



Original article

Telemedicine in rheumatology: a mixed methods study exploring acceptability, preferences and experiences among patients and clinicians

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Abstract

Objectives. The Covid-19 pandemic necessitated a rapid global transition towards telemedicine; yet much remains unknown about telemedicine's acceptability and safety in rheumatology. To help address this gap and inform practice, this study investigated rheumatology patient and clinician experiences and views of telemedicine.

Methods. Sequential mixed methodology combined analysis of surveys and in-depth interviews. Between and within-group differences in views of telemedicine were examined for patients and clinicians using t-tests.

Results. Surveys (patients $n = 1340$, clinicians $n = 111$) and interviews (patients $n = 31$, clinicians $n = 29$) were completed between April 2021 and July 2021. The majority of patients were from the UK (96%) and had inflammatory arthritis (32%) or lupus (32%). Patients and clinicians rated telemedicine as worse than face-to-face consultations in almost all categories, although >60% found it more convenient. Building trusting medical relationships and assessment accuracy were great concerns (93% of clinicians and 86% of patients rated telemedicine as worse than face-to-face for assessment accuracy). Telemedicine was perceived to have increased misdiagnoses, inequalities and barriers to accessing care. Participants reported highly disparate telemedicine delivery and responsiveness from primary and secondary care. Although rheumatology clinicians highlighted the importance of a quick response to flaring patients, only 55% of patients were confident that their rheumatology department would respond within 48 hours.

Conclusion. Findings indicate a preference for face-to-face consultations. Some negative experiences may be due to the pandemic rather than telemedicine specifically, although the risk of greater diagnostic inaccuracies using telemedicine is unlikely to be fully resolved. Training, choice, careful patient selection, and further consultation with clinicians and patients is required to increase telemedicine's acceptability and safety.

Trial registration. This telemedicine study is part of a pre-registered longitudinal multi-stage trial, the LISTEN study (ISRCTN-14966097), with later Covid-related additions registered in March 2021, including a pre-registered statistical analysis plan.

Key words: telemedicine, rheumatology, patient–physician interactions, digital technology in medicine, pandemic, mixed-methods, rare autoimmune rheumatic diseases

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Rheumatology key messages

- Concerns about telemedicine included: reduced assessment accuracy; impaired medical relationship building; and increased inequalities for vulnerable and/or disadvantaged patients.
- Barriers to patient-initiated contact, including 'gate-keeping' administrators and non-response, are limiting emergency access.
- Telemedicine is convenient and acceptable for some rheumatology patients. Careful selection and choice are key.

Introduction

The Covid-19 pandemic necessitated a rapid reorganisation of patient care to predominantly telemedicine in the UK [1] and elsewhere [2–4]. This trend seems set to continue [5], with support from governments and health services [6]. NHS England's 2021/2022 planning guidance, for example, states that at least 25% of outpatient appointments should be by telephone or video [6]. However, telemedicine's suitability, acceptability and safety in rheumatology has yet to be ascertained. The majority of rheumatology studies have focussed on RA, and there is limited evidence relating to the rare autoimmune rheumatic diseases [7, 8] such as lupus or systemic sclerosis, which can have life-threatening [9], yet less visible [10] manifestations.

McDougal *et al.*'s tele-rheumatology systematic review found that most studies reviewed 'demonstrated a high risk of bias' [11]; and studies have produced conflicting results. Some report high levels of patient satisfaction [12, 13] and suggest that telemedicine could be as effective as face-to-face for autoimmune rheumatic diseases [14]. However, there are concerns regarding the use of telemedicine for diagnosis and assessment of disease activity [15], particularly as a result of lack of physical examinations [16]. Studies to date have tended to be limited by sample size [14], only reporting the views of one side of the medical relationship and/or only including patients from the investigators' hospital [13, 17], which could increase the risk of bias.

The pandemic-initiated extensive use of telemedicine has highlighted the need for detailed research ahead of more permanent digital service delivery. Our study therefore elicited the views and experiences of clinicians, and patients with a wide range of inflammatory rheumatic diseases.

Methods

Participants and design

A pre-tested survey for rheumatology patients was made available online in April 2021 using Qualtrics, via multiple disease support groups. A similar online survey for rheumatology clinicians was disseminated through rheumatology networks, including the British Society for Rheumatology, in May/June 2021. This telemedicine sub-study is part of a pre-registered longitudinal multi-stage trial (ISRCTN-14966097, including a statistical analysis

plan with Covid-related additions registered March 2021). Ethical approval was obtained through the Cambridge Psychology Research Committee. Respondents gave informed written (electronic) consent on the survey and/or verbally recorded consent prior to interviews.

