

Title: Psychological and self-management support for people with vasculitis or connective tissue diseases: UK health professionals' perspectives

Authors:

Robson JC<sup>1,2</sup>, Shepherd M<sup>1,2</sup>, Harper L<sup>3,4</sup>, Ndosi M<sup>1,2</sup>, Austin K<sup>1,2</sup>, Flurey C<sup>5</sup>, Logan S<sup>4</sup>, Dures E<sup>1,2</sup>.

1. Department of Nursing and Midwifery, Faculty of Health and Applied Science, University of the West of England, Bristol, UK.
2. Rheumatology Research, Rheumatology Department, University Hospitals Bristol NHS Foundation Trust, Bristol, UK.
3. Institute of Clinical Sciences, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK
4. Nephrology Department, University Hospital Birmingham NHS Foundation Trust, Birmingham, UK
5. Department of Health and Social Sciences, Faculty of Health and Applied Science, University of the West of England, Bristol, UK.

Abstract:

### Objectives

Connective tissue diseases (CTD) and systemic vasculitis impact on health-related quality of life. Treatment can be complex involving multiple medical specialities. This study's aim was to investigate psychological and self-management support for patients in secondary care.

### Methods

Online survey of health professionals in the UK including 45 multiple-choice and free-text questions analysed descriptively. Free-text survey responses were analysed thematically to identify health professionals' perceptions of best practice and unmet needs.

### Results

Online survey included 120 health professionals (34% specialist nurses, 51% doctors, 12% allied health professionals), predominantly working in rheumatology (52.9%) and nephrology (21.5%) departments. Access to self-management programmes or clinics for people with CTD or vasculitis was available in 23% of rheumatology and 8% of nephrology departments. In response to "How well is your team providing self-management support to people with CTD or vasculitis?", 38% of respondents reported "not very well" or "not well at all". Direct access to psychological support was available in 76.9% nephrology and 32.8% rheumatology departments. Over 80% of respondents would like additional training. Key themes from the qualitative data (free-text survey responses) included importance of: dedicated psychological support and self-management programmes for people with CTD and vasculitis, whole team approach (specialist teams empowering people to manage their own care), staff training (e.g. brief psychological interventions) and signposting to resources including patient charities.

### Conclusion

People with CTD and vasculitis have complex needs and improvements in self-management and psychological support are required in UK rheumatology and nephrology departments.

### Key Messages:

1. Connective tissue diseases (CTDs) and systemic vasculitis impact on peoples' health-related quality of life.
2. Two thirds of rheumatology professionals report no psychological support available for people with CTD/vasculitis.
3. Eighty percent of health professionals report no self-management support available for people with CTD/vasculitis.

Keywords: Self-management, psychological, Lupus, vasculitis, myositis, rheumatology, nephrology, health-professionals, education.

Funding: This work was supported by a grant from the Faculty of Health and Applied Sciences (HAS) Quality-Related Research (QR) Fund for Cross-Research Centres/Groups Collaboration, University of the West England, Bristol.

## Introduction

The rare autoimmune rheumatic diseases include the systemic vasculitides (e.g. ANCA associated Vasculitis (AAV), Behcets disease, polyarteritis nodosa, Takayasu arteritis and giant cell arteritis) and the connective tissue diseases (CTD, e.g. systematic lupus erythematosus (Lupus), inflammatory muscle diseases, systemic sclerosis, antiphospholipid disease and Sjögren's syndrome).<sup>1</sup>

People with CTD and vasculitis present with multi-organ disease which can require complex treatment regimens including glucocorticoids, chemotherapy, and biological medications; many of these therapies can cause significant morbidity to patients.<sup>2-4</sup> These diseases can be life and organ threatening; 25% of patients with AAV will die within 5 years of diagnosis,<sup>5</sup> a higher proportion than that seen with breast and prostate cancer. Care is usually led by rheumatology or nephrology teams but a range of medical and surgical specialists can be involved depending on the nature of the person's specific disease.<sup>6</sup> The care available to people with CTD and vasculitis is often fragmented across different medical specialities and hospitals, and people can find it difficult to navigating the healthcare system.<sup>7</sup> The impact of fatigue is consistently ranked as a key aspect of health-related quality of life in people with CTD or vasculitis.<sup>8-11</sup> Having a rare autoimmune disease can also be isolating;<sup>12,13</sup> family, friends and health care professionals can lack detailed knowledge and understanding<sup>14</sup>. These factors can contribute to the high levels of distress seen in this group of patients.<sup>15,16</sup> The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) UK survey (n=2000) of people with Lupus, scleroderma and vasculitis highlighted that 61% struggle to cope with their condition.<sup>14</sup>

Lorig<sup>17</sup> conceptualised self-management as three aspects of management that patients must address when dealing with having a chronic disease: medical (e.g. interacting with healthcare professionals, adhering to medications); role (e.g. adapting to changes in relationships and social roles); and emotional (e.g. processing negative emotions such as anger and anxiety). A Europe-wide survey (EURODIS) found that 42% of people who live with rare diseases spend more than 2 hours a day in tasks related to their illness, while 25% spend more than 6 hours.<sup>18</sup> The need for better patient support to manage their own care and navigate through complex care pathways are key recommendations from the 2013 Department of Health Strategy for Rare Diseases and the 2014 British Society of Rheumatology Workshop on autoimmune rheumatic diseases.<sup>19,20</sup> The NHS 5-year forward plan also highlights self-management as a key element in the care of patients with long-term conditions<sup>21</sup>.

Psychological need can be conceptualised as a pyramid; the majority of people will have lower levels of need, whilst a smaller proportion will have greater needs, as represented by the top of the pyramid<sup>7</sup>. For many patients who have psychological symptoms, self-management programmes can provide information about their condition and coping strategies to help with anxiety, depressive symptoms and disease activity.<sup>22-24,25</sup> Those with more severe emotional or mental health problems require specialist psychological interventions, that take account of their physical health status.<sup>7,18</sup>

The RAIRDA and EURODIS surveys<sup>14,18</sup> have highlighted the range of unmet needs of importance to people with CTD and vasculitis, including peoples' views on what their support needs are from health professionals.

