to analyses. Thematic analyses were subsequently being undertaken (HL) to identify core themes to then inform phase II (survey).

Findings from the earlier quantitative analyses were shown within each consensus workshop to set the scene. Discussion and sharing of healthcare service experiences was encouraged, based on a team-developed workshop guide (online supplemental file 1), including presenting hypothetical examples of patients to stimulate conversation and invite advice from each member. At the end of each session, participants were asked to consolidate the discussion by considering the following questions: (1) *Does every RA patient need to have input from the following MDT members: clinicians (rheumatologist, nurse specialist), AHPs—physiotherapists, occupational therapists, psychologists (health/clinical/occupational), social workers, dieticians, podiatrists, pharmacists, other clinical specialties (eg, pain team, orthopaedics,), and primary care physicians? (2a) Inclusion of additional clinicians? (2b) At which stage of their disease progress will colleagues be approached? (3) How formalised does the MDT input need to be?*

### Data analysis

A thematic analysis was manually undertaken, synthesising key themes to support the next phase of the study, the development of a survey. Themes were reviewed and defined by the core research team (HL, EN, AB, MD). The thematic analysis followed the recommended six steps by Braun and Clarke, for example, (1) familiarisation with the transcribed workshop content; (2) generating initial codes (eg, education about RA, navigation of the NHS, available resources in hospital and community, ongoing self-management, importance of annual review, importance of personalised care); (3) followed by identifying themes for example, continuity of care by core staff, importance of core team members, role of the general practitioner (GP)/specialist/AHPs; and (4) review and refinement of the themes with the research team for its relevance and plausibility. (5) Finally, the themes were defined and named within the identified care packages with the research team and patients, for example, early care package, continuity of care package and personalised holistic care package for (6) inclusion in our final

report and manuscript.<sup>18</sup> Patients who attended two of the workshops validated the content of the audio from the recorded workshops and endorsed the key themes identified.

### Phase II: online survey

#### Survey development

A number of online survey questions were subsequently developed by the core research team, based on (I) the two key themes identified by the thematic analysis from the consensus workshops (phase I), and (II) results from previous findings from the quantitative dataset analyses, investigating the relationship between socio-demographic circumstances, clinical factors and disease outcomes.<sup>7 14</sup> Specifically, views were sought on potential care packages for people ranging from early onset of RA across key points of their disease progression. Before dissemination to additional healthcare staff and patients, the online survey underwent extensive revisions by the core research team including a logical structure to the content and based on feedback from patient research partners.

The first two questions of the survey sought consent for participation in the survey and the use of the collected, anonymised data. Information about the professional role of each participant was obtained, to receive expert input from a broad range of HCPs employed in rheumatology outpatient services across UK Trusts, as well as patients. The remaining questions asked colleagues/patients to draw on their experience and views on care for people with RA by rating proposed packages of care and treatment. In particular, Q7 asked participants their opinion about ‘standard care packages’, with Q8 giving participants the opportunity to provide further information about why they answered the previous question in a particular way. Four questions (Q5–Q8) used a positive/neutral/negative scale, two (Q9–Q10) required a free-text response and two (Q11–Q12) were on a 0–10 scale. [Table 1](#) shows all questions asked, alongside response types and any multiple-choice options.

#### Data collection

Once finalised, the survey was circulated among patients and HCPs based in the UK via email, through purposive recruitment of staff and patients (initially disseminated on 1 June 2022).<sup>19 20</sup> The survey was disseminated via a link to the Microsoft Forms platform. Prior to completion, all invitees were provided with a Participant Information Sheet describing the study and the survey process itself. Patients/professionals were asked to respond to the survey by based on their personal and professional experiences of the care of people with RA or the delivery of care in outpatient clinics, as appropriate.

The online survey was open for 8 weeks. At the survey close (29 July 2022), the quantitative data were transferred into an Excel workbook and prepared for analysis.