Inclusion criteria: Patients: age ≥ 18 years, reporting a diagnosis of an autoimmune inflammatory rheumatological condition on their clinic letters and having received at least one telemedicine appointment. Clinicians: UK-based clinicians involved in the care of rheumatology patients [including consultants, registrars, specialist nurses and General Practitioners (GPs)].

Questions elicited demographic, and quantitative [predominately using Likert scales comparing telemedicine with face-to-face (F2F)] and qualitative responses about telemedicine views and experiences. Medical security was measured on a scale of 0–100 with 0 signifying 'completely medically abandoned' to 100 signifying 'completely medical secure'. Interviewees were largely purposively selected from the questionnaires to ensure a range of characteristics and views. Interviews were semi-structured, continued until thematic saturation was reached and were conducted by M.S., an experienced, qualitatively-trained researcher. Interviews lasted for 0.5–3 h and were transcribed verbatim.

Analysis

This study used multi-stage sequential mixed methods. Interview data was collected both before survey design to ascertain patient and clinician priorities for research directions, and also after initial analysis (using SPSS v.26) of quantitative data to further explore and explain quantitative findings. Both types of data were given equal priority and the use of mixed methods reduced the inherent weaknesses in each individual method. Mean differences between patients and clinicians, and within-groups differences were tested for statistical significance using t-tests. Pearson's or Spearman's rank were used for correlations as appropriate. Thematic analysis [18] was used for the interviews and the qualitative data from the surveys, using NVivo12 to assist in managing and coding the qualitative data. The coding frame was developed by M.S., R.H. and M.B., with coding agreed by F.N., E.L., P.H. and C.G. to improve reliability. Emerging themes were discussed and agreed by the wider team, including patient representatives and clinicians. Validity was strengthened by triangulation of quantitative and qualitative results [19], which were combined at all stages from planning through analysis