The aims of the present study were to:

1. identify health professionals' perceptions of the presence and quality of self-management and psychological support available to people with CTD and vasculitis in secondary care in the UK
2. explore best practice and potential improvements in terms of self-management and psychological support for people with CTD and vasculitis
3. explore the training needs of health-professionals in terms of self-management and psychological support for people with CTD and vasculitis.

## **Methods**

### *Design*

This project comprised an online cross-sectional survey including closed and short-answer questions. The survey was designed by the steering committee (including health professionals from rheumatology and nephrology, researchers and methodologists) and piloted by rheumatology specialist nurses and clinicians at the Bristol Royal Infirmary.

The study was given ethical approval by the Faculty Research Ethics Committee at UWE Bristol (Reference: HAS.19.03.152). Participants were informed that by completing and submitting the online survey they were giving their implied consent. No personally identifiable data was used, although to enable late withdrawal requests, the online system randomly assigned an identifier to each participant, which they were asked to quote if they wished to withdraw.

### *Participants*

Health professionals (including specialist nurses, clinicians, allied health professionals (AHPs), psychologists and pharmacists) working with people living with CTD or vasculitis in secondary care in the UK were invited to participate in the online cross-sectional survey.

### *The Survey*

The survey questionnaire was developed in Qualtrics<sup>™</sup><sup>26</sup>, an online survey platform which enables survey construction and hosting of the data on secure servers during data collection. The survey comprised 45 items including multiple choice response and open-ended questions. The regional location was compulsory in order to ensure that the response was limited to UK-based staff. The items were divided into three sections: i) Participant demographics, including professional background, experience and geographical region; ii) Questions related to self-management support for people with CTD and vasculitis in their service; and iii) Questions related to psychological support for people with CTD and vasculitis in their service.

During the online survey, participants were shown the definition of self-management as defined by Lorig,<sup>17</sup> (i.e. the medical, role and emotional management required of people when adapting to a chronic disease) to refer to when answering questions related to self-management.

Items on the team's ability to provide self-management and psychological support services were designed as five-point Likert scales ranging from 'Extremely well' to 'Not well at all'. Participants were also asked to rate their own confidence in providing self-management support and in recognising a patient's need for psychological support (four-point scale, from 'completely confident' to 'not at all confident').

Seven free text, open-ended questions were used to explore current provision and best practice and potential improvements identified by health professionals working with people with CTD and vasculitis. These included questions about current self-management clinics or programmes for people with CTD or vasculitis held in their department; what worked well and what could be improved; what was available in terms of psychological support, including what was good about the support and what could be improved, and what are the training needs for staff in terms of self-management and psychological support for people with CTD and vasculitis.

#### *Data collection procedures*

Health professionals from different medical specialities (particularly rheumatology and nephrology), professional background, geographical regions, and type of hospital setting (district general hospitals (DGHs) and NHS England Specialist Centres were actively targeted to ensure a broad representation of experiences and views).

Participants were recruited via social media with the post: "Are you a nurse, doctor, AHP or psychologist who has ever worked with people with Vasculitis or CTD? Please complete our quick survey of psych and self-management support in the UK. Interested in renal/rheum/DGH or specialist opinions". A link was provided to the Qualtrics survey<sup>26</sup>. The post was tweeted via the study account (@SelfSurvey), the British Society of Rheumatology account (@RheumatologyUK), posted on the Royal College of Nursing Rheumatology nursing forum and distributed via the United Kingdom and Ireland Vasculitis Registry (UKIVAS) and UK GCA Consortium email lists. The survey was also advertised during a talk at the British Society for Rheumatology Conference, 2019<sup>27</sup>.

#### *Data analysis:*

For statistical analysis the following combined items were defined: 'Doctors' combined 'Consultants' and 'Registrars'; 'Nurses' combining 'Advanced Nurse Practitioners', 'Nurse specialists' and 'Staff Nurses'. 'Allied Health Professionals' were also defined as including 'Occupational Therapists', 'Physiotherapists', 'Pharmacists' and 'Podiatrists'.

Analysis of survey data was initially undertaken within Qualtrics<sup>xm26</sup>, with further analyses in IBM SPSS for Windows (Version 25.0. Armonk, NY: IBM Corp). Data were summarised and analysed descriptively, categorical data presented as proportions. Contingency tables with  $X^2$  statistics were used to test the significance of the association between categorical variables. Where appropriate, odds ratios (OR) were calculated to quantify the magnitude of the association<sup>28</sup>. Analysis of the Likert Scale questions used the Kruskal-Wallis test<sup>29</sup> to assess differences between groups.

Free text survey responses were organised using NVivo v12<sup>30</sup> software. A combined inductive and deductive approach was used<sup>31</sup>. Themes of importance were identified by three independent researchers (MS, JR and KA), including key elements of good practice, how self-management and psychological support could be improved, and health-professional training needs. The Chronic Care Model (CCM)<sup>32</sup> was chosen as the framework for the deductive analysis. The CCM is an evidence-based framework which highlights the key modifiable components of a health care system which can support high-quality, patient-centred chronic disease management. The CCM accounts for the many factors that influence clinical practice and care in real world settings.

## Results:

### *Participant characteristics:*

A total of 120 responses were received from the online survey, which was open for six weeks from April 16<sup>th</sup> to May 31<sup>st</sup> 2019.

Table 1 describes the professional background and demographic details of the survey participants. Most of the health professionals worked in either rheumatology (52.9%) or nephrology (21.5%) departments. There was a range of participants with different professional backgrounds (specialist nurses, allied health professionals and doctors) and types of hospitals (DGH versus teaching and NHS England specialist centres). Most participants (86%) reported that they regularly saw patients with CTD or vasculitis. Survey participants were from across the UK although most came from English hospitals (supplementary materials 1).