**Table 1** Survey questions and response type required

	Question	Response type
Q1	I consent to my responses being used as described in the data protection statement	AGREEMENT
Q2	I have read and understand the data protection statement	AGREEMENT
Q3	Please indicate which description best fits your role	SELECT ONE: Rheumatologist—consultant, rheumatologist—trainee, rheumatology specialist nurse, physiotherapist, occupational therapist, psychologist, pharmacist, patient, other
Q4	If you answered 'Other' to question 3, please indicate in text box below	FREE TEXT
Q5*	Do you agree that people with RA need all have access to the <i>same 'early' care package</i> (comprising a core multidisciplinary team) at the time of diagnosis?	SELECT ONE: Agree, disagree, unsure
Q6*	On subsequent clinical reviews, do you think that the care package for people with early RA may need to change?	SELECT ONE: Yes, no, do not know/Unsure
Q7*	Do you think that a <i>standard care package</i> comprising input from: a consultant rheumatologist, clinical nurse specialist/patient educator, primary care physician and a pharmacist is suitable for all patients with RA in the early stages of their disease, irrespective of patient or disease-related factors?	SELECT ONE: Yes, no, unsure
Q8†*	Not all of these healthcare professionals are relevant to patient care at the time of diagnosis	SELECT ONE: Agree, disagree, unsure
Q9	Additional members of the multidisciplinary team are required at time of diagnosis (please list below)	FREE TEXT
Q10	Other reason (please state below)	FREE TEXT
Q11*	A <i>care package</i> comprising core members of the multidisciplinary rheumatology team need to be available to people newly diagnosed with RA.	0–10, where 0=completely disagree, 10=completely agree
Q12*	Personalised <i>comprehensive care packages</i> , comprising a core plus various additional members of the multidisciplinary team, need to be offered and adapted according to a person's individual disease characteristics and socioeconomic circumstances.	0–10, where 0=completely disagree, 10=completely agree

\*Quantitative questions, included in measurement of agreement calculations.  
 †Instructed to complete if answered no/unsure in Q7.

### Analysis

Quantitative responses were summarised using frequencies and proportions. Although not normally distributed, means and SD were calculated where appropriate to provide an overview statistic. Agreement between the participants (known as 'raters') was measured using Fleiss' Kappa across the quantitative questions.<sup>21</sup> This process measured inter-rater reliability, that is, the degree of agreement among independent individuals providing ratings. Fleiss' Kappa is an extension of Cohen's Kappa, allowing for more than two participants ('raters') to assign categorical ratings to a number of items. To calculate Fleiss' Kappa with varying numbers of raters and categories across questions, assumptions were applied to obtain the required consistency across the dataset.<sup>21</sup> Responses for Q5–Q8 were coded as positive, neutral or negative, and anyone who did not answer Q8 was deemed to have provided a neutral response. Q11 and

Q12 statement responses were re-categorised as follows: positive (7–10), neutral (4–6) and negative (1–3). On this basis, Fleiss' Kappa was calculated across Q5–Q8 and Q11–Q12. All quantitative analyses were performed using Stata/IC V.15.1.

Free-text comments were assessed for common emergent themes and summarised accordingly.

## RESULTS

### Phase I: consensus workshops

A total of 16 individuals participated across the three consensus workshops: 2 patient partners, 1 pharmacist, 1 dietician, 2 occupational therapists, 1 podiatrist, 1 psychologist, 1 specialist nurse, 3 consultant rheumatologists, 1 rheumatology trainee, 1 former GP and two academics (medical sociologist and medical statistician).

Thematic analysis identified two conceptual care pathways, each with distinct MDT care packages, allowing for the expansion of the core MDT as needed.<sup>18</sup> The first pathway related to the timepoint around diagnosis of RA, since this was considered by the attendees as an early opportunity to potentially impact the disease course. For example, participants highlighted the importance of identification of early risk factors, for example, obesity, smoking, environmental exposure, synovitis, unspecified arthralgia, social deprivation and family history. In parallel, screening for comorbidities/multimorbidities, social deprivation and family history (specifically in primary care) need to be prioritised.

Education of secondary care clinicians regarding holistic management and appropriate signposting for individuals to relevant members of the MDT was perceived as important. In addition, workshop participants identified that ongoing education sessions for patients, held by MDT members in secondary care including primary care nurses, would be useful for joint goal setting and helping patients and carers to understand their disease and its progression in greater depth. Specifically, these sessions would focus on information about screening for factors such as mental health support, employment conditions, dietetic/nutrition assessment and lifestyle changes, for example, exercises, involvement in local community activities, such as local park runs.

The second pathway related to individuals with an established RA diagnosis, where a key theme, highlighted by participants at all three consensus workshops, was the importance of 'the right MDT member at the right time'.