TABLE 1 Participant characteristics

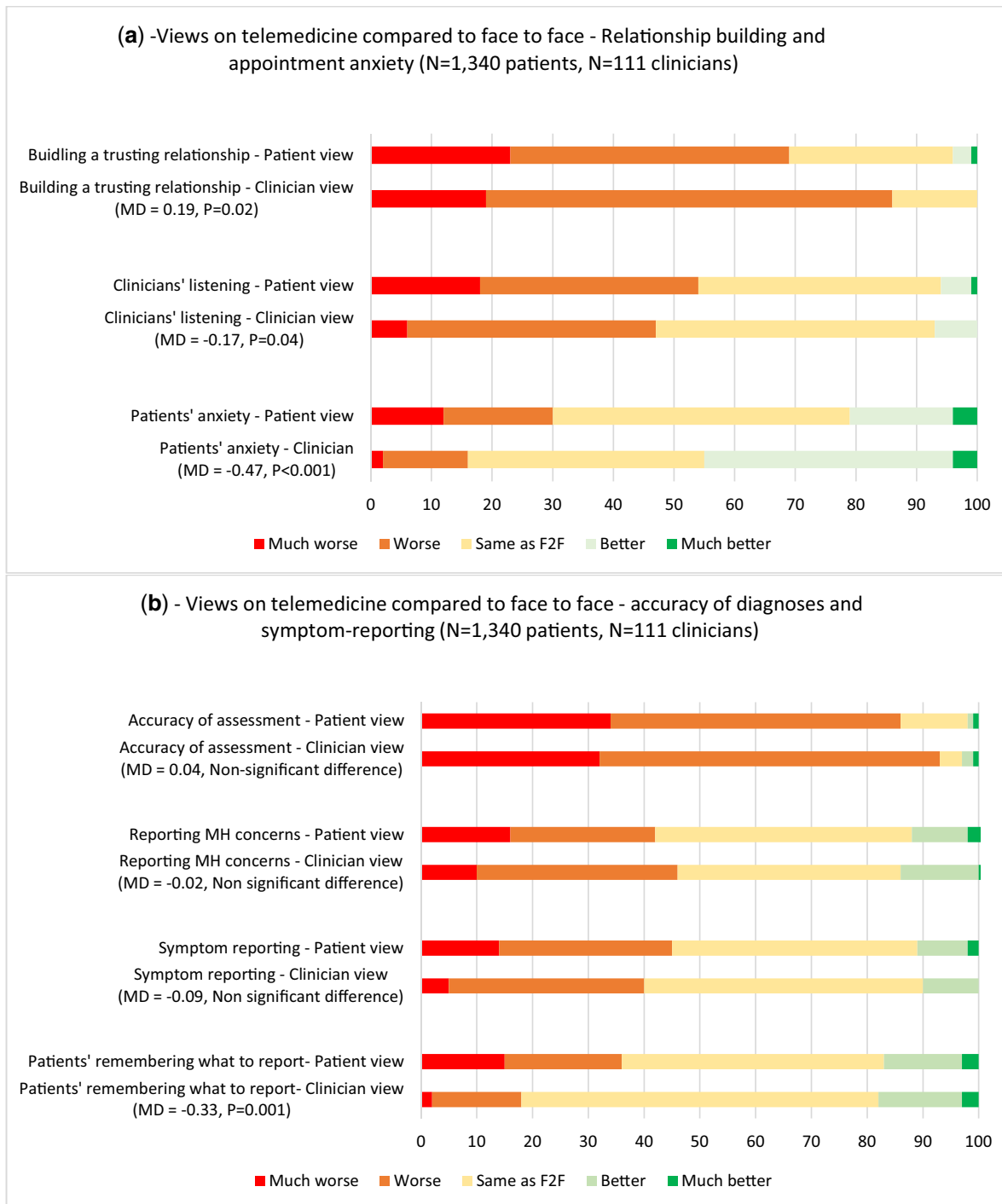
Characteristic	Patient survey (n = 1340)	Patient interviews (n = 31)	Clinician survey (n = 111)	Clinician interviews (n = 29)
Age				
<30	222 (17%)	4 (13%)	5 (5%)	0
30–39	247 (18%)	3 (10%)	19 (17%)	9 (31%)
40–49	406 (30%)	8 (26%)	39 (35%)	5 (17%)
50–59	308 (23%)	9 (29%)	37 (33%)	11 (38%)
60+	155 (12%)	7 (23%)	11 (10%)	4 (14%)
Gender				
Female	1275 (95%)	27 (87%)	77 (69%)	11 (38%)
Male	59 (4%)	4 (13%)	34 (31%)	18 (62%)
Other/undisclosed	6 (<1%)	0	0	0
Country/region				
England	1060 (79%)	17 (55%)	87 (78%)	24 (83%)
Scotland	112 (8%)	4 (13%)	13 (11%)	2 (7%)
Wales	68 (5%)	8 (26%)	9 (8%)	1 (3%)
N. Ireland	36 (3%)	0	2 (2%)	2 (7%)
US/Canada	30 (2%)	1 (3%)	0	0
Europe	16 (1%)	1 (3%)	0	0
Other	18 (1%)	0	0	0
Disease				
Inflammatory (pre-dominantly rheumatoid) arthritis	424 (32%)	7 (23%)		
Lupus	419 (32%)	12 (39%)		
Sjögrens	119 (9%)	2 (6%)		
Systemic sclerosis	100 (8%)	3 (10%)		
Vasculitis	47 (4%)	1 (3%)		
UCTD	45 (3%)	3 (10%)		
PMR	44 (3%)	2 (6%)		
MCTD or two or more inflammatory rheumatic diseases	91 (7%)	1 (3%)		
Other inflammatory rheumatic disease	47 (4%)	0		
Time since diagnosis				
<1 year	80 (6%)	3 (10%)		
1–2 years	166 (12%)	5 (16%)		
3–5 years	268 (20%)	5 (16%)		
6–9 years	253 (19%)	9 (29%)		
10+ years	568 (42%)	9 (29%)		
Unsure or missing	5 (<1%)	0		
Clinician role				
Rheumatology consultant			72 (65%)	13 (45%)
Rheumatology registrar			13 (12%)	5 (17%)
Rheumatology nurse			19 (17%)	5 (17%)
GP			0 (not surveyed)	5 (17%)
Other speciality			7(6%)	1(7%)

to reporting, consideration of cases that deviated from the emerging conclusions [20] and member checking [21]. The criteria for reporting qualitative research (COREQ) [22], detailed methodology and limitations are included in [Supplementary Data S1](#), available at *Rheumatology* online. Further statistical analysis is available in [Supplementary Data S2](#), available at *Rheumatology* online.

Results

A total of 1340 patients and 111 clinicians completed the surveys; 60 (31 patients and 29 clinicians) were interviewed ([Table 1](#)). The four most commonly reported rheumatological diseases were inflammatory arthritis (32%), lupus (32%), Sjögren's (9%) and systemic sclerosis (8%). The survey was open to clinicians working in

Fig. 1 Views of telemedicine compared with F2F – medical relationships and assessment accuracy



(a) Views on telemedicine compared with face to face – relationship building and appointment anxiety ($n=1340$ patients, $n=111$ clinicians). **(b)** Views on telemedicine compared with face to face – accuracy of diagnoses and symptom reporting ($n=1340$ patients, $n=111$ clinicians). Note: T-tests comparing means of ratings from 1 (much worse) to 5 (much better) from clinicians and patients regarding views of telemedicine compared to F2F. MD: mean difference between scores of patients and clinicians assessed by t test. If $P > 0.05$, it is reported as non-significant.

the UK and patients of any nationality, but patient respondents were largely from the UK (96%). Numerical values given are from survey quantitative data. Within-text quotes were not given participant numbers if the term used was given by multiple participants.