### *Who is providing self-management and psychological support for patients with CTD and vasculitis?*

Overall, 18.3% of participants (n=17) reported having self-management clinics (i.e. one to one support) or group programmes in their department which included people with CTD and vasculitis (14 from rheumatology and 2 from nephrology).

Health professionals reported that the self-management support currently provided is delivered by AHPs (53%), nurses (52.5%), doctors (12.5%) and psychologists (10%). Differences were seen between rheumatology and nephrology departments in terms of who provided self-management support, with a higher proportion of nurse specialists and AHPs in rheumatology (Figure 1A).

Approximately 40% of health professionals were able to provide direct access to psychological support for their patients with CTD or vasculitis, either in their department or hospital. There was greater access within nephrology (20/26; 76.9%) compared to rheumatology departments (21/64; 32.8%) ( $X^2=19.10$ ,  $p<0.001$ ,  $OR=6.8$ ). Health professionals in nephrology were also more likely to have a psychologist in their team (15/26; 57.7%) than in rheumatology departments (14/64; 21.9%), ( $X^2=13.83$ ,  $p<0.001$ ,  $OR=4.9$ ). Health professionals working in rheumatology departments were more likely than those in nephrology departments to rely on indirect referrals for psychological support (signposting to general practice or self-referral to community providers) ( $X^2=14.93$ ,  $p=0.001$ ,  $OR=4.82$ ). See Figure 1B.

### *Health professionals' ratings of self-management support provision for people with CTD and vasculitis*

The quality of the self-management support provided was rated by 61.8% of respondents as providing support 'extremely well', 'very well' or 'quite well', 38.2% rated their service as providing support 'not very well' or 'not well at all'. There were no differences between those working in nephrology and rheumatology ( $X^2=0.036$ ,  $p=0.982$ ), or between those working in DGHs and those in teaching hospitals or NHS England specialist centres ( $X^2=0.308$ ,  $p=0.579$ ). There were no differences in ratings between the assessments given by doctors (57.1% rated self-management provided 'quite well' or better), nurses (64.3%) and allied health professionals (57.1%,  $X^2=2.39$ ,  $p=0.495$  see Figure 2a/2b).

### *Health professionals' ratings of psychological support provision for people with CTD and vasculitis*

Psychological support was assessed as being provided quite well, very well or extremely well provided by 53% of those responding overall. Nephrology staff rated the provision as better, with

77.3% rating their provision as 'quite well' or better; 46.6% rheumatology staff gave this rating, ( $X^2=0.431$ ,  $p=0.014$ ,  $OR=3.90$ ). (Figure 2c)

Where referrals were direct, within the department itself, within the hospital or directly to psychologists or counsellors in the community, more respondents (31/42, 73.8%) rated the quality of the service as higher ("well" or "extremely well" provided) than respondents (14/42, 33.3%) in departments where the referrals were indirect ( $X^2=13.832$ ,  $p<0.001$ ,  $OR=5.6$ ).

Health professionals from DGHs assessed their psychological support as 'not very well' or 'not at all well' provided in (16/22, 72.7%) of cases, compared to (15/40, 37.1%) of those from teaching hospitals or NHS England specialist centres ( $X^2=8.288$ ,  $p=0.004$ ,  $OR=4.4$ ). There were no significant differences between professional groups; doctors assessed psychological support as being provided 'quite well' or better in 52.1% of cases, nurses assessed support at this level in 53.8% and allied health professionals assessed it at this level in 50% ( $X^2= 1.82$ ,  $p=0.611$ ), see also Figure 2d.

#### *Health professionals' confidence and training needs*

Self-management support was a role that health professionals undertook regularly (36.5%) or occasionally (48.2%), a smaller number of respondents rarely or never (10.9%) provided support. Fifty-two percent of nurses, 71.4% of AHPs and 61.2% of doctors said that they felt confident in delivering self-management support. As expected, those who provide self-management support 'regularly' were more likely to be confident in undertaking this task than those who do not do this regularly ( $X^2=26.0$ ,  $p<0.001$ ,  $OR=44.2$ ).

Over eighty percent of respondents reported that they would like additional training in self-management support for people with CTD and vasculitis. Those less confident were more likely to see training as a priority ( $X^2=4.36$ ,  $p=0.037$ ,  $OR=3.9$ ). Free-text responses showed that training might include brief psychological interventions, communication skills and how to set up a self-management programme (Table 2).

Most professionals felt that they were confident in recognising patients who would benefit from psychological support (76.9% of nurses, 87.5% of AHPs and 79.2% of doctors).

#### *Analysis of short answer responses*

Responses to individual open-ended questions varied from a single phrase or sentence, to several paragraphs, with many of the responses being 3 or 4 sentences for individual questions. Deductive analysis using the chronic care model as a reference framework was used to analyse the data across responses to these questions. After discussion between the three researchers, 162 references were organised into 13 key overarching themes and aligned with one of the six interrelated elements of the CCM (Health systems (Table 2), Decision Support, Clinical Information systems, Patient self-management support, Community resources and Delivery system design (Table 3)). No themes were identified in relation to C. Clinical Information Systems. Key themes including the importance of a positive departmental ethos towards supporting self-management (particularly in terms of investment in training and resources), multiple benefits of having psychological support embedded within rheumatology and renal departments, and the importance of multidisciplinary working. Developing a self-management programme specifically for people with CTD and vasculitis or sharing resources provided to people with other conditions, plus staff training to improve confidence in short psychological intervention within clinic appointments were identified as areas of potential service improvement.

## Discussion

This is the first study to examine provision of self-management and psychological support for people with vasculitis and connective tissue disease within secondary care in the UK.