Based on participants' responses and results of the thematic analysis, core care packages were identified, containing three distinct components. Two were mapped to the above care pathways (ie, early or at time of diagnosis of RA; and established RA), with one additional overarching package, applicable throughout a patient's disease trajectory:

1. Early care package (time of diagnosis) with introduction to MDT, education about RA disease to patients/carers, available hospital/community resources.
2. Continuity of care package (for those with established RA): shared care between primary and secondary providers, for example, annual review, prompt referral to MDT during flare ups
3. Personalised holistic care package (for all individuals at all stages of disease), in collaboration with AHPs, for example, physiotherapists, occupational therapists alongside others, such as psychologists, nurses, primary care staff. This package is an overarching care plan, intended to be implemented alongside each of (1) and (2), with relevant members of the MDT included as and when appropriate to an individual's care. A personalised care package would require one-to-one consultation with a rheumatology nurse specialist or rheumatologist to determine and agree the input required for an individual patient. Such a care package needs to be available at all stages of the disease

trajectory and/or care pathway and could focus on those individuals identified as having potential poorer disease outcomes, for example, due to sociodemographic factors.

Participants identified core members of the MDT for each care package who need to be involved as the care requirements develop over time. The core team consisted of GPs, rheumatologists, clinical nurse specialists and pharmacists, with the additional care provider group split into those who offered direct care as needed (eg, podiatry/orthotics, occupational therapy, clinical psychology) and indirect care (eg, social prescribing, national charities) (figure 2).

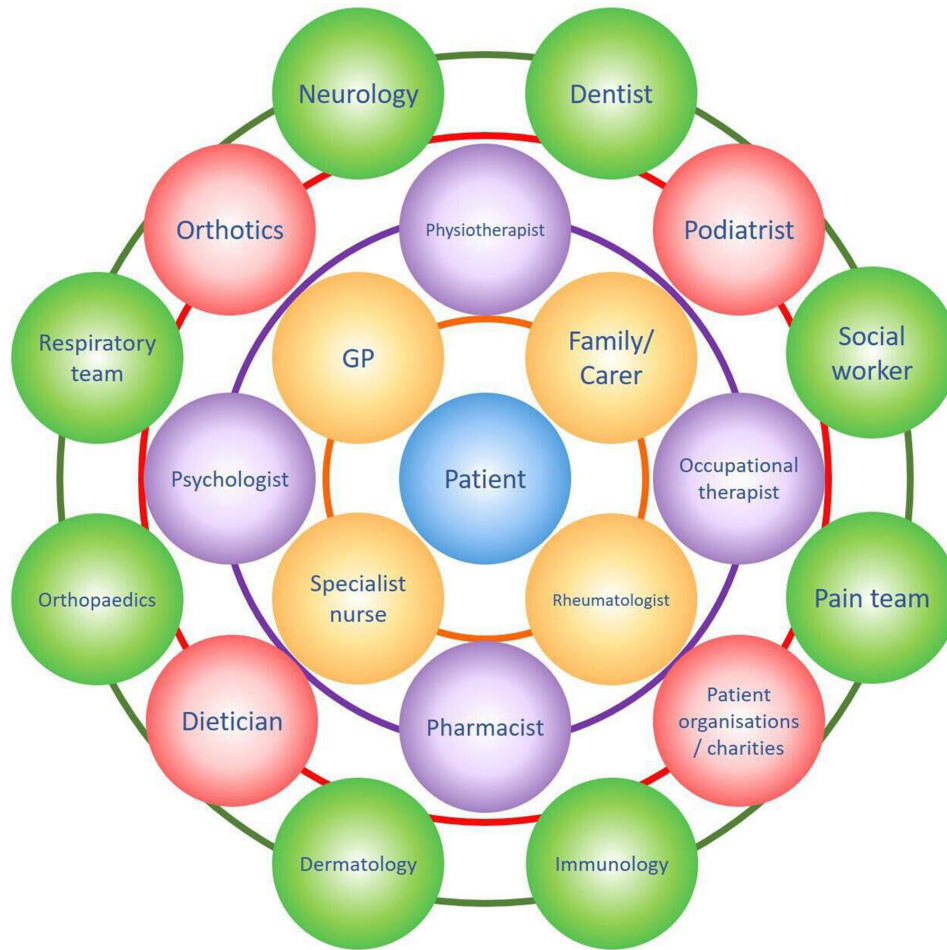
### Phase II: online survey

A total of 41 complete responses were received: 17 (43%) rheumatology consultants, 7 (18%) specialist nurses, 6 (15%) rheumatology trainees, 5 (13%) occupational therapists, 3 (8%) physiotherapists, 1 (3%) patient and 1 (3%) dietician. All responses were complete.