Over eighty percent of health professionals reported they had no self-management clinics or programmes that catered for patients with CTD or vasculitis in their centres; within nephrology this rose to over ninety percent. The RAIRDA survey of people with vasculitis and CTDs highlighted that 60% struggle to cope with their disease and 40% felt that they did not have enough information and support from the hospital in living with their condition<sup>14</sup>. In this survey, almost the same proportion of health professionals (also 40%) felt that self-management was “not provided well” to people with CTD and vasculitis in their secondary care departments. These results highlight the unmet needs in terms of support for people with rare rheumatic diseases.

Access to specialist psychological support was identified as a key requirement by health professionals in this survey, in the support of people with CTD and vasculitis. This survey demonstrates some inequalities in access across secondary care due to location and speciality. Direct access to psychological support for patients with vasculitis or CTD was available in almost 80% of nephrology departments; but only one third of rheumatology departments. Psychological support provision in DGHs was reported as worse, (rated as “not well provided” by 72.7% of health professionals in those centres), compared to that available in teaching hospitals and NHS England specialist centres, (rated as “not well provided” by 37.1%). Health professionals identified similar barriers to providing self-management and psychological support to people with CTD and vasculitis (lack of time, skills and management support) as previously highlighted by a survey of psychological support provision for people with RA in the UK<sup>33</sup>.

The main strength of this survey is the breadth of health professional participants: from a range of medical specialties (predominantly rheumatology and nephrology), with a range of professional backgrounds (nurses, allied health professionals and doctors), from different types of hospitals (teaching, district general and specialist centres for CTD and vasculitis) and geographical regions across the UK. This study also used mixed methods, using survey data to gain a breadth of perspectives and then short-answer and in-depth interviews to explore topics of greatest interest in more depth.

While online surveys have advantages in terms of cost and timeliness, there are also disadvantages in control over samples and selection bias.<sup>34 35</sup> One limitation in this survey is that a higher proportion of participants were from rheumatology departments compared to other departments, and a higher proportion of renal physicians versus renal nurses were included. This may be due to the fact that renal nurses are less likely to see patients with CTD/vasculitis unless they are on dialysis, as they do not tend to do outpatient clinics, as opposed to rheumatology specialist nurses who may lead or work in parallel with rheumatologists in the outpatient clinics. There was also a higher proportion of allied health professionals working within rheumatology, as would be expected for a speciality focused on MSK conditions.

The biggest limitation to this survey, is that it is likely to have been completed by health professionals with an interest in these topics, therefore the survey may not capture the full breadth of views and experiences. However, 80% of health professionals were keen to receive further training specific to self-management in CTD and vasculitis. There were also a higher proportion of



respondents from teaching hospitals/ specialist CTD or vasculitis centres than DGHs. Specialist centres may potentially benefit from an increase in psychological and self-management provision due to having a greater pool of patients with these diseases. The true provision across DGHs across the UK may therefore be much lower outside these centres. In order to maintain anonymity, we did not record the exact institution each health professional came from; this could be a limitation of the survey if more than one respondent came from the same hospital. We did however record respondents' geographical distribution (Supplementary material A). Respondents were from 9 different English regions, plus Wales, Northern Ireland and Scotland and this supports the generalisability of the findings across the UK.

Management guidelines for treatment of people with CTDs and vasculitis focus mainly on treatment of physical symptoms, although patient education and care within a wider multidisciplinary team are also highlighted<sup>2 36-39</sup>. This survey demonstrates the range of health professionals who are currently delivering self-management support for people with CTDs and vasculitis in the UK, primarily within individual clinic appointment settings. Evidence from studies in Lupus and rheumatoid arthritis (RA) have demonstrated the potential positive impact of self-management programmes on patient wellbeing and reduction in resource utilisation.<sup>40-42 17 43 44</sup> Current research studies targeting fatigue include a remotely delivered cognitive behavioural and graded exercise programme for people across the inflammatory rheumatic diseases<sup>45 46</sup> and a disease-specific feasibility study of a combined physical activity and behavioural support intervention in AAV.<sup>47</sup>

This study highlights a range of proposals on how to improve provision of self-management and psychological support, identified by health professionals working with people with CTD and vasculitis. These include broadening access to generic self-management courses, developing new courses specifically designed for people with CTD or vasculitis; or use of brief psychological interventions for use within routine clinic appointments by all health professionals. Development of future interventions will need to include all stakeholders including patients, staff and funders. The key finding in terms of psychological support is the broad ranging benefits of having an embedded psychologist within the clinical team for people with CTD and vasculitis; through contributing to a supportive team ethos focused on self-management and psychological support, delivery of specialist group and one to one interventions, and practical support and training of the wider multidisciplinary team.

## References

### References

1. NHS England. NHS Standard Contract for Specialised Rheumatology Services (Adult). In: NHS England, ed. London, 2014.
2. Ntatsaki E, BSR obot, BHPR Standards G, et al. BSR and BHPR guideline for the management of adults with ANCA-associated vasculitis. *Rheumatology* 2014;53(12):2306-09. doi: 10.1093/rheumatology/ket445 %J Rheumatology
3. Denton CP, Hughes M, Gak N, et al. BSR and BHPR guideline for the treatment of systemic sclerosis. *Rheumatology (Oxford)* 2016;55(10):1906-10. doi: 10.1093/rheumatology/kew224 [published Online First: 2016/06/09]
4. Gordon PA, Winer JB, Hoogendijk JE, et al. Immunosuppressant and immunomodulatory treatment for dermatomyositis and polymyositis. *The Cochrane database of systematic*

reviews 2012(8):Cd003643. doi: 10.1002/14651858.CD003643.pub4 [published Online First: 2012/08/17]

5. Flossmann O, Berden A, de Groot K, et al. Long-term patient survival in ANCA-associated vasculitis. 2011;70(3):488-94.
6. Quaresma M, Coleman MP, Rachet B. 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971&#x2013;2011: a population-based study. *The Lancet* 2015;385(9974):1206-18. doi: 10.1016/S0140-6736(14)61396-9
7. Fellow-Smith E, Moss-Morris R, Tylee A, et al. Investing in emotional and psychological wellbeing for patients with long term conditions. London: NHS Confederation., 2012.
8. Basu N, Jones GT, Fluck N, et al. Fatigue: a principal contributor to impaired quality of life in ANCA-associated vasculitis. *Rheumatology* 2010;49(7):1383-90. doi: 10.1093/rheumatology/keq098 %J Rheumatology
9. McElhone K, Abbott J, Gray J, et al. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus* 2010;19(14):1640-7. doi: 10.1177/0961203310378668 [published Online First: 2010/08/17]
10. van Lankveld WG, Vonk MC, Teunissen H, et al. Appearance self-esteem in systemic sclerosis--subjective experience of skin deformity and its relationship with physician-assessed skin involvement, disease status and psychological variables. *Rheumatology (Oxford, England)* 2007;46(5):872-6. doi: 10.1093/rheumatology/kem008 [published Online First: 2007/02/20]
11. Leclair V, Regardt M, Wojcik S, et al. Health-Related Quality of Life (HRQoL) in Idiopathic Inflammatory Myopathy: A Systematic Review. *PLoS One* 2016;11(8):e0160753. doi: 10.1371/journal.pone.0160753 [published Online First: 2016/08/10]
12. Sutanto B, Singh-Grewal D, McNeil HP, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis care & research* 2013;65(11):1752-65. doi: 10.1002/acr.22032 [published Online First: 2013/04/24]
13. Brennan KA, Creaven AM. Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2016;25(5):1227-35. doi: 10.1007/s11136-015-1151-z [published Online First: 2015/10/10]
14. Feinmann J, Hopgood J, Lanyon P, et al. Reduce, Improve, Empower: Addressing the shared needs of rare autoimmune rheumatic diseases: Rare Auto-immune Rheumatic Disease Alliance, 2018.
15. Hyphantis TN, Tsifetaki N, Siafaka V, et al. The impact of psychological functioning upon systemic sclerosis patients' quality of life. *Seminars in arthritis and rheumatism* 2007;37(2):81-92. doi: 10.1016/j.semarthrit.2007.03.008 [published Online First: 2007/05/22]
16. Nguyen C, Ranque B, Baubet T, et al. Clinical, functional and health-related quality of life correlates of clinically significant symptoms of anxiety and depression in patients with systemic sclerosis: a cross-sectional survey. *PLoS One* 2014;9(2):e90484. doi: 10.1371/journal.pone.0090484 [published Online First: 2014/03/04]
17. Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis and rheumatism* 1993;36(4):439-46. doi: 10.1002/art.1780360403 [published Online First: 1993/04/01]
18. Courbier S, Berjonneau E. Juggling care and daily life: The balancing act of the rare disease community. Paris: EURODIS, 2017.
19. Department of Health, Northern Ireland Executive , Scottish Government, et al. The UK Strategy for Rare Diseases. In: Department of Health, ed. London: Department of Health, 2013.
20. A collaborative approach to improving outcomes in rare rheumatic and musculoskeletal diseases: report from a national workshop. The British Society for Rheumatology; 2016; London.
21. NHS England. Five Year Forward View. In: NHS England, ed. London, 2014.

22. Mooney J, Poland F, Spalding N, et al. 'In one ear and out the other - it's a lot to take in': a qualitative study exploring the informational needs of patients with ANCA-associated vasculitis. *Musculoskeletal Care* 2013;11(1):51-9. doi: 10.1002/msc.1030 [published Online First: 2012/07/11]
23. Mooney J, Spalding N, Poland F, et al. The informational needs of patients with ANCA-associated vasculitis-development of an informational needs questionnaire. *Rheumatology (Oxford, England)* 2014;53(8):1414-21. doi: 10.1093/rheumatology/keu026 [published Online First: 2014/03/15]
24. Waldron N, Brown S, Hewlett S, et al. 'It's more scary not to know': a qualitative study exploring the information needs of patients with systemic lupus erythematosus at the time of diagnosis. *Musculoskeletal Care* 2011;9(4):228-38. doi: 10.1002/msc.221 [published Online First: 2011/10/14]
25. Zhang J, Wei W, Wang CM. Effects of psychological interventions for patients with systemic lupus erythematosus: a systematic review and meta-analysis. *Lupus* 2012;21(10):1077-87. doi: 10.1177/0961203312447667 [published Online First: 2012/05/10]
26. Qualtrics [program]. 01/19- 08/19 version. Provo, UT: Qualtrics, 2005.
27. Robson J. Unmet needs of patients with rare rheumatic diseases. British Society for Rheumatology. Birmingham, 2019.
28. Szumilas M. Explaining odds ratios. *J Can Acad Child Adolesc Psychiatry* 2010;19(3):227-29.
29. Colman AM. A Dictionary of Psychology 3rd ed. Oxford: Oxford University Press 2008.
30. Nvivo qualitative data analysis software. [program]. Version 12 version. Doncaster, VC, Australia: QSR International, 2018.
31. Thomas D. A General Inductive Approach for Qualitative Data Analysis. *The American Journal of Evaluation* 2006;27:237-46.
32. Wagner E. Chronic disease management: what will it take to improve care for chronic illness? *J Eff Clin Pract* 1998;1
33. Dures E, Almeida C, Caesley J, et al. A Survey of Psychological Support Provision for People with Inflammatory Arthritis in Secondary Care in England. *Musculoskeletal Care* 2014;12(3):173-81. doi: doi:10.1002/msc.1071
34. Aerny-Perreten N, Domínguez-Berjón MF, Esteban-Vasallo MD, et al. Participation and factors associated with late or non-response to an online survey in primary care. *Journal of Evaluation in Clinical Practice* 2015;21(4):688-93. doi: 10.1111/jep.12367
35. Arafa AE, Anzengruber F, Mostafa AM, et al. Perspectives of online surveys in dermatology. 2019;33(3):511-20. doi: 10.1111/jdv.15283
36. Gordon C, Amissah-Arthur M-B, Gayed M, et al. The British Society for Rheumatology guideline for the management of systemic lupus erythematosus in adults. *Rheumatology* 2017;57(1):e1-e45. doi: 10.1093/rheumatology/kex286
37. Denton CP, Hughes M, Gak N, et al. BSR and BHPR guideline for the treatment of systemic sclerosis. *Rheumatology (Oxford, England)* 2016;55(10):1906-10. doi: 10.1093/rheumatology/kew224 [published Online First: 2016/06/11]
38. Price EJ, Rauz S, Tappuni AR, et al. The British Society for Rheumatology guideline for the management of adults with primary Sjogren's Syndrome. *Rheumatology (Oxford, England)* 2017;56(10):1828. doi: 10.1093/rheumatology/kex375 [published Online First: 2017/09/29]
39. Schmidt J. Current Classification and Management of Inflammatory Myopathies. *J Neuromuscul Dis* 2018;5(2):109-29. doi: 10.3233/jnd-180308 [published Online First: 2018/06/06]
40. Sharpe L, Sensky T, Timberlake N, et al. A blind, randomized, controlled trial of cognitive-behavioural intervention for patients with recent onset rheumatoid arthritis: preventing psychological and physical morbidity. *Pain* 2001;89(2-3):275-83. doi: 10.1016/s0304-3959(00)00379-1 [published Online First: 2001/02/13]
41. Sharpe L, Sensky T, Timberlake N, et al. Long-term efficacy of a cognitive behavioural treatment from a randomized controlled trial for patients recently diagnosed with rheumatoid arthritis.