Table 2 presents the findings of the survey study. Thirty-four respondents (82.9%) agreed that all people with RA need access to the same 'early care package', comprising a core MDT, at time of diagnosis (Q5). A further 35 (85.4%) agreed that a care package for people with early RA may need to be tailored to an individual's clinical, psychological and social needs at subsequent clinical review (Q6). There was less consensus among responders that a standard core package, irrespective of patient or disease-related factors (Q7), was appropriate, with 25 (58.5%) agreeing with this statement. Thirty responses were received for Q8, of which 11 (36.7%) stated that they did not agree that all those specialities defined in Q7 were relevant to patient care at time of diagnosis.

When asked to list additional MDT members required for people at the time of diagnosis (Q9), the most suggested professionals were occupational therapists (n=18, 64.3%), physiotherapists (n=12, 42.9%), psychologists/cognitive behavioural therapists (n=10, 35.7%) and podiatrists (n=10, 35.7%). Nutritionists/dieticians (n=2, 7.1%), social workers (n=2, 7.1%) and occupational adviser (n=1, 3.6%) were mentioned in a handful of cases. Nine free-text responses related to the above item are shown in table 3. Some participants posited that primary care staff may need to be included only occasionally since a rheumatologist may be sufficient, and that additional MDT members' expertise may be considered overwhelming by patients or may require frequent clinic visit reviews and monitoring during the early stage of their disease journey.

There was strong consensus (median 10/10 on a 0–10 scale) for the following two statements: 'A care package with core members of the multidisciplinary rheumatology team needs to be available to people newly diagnosed with RA' (Q11) and 'Personalised comprehensive care packages, including a core plus various additional members of the multidisciplinary team, need to be offered and adapted according to a person's individual



**Figure 2** Members of the multidisciplinary team involved in patient care, starting with a ‘core’ package (towards the centre of the circle), developing to an ‘established’ care package, tailored to individual need (towards outer circles).

disease characteristics and socio-economic circumstances’ (Q12), although one participant answered 1 in Q11, suggesting almost complete disagreement.

Fleiss’ Kappa across Q5–Q8 and Q11–Q12 was  $\kappa=0.230$  (95% CI 0.209 to 0.252). As a strong assumption was made for Q8 (with anyone not answering deemed to have provided a neutral response), the values were excluded from analysis and Kappa recalculated; the resulting value  $\kappa=0.268$  (95% CI 0.244 to 0.292) suggested a fair level of agreement among survey respondents,<sup>21</sup> where strength

of agreement is categorised as follows: <0.2 poor, 0.2–0.4 fair, 0.4–0.6 moderate, 0.6–0.8 good and 0.8–1.0 very good.

### DISCUSSION

This study aimed to develop tailored care packages which are acceptable, beneficial and relevant for the management of people with early RA. The mixed-methods approach facilitated the inclusion of the views of both

**Table 2** Quantitative survey results

	N	Mean (SD)	Positive	Neutral	Negative
Q5	41	–	34 (82.9%)	2 (4.9%)	5 (12.2%)
Q6	41	–	35 (85.4%)	3 (7.3%)	3 (7.3%)
Q7	41	–	24 (58.5%)	2 (4.9%)	15 (36.6%)
Q8*	30	–	11 (36.7%)	3 (10.0%)	16 (53.3%)
Q11†	41	9.0 (1.7)	39 (95.1%)	1 (2.4%)	1 (2.4%)
Q12†	41	9.5 (1.0)	41 (100.0%)	0 (0.0%)	0 (0.0%)

Question 8 only applied if question 7 answered negatively, although was answered by more participants.

\*Negatively framed question.

†Questions 11 and 12 used a 0–10 scale, so have been grouped as follows: 7–10 positive, 4–6 neutral, 0–3 negative.