- Rheumatology (Oxford, England)* 2003;42(3):435-41. doi: 10.1093/rheumatology/keg144 [published Online First: 2003/03/11]
42. Hewlett S, Ambler N, Almeida C, et al. Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Annals of the rheumatic diseases* 2011;70(6):1060. doi: 10.1136/ard.2010.144691
  43. Brady TJ, Murphy L, O'Colmain BJ, et al. A meta-analysis of health status, health behaviors, and health care utilization outcomes of the Chronic Disease Self-Management Program. *Prev Chronic Dis* 2013;10:120112-12. doi: 10.5888/pcd10.120112
  44. Panagioti M, Richardson G, Small N, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: a systematic review and meta-analysis. *BMC Health Serv Res* 2014;14:356-56. doi: 10.1186/1472-6963-14-356
  45. Thorpe CT, Devellis RF, Lewis MA, et al. Development and initial evaluation of a measure of self-management for adults with antineutrophil cytoplasmic antibody-associated small-vessel vasculitis. *Arthritis and rheumatism* 2007;57(7):1296-302. doi: 10.1002/art.23017 [published Online First: 2007/10/02]
  46. Al-Janabi H, Flynn TN, Coast J. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2012;21(1):167-76. doi: 10.1007/s11136-011-9927-2 [published Online First: 2011/05/21]
  47. Harper L, Morgan MD, Chanouzas D, et al. Treatment of fatigue with physical activity and behavioural change support in vasculitis: study protocol for an open-label randomised controlled feasibility study. *BMJ Open* 2018;8(10):e023769. doi: 10.1136/bmjopen-2018-023769 [published Online First: 2018/11/01]

#### Acknowledgements

the project was funded by UWE Quality-Related Research Funds for Cross-Research Groups Collaboration.

#### Disclosures

The authors do not report any specific disclosures to this project.

## Tables and Figures

**Table 1: Description of online survey participants**

<b>Speciality n (%)</b>			
<b>Nephrology</b>		26 (21.7%)	
<b>Rheumatology</b>		64 (53.3%)	
<b>Other Speciality</b>	Research (4) Psychiatry (1) Podiatry (2) Anaesthesia (1) Respiratory (1)	9 (7.5%)	
<b>Specialty not given</b>		21 (17.5%)	
<b>Type of hospital n (%)</b>			
		<b>Rheumatology</b>	<b>Nephrology</b>
<b>District general hospital</b>		19 (30.2%)	3 (11.5%)
<b>Teaching hospital</b>		23 (36.5%)	17 (65.4%)
<b>NHS England specialist centre</b>		21 (33.3%)	6 (23.1%)
<b>Professional background n (%)</b>			
<b>Nurses</b>	Nurse Specialists (31) Staff Nurses (2) Research Nurses (2) Advanced Nurse Practitioner (1)	24 (38.1%)	5 (19.2%)
<b>Allied Health Professionals</b>	Physiotherapists (4) Podiatrists (3) Occupational Therapist (3)	9 (14.3%)	2 (7.7%)
<b>Doctors</b>	Consultants (41) Doctor in training (10)	30 (47.6%)	19 (73.1%)
<b>Others</b>	Psychologists (1) Pharmacists (1)		
<b>Experience in specialty n (%)</b>			
<b>Under 5 years</b>		8 (12.7%)	5 (19.2%)
<b>5 to 10 years</b>		17 (27%)	2 (7.7%)
<b>10 to 20 years</b>		23 (36.5%)	10 (38.5%)
<b>Over 20 years</b>		15 (23.8%)	9 (34.6%)
<b>Level of experience and interest in working with patients who have CTD and Vasculitis n (%)</b>			
<b>Regularly see patients, and have a special interest</b>		27(43.5%)	20 (76.9%)
<b>Regularly see patients, but not a special interest</b>		26 (41.9%)	5 (19.2%)
<b>Do not regularly see patients, but interested</b>		6 (9.7%)	0 (0.0%)
<b>Rarely see patients with CTD or vasculitis</b>		3 (4.8%)	1 (3.8%)

**Figure 1 Who is providing self-management and psychological support for people with Systemic Vasculitis or Connective Tissue Diseases?**