**Table 3** Question 10 results—‘(Other reasons why) not all of these healthcare professionals are relevant to patient care at the time of diagnosis’

1	May not require primary care and rheumatologist?
2	MDT requirements should be tailored to individual needs
3	Patient may need to access info at different times
4	Help with discussing work, introduction to their potential future role if not currently required
5	Everyone should be treated as an individual
6	Too much input at this early stage may feel overwhelming, however, optional access would be beneficial at times, based on patient specific needs
7	Depends on key impacts of early disease on patient, physical, social, psychological
8	People have different expectations, experiences and social contexts that will shape their needs
9	Care package should be customisable/ tailored to patients' educational and support needs
MDT, multidisciplinary team.	

people diagnosed with RA and HCPs directly involved in their care, building on results of the quantitative data analyses.

The consensus workshops identified three distinct care packages in the management of patients with RA: (1) early care package; (2) continuity of care package; and (3) personalised holistic care package. Participants emphasised the need for early recognition and management of modifiable factors associated with disease outcomes, such as lifestyle (eg, smoking, exercise) and social circumstances, where possible (eg, employment, geography) in keeping with previous research findings.<sup>7 8 22 23</sup>

There has been growing interest in stratified approaches for the lifelong management of patients with RA, with increasing recognition of the association between individual biological, social and psychological circumstances and disease outcomes.<sup>8 24</sup> Results from earlier quantitative analyses showed that, in models adjusted for comorbidity burden, associations with sociodemographic factors (female gender, worse deprivation) and poorer baseline health assessment questionnaire (HAQ) were associated with moderate/high disease activity score (DAS)28 values at both 5-year and 10-year post-baseline.<sup>7</sup> Similarly, poorer baseline HAQ scores, increased age at disease onset, female gender and minoritised ethnicity were associated with higher odds of HAQ values of at least 1.5 at 5 and 10 years, with worse deprivation additionally associated with high HAQ at 10 years.<sup>14</sup> These predominantly sociodemographic factors could form a useful guidance

when considering which individuals would benefit most from the offering a holistic care package.

In addition, our systematic literature review<sup>8</sup> confirmed that low SE status is associated with poorer RA outcomes (in all domains) and emphasised the contribution of other important aspects such as the biological (eg, comorbidities) and psychological (eg, mental health) factors.<sup>8</sup> The care pathways identified in the consensus workshops and the survey reflect the multiple relationships and the biopsychosocial factors which may have unexpected or positive impacts on patients and their disease outcomes, often in tandem.

Current EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis highlight that early identification of modifiable factors associated with disease outcomes, as well as requirement for MDT input, ought to be assessed throughout the disease trajectory, with regular personalised *joint goal-setting and shared decision-making*.<sup>9</sup> Such a collaborative approach was also reflected in our survey findings, with strong consensus that ‘personalised comprehensive care packages, embracing a core plus various additional members of the MDT, need to be offered and adapted according to a person’s individual disease characteristics and socio-economic circumstances’. Patient and carers education about RA, and awareness of patient-modifiable factors and impact on their disease, is crucial. Our workshop discussions, however, emphasised the importance of HCPs and clinician education with regard to paying attention to patients’ biopsychosocial circumstances, as well as acquiring the relevant knowledge and training to address lifestyle factors, for example, during consultations. Such education may be delivered via specific e-learning modules through organisations such as British Society for Rheumatology and EULAR, as well as dissemination via relevant documents including EULAR ‘points-to-consider’ and guidelines on self-management strategies and multidisciplinary management of inflammatory arthritis.

An overarching theme identified by the consensus workshop members was to ensure that patients have access to the appropriate members of the MDT at ‘the right’ time. Despite several attempts to predict disease trajectories in RA, including response to treatment and comorbidity burden, future organ involvement and disease severity remains unclear at diagnosis.<sup>24 25</sup> It is therefore vital to assess an individual’s circumstances and evolving disease at every follow-up appointment, enabling swift recognition of their changing needs. Prompt agreement from patients for referral to AHPs and clinical specialists (eg, podiatry, occupational health, respiratory for lung involvement, orthopaedics for joint replacement) could then be obtained. Workshop participants identified a *core team* for the care of patients with RA comprising the GPs, rheumatologists, clinical nurse specialists and pharmacists, with an extended team including AHPs with rheumatology expertise. The British Society for Rheumatology NEIAA defines a core MDT as a rheumatologist



(consultant or specialist trainee), specialist nurse, occupational therapist physiotherapist and podiatrist yet in many centres, access to these MDT members remain variable.<sup>26</sup> A proportion of the study HCP respondents (35.7%) suggested availability of clinical psychologists or other psychological services, for example, Improving Access to Psychological Therapies programme (IAPT) may be as important in the care of patients with RA. One of our findings is closely aligned with the NEIAA results, and emphasises the importance of the mental health comorbidity in this patient cohort.<sup>27,28</sup> A holistic approach to care, including assessing mental health, corresponds with recommendations from the NICE which gives stringent recommendations on the implementation of annual reviews for people with RA, often led by AHPs, and an effective way to ensure relevant members of the MDT are involved at the appropriate stages of a person's disease trajectory.<sup>5</sup> Nonetheless, in practice, care remains fragmented, with relevant members of the MDT rarely available simultaneously when a person attends clinic for review of their condition, in a 'one stop clinic' format, where multiple services are offered to patients during one outpatient appointment. Patients are disadvantaged due to multiple visits to HCPs both within the hospital setting and within the community, something which may pose practical difficulties for those with multiple comorbidities, employment, chronic pain and mobility difficulties.

Although this work was conducted in the UK, the results are applicable to a global audience, especially the European rheumatology community. Outcomes from the 'emusc.net' project previously highlighted the importance of MDT involvement in patient care across Europe, while MDT input is discussed in depth in the recent EULAR guidance on self-management strategies in RA.<sup>9,12</sup>

### Strengths and limitations

Our study is strengthened by the diversity of the members participating in the consensus workshops and survey, especially from AHPs who are often under-represented in similar research, including occupational therapists and physiotherapists, as well as specialist nurses.<sup>29</sup> Individuals with lived experiences of RA and patient research partners were involved throughout the study, a group which is sometimes excluded from research. For example, through to consensus workshop participation, design and validation of the survey, and review and dissemination of the final results (including at a patient engagement event in 2023).<sup>30,31</sup> However, responses to the survey were predominantly from rheumatologists (consultants and trainees) and one patient (although people with an RA diagnosis were well represented in the consensus workshops). Additionally, psychologists and pharmacists did not take part in the online survey. Limitations of the study were the inclusion of two historical data sets for the quantitative data analysis prior to phase I. RA management during 1986–20212 may not have reflected current treatment paradigms. Although this fact of historical

datasets limits the generalisability of the findings, this is overcome in part by considering the results through the modern lens of consensus workshop with patients, clinicians and national charity members who brought to bear their expertise. A further limitation of this work is the involvement of only patients and HCPs directly involved in the care of people with RA, as opposed to including those working at an organisational and national level, which may have brought more in-depth and alternate perspective to inform our care packages. Nonetheless, such individuals would likely be involved at the implementation, rather than preliminary, stages, and we plan to engage them in future work focusing on applying our findings in clinical practice.

In conclusion, this study highlighted an unmet clinical need, recognised by patients and HCPs alike, to offer individualised care packages for optimised management of people with RA from the early years of disease and onwards. Future work will determine how to embed such packages in clinical practice, embedded within existing clinical services. Specifically, two care pathways, with nuanced approaches to these packages were identified which, if implemented, may help to optimise and focus disease management for people with RA. These results reiterate the benefits of a holistic and comprehensive approach, both in early and established disease, which could go some way to explaining the close links between the biopsychosocial factors influencing RA disease outcomes. Future research will determine implementation and the impact of these care packages on clinical outcomes in people with RA.