A. Comparison between health professionals. Other is defined as including podiatrists, pharmacists and wellness team. \* $p < 0.05$ , \*\* $p < 0.001$

B. Comparison between rheumatology and nephrology departments. Direct access defined as psychologist available to patients with CTD or vasculitis within the team or hospital. Indirect access to psychologist defined as health professionals either signposting patients back to general practitioners or advising self-referral to community providers. \* $p < 0.05$ , \*\* $p < 0.001$

**Figure 2. How well do you think self-management and psychological support is provided in your Department?**

A. Comparison between rheumatology and nephrology departments. \* $p < 0.05$ , \*\* $p < 0.001$

B. Comparison between rheumatology and nephrology departments. \* $p < 0.05$ , \*\* $p < 0.001$

**Table 2. Key elements of self-management and psychological support for people with CTD and Vasculitis identified by rheumatology and nephrology health professionals in the UK. Mapped to the Chronic Care Model (A. Health systems).**

Aspect of CCM	Key themes	Sample quotes	No. of quotes
<p><b>A. Health Systems</b> Includes culture, structures and mechanisms to promote safe, high-quality care</p>	<p><b>SELF MANAGEMENT SUPPORT FOR PEOPLE WITH CTD AND VASCULITIS</b></p> <p><b>Supportive organisational and team ethos is key:</b></p> <ul style="list-style-type: none"> <li>- Culture of valuing self-management across the whole team</li> <li>- Having a well informed and trained MDT to provide support</li> <li>- Clinical leadership/clinician with a specialist interest in CTD/vasculitis</li> <li>- Forward looking view of department</li> <li>- Good communications between consultants and the MDT</li> </ul> <p><b>Resources needed to promote self-management:</b></p> <ul style="list-style-type: none"> <li>- Resources to deliver self-management courses</li> <li>- Financial support</li> <li>- Adequate staffing</li> <li>- Adequate time within clinic appointments</li> <li>- Clinic capacity</li> <li>- Note that patients and staff can be geographically diverse.</li> </ul> <p><b>Specific investment in training required:</b></p> <ul style="list-style-type: none"> <li>- Training in brief interventions to support self-management within clinic appointments, e.g. behaviour change management</li> <li>- Training in management of fatigue and emotional impact of CTD and vasculitis</li> <li>- Training in how to develop self-management programmes</li> </ul>	<p><b>Examples of facilitators of self-management</b></p> <ul style="list-style-type: none"> <li>- <i>Having resources within the team to be able to deliver the self-management support, such as time, trained staff, ongoing support in the delivery of self-management such as supervision; good referral pathways and dissemination of support offered amongst the team so that the team is aware of the support and can discuss this with patients. A platform from which to let patients know directly about the support that is offered so that they can access this themselves. (AHP, SW England, Rheumatology)</i></li> <li>- <i>Acknowledgment from the whole team that this [self-management] is needed and wanted by patients, and an essential part to their whole and holistic care. (Specialist Nurse, Nephrology, W Midlands)</i></li> </ul> <p><b>Barriers to self-management support</b></p> <ul style="list-style-type: none"> <li>- <i>Limited psychology support, no specialist nurse or dedicated clinic. These patients are spread through 5 consultants and a geographical spread of clinics. (Consultant, SW England, Nephrology)</i></li> <li>- <i>Time and staff availability are the main barriers. We have existing self-management group structures and clinical expertise at delivering self-management in group format for different conditions that would support creation of a self-management programme for vasculitis or CTDs. (AHP, SW England, Rheumatology)</i></li> </ul>	<p>30</p>

	<p><b>PSYCHOLOGICAL SUPPORT FOR PEOPLE WITH CTD AND VASCULITIS</b></p> <p><b>Need for clinical psychologists to be embedded within the clinical team:</b></p> <ul style="list-style-type: none"> <li>- Support patients with different psychological needs: IAPT to full clinical health psychology.</li> <li>- Routine psychological support for all people with CTD/vasculitis rather than as required</li> <li>- Work with MDT in group psychological and self-management programmes</li> <li>- Training and supervision of other health professionals within the MDT</li> <li>- Good communication between clinicians and psychologists</li> <li>- Psychologists can help with service development</li> <li>- Better liaison between local psychology team and community mental health services</li> </ul> <p><b>Specific training needs:</b></p> <ul style="list-style-type: none"> <li>- Training of health professionals in brief psychological interventions</li> <li>- Training of health professionals in identifying who would benefit from psychological support</li> </ul>	<p><b><i>Quotes highlighting range of perceived benefits of having specialist psychological support embedded within teams</i></b></p> <ul style="list-style-type: none"> <li>- <i>Patients with chronic condition require psychological support and ideally it should be offered and be available in routine practice; it would be highly effective to have psychologist working alongside us and providing support when needed (Consultant, Rheumatology, W Midlands)</i></li> <li>- <i>We have an embedded counselling team in the renal unit for all patients and can access them this way (Consultant, Nephrology, London)</i></li> <li>- <i>Need increased provision of clinical psychology, to help with service development, increased supervision and training, group support and increased provision of brief psychological support by other AHPs (AHP, SW England, Rheumatology)</i></li> <li>- <i>Better liaison with local psychology team and with the community mental health services (Consultant, Rheumatology, SE England)</i></li> <li>- <i>All Rheumatology health professionals should have training in how to provide some psychological support themselves (Specialist Nurse, Rheumatology, SW England)</i></li> </ul>	<p>45</p>
--	---	--	-----------



**Table 3. Key elements of self-management and psychological support for people with CTD and Vasculitis identified by rheumatology and nephrology health professionals in the UK. Mapped to the Chronic Care Model (B-F). B. Decision Support, D Patient self-management, E. Personal and Community resources, F. Delivery system design. No themes mapped to C. Clinical Information Systems**

<p><b>B. Decision Support</b> Decisions based on evidence and patients' preferences and needs</p>	<p><b>Patient centred</b></p> <ul style="list-style-type: none"> <li>- Use agenda setting tool within clinic appointments</li> <li>- Engage with patients to understand psychological impact</li> <li>- Training health professionals on what support is available</li> <li>- Variety of options to suit different patients</li> </ul> <p><b>Evidence required</b></p> <ul style="list-style-type: none"> <li>- Understanding and prioritising main issues faced by patients (as a group)</li> <li>- Understanding how disease affects individual patients to support them better</li> <li>- Evidenced- based interventions to support self-management</li> <li>- Interventions tailored with disease specific components</li> </ul>	<p><b>Decision support requirements</b></p> <ul style="list-style-type: none"> <li>- <i>Engage with patients and understand psychological impact due to their condition</i> (Doctor, Rheumatology, NW England)</li> <li>- <i>More variety of options to offer people who need help (not everyone responds to the same approach), better links with primary care to join up care and step-down support from hospital to community</i> (Consultant, NE England, Rheumatology)</li> <li>- <i>Develop a more comprehensive, structured approach, supported by evidence for demonstrably effective interventions</i> (Consultant, Nephrology, Wales)</li> <li>- <i>Tailoring more to disease specific components. Service design to facilitate referral in all team same message.</i> (AHP, Yorks &amp; Humber, Rheumatology)</li> </ul>	<p>9</p>
<p><b>D. Patient self-management support</b> Self-management support to enable patients to manage their health-related quality of life and health care</p>	<p><b>Potential methods of support for self-management within secondary care</b></p> <ul style="list-style-type: none"> <li>- Specific self-management programmes for people with CTD and vasculitis</li> <li>- Opening-up generic self-management programmes</li> <li>- 1 to 1 self-management support</li> <li>- Written information</li> <li>- Online self-management programme</li> </ul> <p><b>Specific topics:</b></p> <ul style="list-style-type: none"> <li>- Managing pain</li> <li>- Managing fatigue</li> </ul>	<p><b>Quotes related to self-management support in secondary care</b></p> <ul style="list-style-type: none"> <li>- <i>The initial approaching of the patient and making him/her realise that their role is vital and empower them to take a leading role for certain aspects of their care</i> (Consultant, W Midlands, Rheumatology)</li> <li>- <i>We have a multi-disciplinary team who deliver self-management support for a wide range of Rheumatology conditions. Self-management support for patients with CTD/Vasculitis is offered on a 1:1 basis at present, however we are looking into adapting our current 'living well with arthritis' programme to offer a more tailored</i></li> </ul>	<p>15</p>

	<ul style="list-style-type: none"> <li>- Managing symptoms of disease</li> <li>- Guidance to patients on navigation through the NHS system</li> </ul>	<p><i>programme to patients with CTD/vasculitis. (AHP, Rheumatology, SW England)</i></p>	
<p><b>E. Personal and Community resources</b> Assets and resources available to help mobilise patient action</p>	<p><b>Community resources – what is helpful?</b></p> <ul style="list-style-type: none"> <li>- Peer support</li> <li>- Local support groups</li> <li>- National patient charities</li> <li>- Online and written information</li> </ul> <p><b>Staff knowledge needed</b></p> <ul style="list-style-type: none"> <li>- Awareness of support options</li> <li>- How/where to signpost to for support</li> </ul>	<p><b>Quotes related to accessing community resources</b></p> <ul style="list-style-type: none"> <li>- <i>Online support via charities and mental health charities/NHS Choices anxiety and depression, Mind, Mindfulness, mood gym etc. (Specialist Nurse, Rheumatology, W Midlands).</i></li> <li>- <i>We don't have a specialist nurse with an interest in vasculitis - I think this would help. We do refer to a peer support group and web-based resources, but don't have specific written information (Consultant, Wales, Nephrology)</i></li> <li>- <i>Patient centred team approach, knowledge of local services and resources for sign posting patients (Specialist Nurse, SW England, Rheumatology)</i></li> </ul>	12
<p><b>F. Delivery system design</b> Design of clinical care and self-management support, including team care and preparation</p>	<p><b>Design of delivery systems to support people with CTD and vasculitis</b></p> <ul style="list-style-type: none"> <li>- Pathway for people with CTD/vasculitis</li> <li>- Timely access to services at diagnosis and during flare/rapid review</li> <li>- Advice line support</li> <li>- Continuity of care</li> </ul> <p><b>Multidisciplinary approach is important for people with CTD and vasculitis</b></p> <ul style="list-style-type: none"> <li>- Specialist nurse with interest in CTD/vasculitis to act as key contact for people</li> <li>- Access to occupation health, physiotherapy and psychological support when needed.</li> <li>- Embedded psychologist has multiple benefits</li> </ul>	<p><b>Importance of service design</b></p> <ul style="list-style-type: none"> <li>- <i>A pathway for patients with CTD/ vasculitis and making appropriate services available to all inflammatory rheumatic diseases rather than disease specific or just inflammatory arthritis. (Specialist Nurse, Rheumatology, SW England)</i></li> <li>-</li> <li>- <i>[importance of] Specialist teams rather than individual clinicians, nurse specialist for vasculitis (Consultant, Nephrology, SW England)</i></li> <li>- <i>Psychologists as part of the team. MDT approach facilitating a joined- up approach. Working with psychologists in group programs. (AHP, Yorks &amp; Humber, Rheumatology)</i></li> </ul>	51

**Supplementary material A. Geographical distribution of participants.**

<b>Geographical region</b>	<b>N</b>	<b>%</b>
Northern Ireland	1	1.0
North East England	2	2.0
North West England	10	9.8
Yorkshire & Humberside	6	5.9
East Midlands	9	8.8
West Midlands	8	7.8
Wales	3	2.9
East England	10	9.8
London	12	11.8
South West England	24	23.5
South East England	14	13.7
Scotland	3	2.9
Missing	19	18.6
<b>Total</b>	<b>102</b>	<b>100</b>