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#### REFERENCES

- Smolen JS, Landewé RBM, Bergstra SA, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2022 update. *Ann Rheum Dis* 2023;82:3–18.
- Verhoeven MMA, Welsing PMJ, Bijlsma JWJ, et al. Effectiveness of remission induction strategies for early rheumatoid arthritis: a systematic literature review. *Curr Rheumatol Rep* 2019;21:24.
- Smolen JS, Landewé RBM, Bijlsma JWJ, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2019 update. *Ann Rheum Dis* 2020;79:685–99.
- NICE. Recommendations | rheumatoid arthritis in adults: management | guidance;
- NICE. Quality statement 5: annual review | rheumatoid arthritis in over 16s | quality standards;
- National early inflammatory arthritis audit (NEIAA) 1ST annual report; 2019.
- Busby AD, Wason J, Pratt AG, et al. P198 The role of comorbidities alongside patient and disease characteristics on long-term disease activity in RA using UK inception cohort data. *Rheumatology (Oxford)* 2022;61:4297–304.
- Dey M, Busby A, Elwell H, et al. Association between social deprivation and disease activity in rheumatoid arthritis: a systematic literature review. *RMD Open* 2022;8:e002058.
- Nikiphorou E, Santos EJF, Marques A, et al. EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis. *Ann Rheum Dis* 2021;80:1278–85.
- Bearne LM, Byrne A-M, Segrave H, et al. Multidisciplinary team care for people with rheumatoid arthritis: a systematic review and meta-analysis. *Rheumatol Int* 2016;36:311–24.
- Crossland V, Field R, Ainsworth P, et al. Is there evidence to support multidisciplinary healthcare working in rheumatology? A systematic review of the literature. *Musculoskeletal Care* 2015;13:51–66.
- Stoffer MA, Smolen JS, Woolf A, et al. Development of patient-centred standards of care for rheumatoid arthritis in Europe: the Eumusc.net project. *Ann Rheum Dis* 2015;74:1145–9.
- Dinsdale E, Hannigan A, O'Connor R, et al. Communication between primary and secondary care: deficits and danger. *Fam Pract* 2020;37:63–8.
- Busby AD, Wason J, Pratt AG, et al. Predictors of poor function in RA based on two prospective UK inception cohorts. *Rheumatology (Oxford)* 2022;61:1563–9.
- Morgan DL. Practical strategies for combining qualitative and quantitative methods: applications to health research. *Qual Health Res* 1998;8:362–76.
- Patton MQ. *Qualitative research and evaluation methods: theory and practice; fourth edition*. SAGE Publ Inc, 2015: 832.
- Prothero L, Georgopoulou S, DeS, et al. Patient involvement in the development of a handbook for moderate rheumatoid arthritis. Available: <http://www.nras> [Accessed 01 Jul 2023].
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- Palys T. Purposive sampling. In: Given LM, ed. *The sage encyclopedia of qualitative research methods*. SAGE Publications, 2008: 697–8.
- Coyne IT. Sampling in qualitative research. purposeful and theoretical sampling; merging or clear boundaries. *J Adv Nurs* 1997;26:623–30.
- Altman DG. *Practical statistics for medical research*. 1990.
- Camacho EM, Verstappen SMM, Symmons DPM. Association between socioeconomic status, learned helplessness, and disease outcome in patients with inflammatory polyarthritis. *Arthritis Care Res (Hoboken)* 2012;64:1225–32.
- Nikiphorou E, Norton S, Walsh DA, et al. 101. Comorbidity in RA. coexistent medical conditions and multimorbidity can be recorded relatively easily in observational research studies. is it feasible to extend this to routine clinical settings? *Rheumatology* 2015;54(suppl\_1):i90.
- Heutz J, de Jong PHP. Possibilities for personalised medicine in rheumatoid arthritis: hype or hope. *RMD Open* 2021;7:e001653.
- England BR, Roul P, Yang Y, et al. Burden and trajectory of multimorbidity in rheumatoid arthritis: a matched cohort study from 2006 to 2015. *Ann Rheum Dis* 2021;80:286–92.
- Ndosi M, Ferguson R, Backhouse MR, et al. National variation in the composition of rheumatology multidisciplinary teams: a cross-sectional study. *Rheumatol Int* 2017;37:1453–9.
- Matcham F, Norton S, Scott DL, et al. Symptoms of depression and anxiety predict treatment response and long-term physical health outcomes in rheumatoid arthritis: secondary analysis of a randomized controlled trial. *Rheumatology (Oxford)* 2016;55:268–78.
- Fragoulis GE, Cavanagh J, Tindell A, et al. Depression and anxiety in an early rheumatoid arthritis inception cohort. associations with demographic, socioeconomic and disease features. *RMD Open* 2020;6:e001376.
- Comer C, Collings R, McCracken A, et al. Allied health professionals' perceptions of research in the United Kingdom national health service: a survey of research capacity and culture. *BMC Health Serv Res* 2022;22:1094.
- van Tuyl LHD, Plass AMC, Lems WF, et al. Discordant perspectives of rheumatologists and patients on COBRA combination therapy in rheumatoid arthritis. *Rheumatology (Oxford)* 2008;47:1571–6.
- Dures E, Hewlett S, Ambler N, et al. Rheumatology clinicians' experiences of brief training and implementation of skills to support patient self-management. *BMC Musculoskelet Disord* 2014;15:108.