Five main telemedicine themes were identified: (i) effect on the patient-clinician relationship; (ii) greater risk of inaccurate assessments; (iii) convenience, technology and logistical considerations; (iv) barriers to safe and effective telemedicine; and (v) cost-cutting, clinical need or choice.

Theme 1: Effect on the patient-clinician relationship

Significantly more ($P = 0.02$) clinicians (90%) than patients (69%) felt that telemedicine was worse than face-to-face for building a trusting relationship (Fig. 1a). The majority of clinicians discussed how non-verbal communication, including 'reassuring' touch, was important in building trust and/or rapport. Many patients used terminology—such as feeling like 'a statistic' or 'uncared for'—indicative of finding telemedicine more impersonal than in-person consultations. However, a substantial number of participants reported that positive relationships continued with telemedicine; and well-established medical relationships were felt to be protective against the limitations of remote appointments.

Around 50% of clinicians and patients rated clinicians' listening as worse with telemedicine, and <10% rated it better than with face-to-face. Many patients felt telemedicine followed an impersonal 'tick list' and felt more 'rushed'. Patients' ratings for telemedicine were significantly lower (mean difference, 0.49, $P < 0.001$) than clinicians for time available to discuss patient concerns (Fig. 3a), and many reported telephone consultations lasting <5 min. Other patients expressed disappointment regarding changes in their clinician's behaviour using telemedicine:

The doctor, who is normally quite sympathetic, seemed very cold . . . very perfunctory and I felt he sounded rather irritated. I didn't feel very cared for at the end of the call, despite getting the outcome I felt I needed (Patient 56, RA)

Some clinicians surmised that pandemic-induced backlogs might be temporarily reducing time available and patience during discussions, while others felt that telemedicine itself hindered displaying empathy or their ability to focus on the patient:

When I am in clinic I am 100% focused on the patient I have in front of me . . . but on the telephone I really struggle . . . we have less time. I am always watching the watch, I feel much more tired than with face to face (Clinician 23, Consultant)

Theme 2: Greater risk of inaccurate assessments

Patients (86%) and clinicians (93%) felt that telemedicine was worse than face-to-face in terms of accuracy of assessment (Fig. 1b). Misdiagnoses and other inaccuracies were frequently reported and often attributed to the absence of examinations and visual cues:

My rheumatologist cannot see/hear how I move, look at my skin, eyes, hair, hands, bones, how I am . . . I was diagnosed with something over the phone, which I know isn't right, and it's getting worse (Patient 293, UCTD)

Compounding these problems was the cancelling of tests that could aid diagnoses. Patients reported having at least one blood (40% of patients) and/or other (48%) test (e.g. imaging) cancelled between March 2020 and March 2021. During that time, routine medication monitoring was restricted to protect patients from Covid-19 infection, but it remains limited, often due to continuing disagreements between primary and secondary care as to responsibility for testing when patients are being reviewed remotely:

Secondary care has gone to much more telephone and requesting that GPs do the blood tests . . . I'm not sure what that abnormal result means, it feels like we're doing secondary care's job for them. It is less safe for the patient (Clinician 29, GP)

The risk of diagnostic errors from lack of examinations and tests was further increased by frequent underplaying of symptom severity by rheumatology patients. Willingness to report symptoms, including mental health (MH) symptoms, was reported as worse/much worse with telemedicine by ~45% of patients and clinicians. Clinicians also found it more difficult to identify MH concerns remotely:

I can tell from somebody's affect and demeanour, and how they look and how they're different from how they've been previously and how they respond, you know those biological features of depression that I just can't gauge over the phone (Clinician 10, Consultant)

A minority of patients and clinicians felt that telemedicine was better than face-to-face for remembering discussion points (16% of patients, 18% of clinicians), and for comfort with symptom-reporting (12% of patients, 10% of clinicians); including, in some cases, for more personal symptoms and MH concerns:

My largely invisible CTDs are easier to speak about to strangers over the phone—especially where it comes to intimate problems and mental wellbeing, or lack of. I feel I'm clearer by phone and less stressed out than I am by clinical environments (Patient 46, mixed/multiple)

Further participant quotes on advantages and disadvantages of telemedicine are reported in Table 2.

Theme 3: Convenience, technology and logistical considerations

Over 60% of patients and clinicians considered telemedicine more convenient than face-to-face (Fig. 2), often citing safety from infection, no travelling, and reduced waiting times, as the main advantages (Table 3a):

I am very glad that telemedicine has become an option as it not only makes me feel more relaxed and safer, but I often have great difficulty getting to hospital (Patient 635, lupus)

Clinicians significantly over-estimated the convenience for patients compared with patient views (mean clinician rating of 3.86, mean patient rating of 3.49, mean difference = 0.37, $P = 0.001$) and many patients reported that

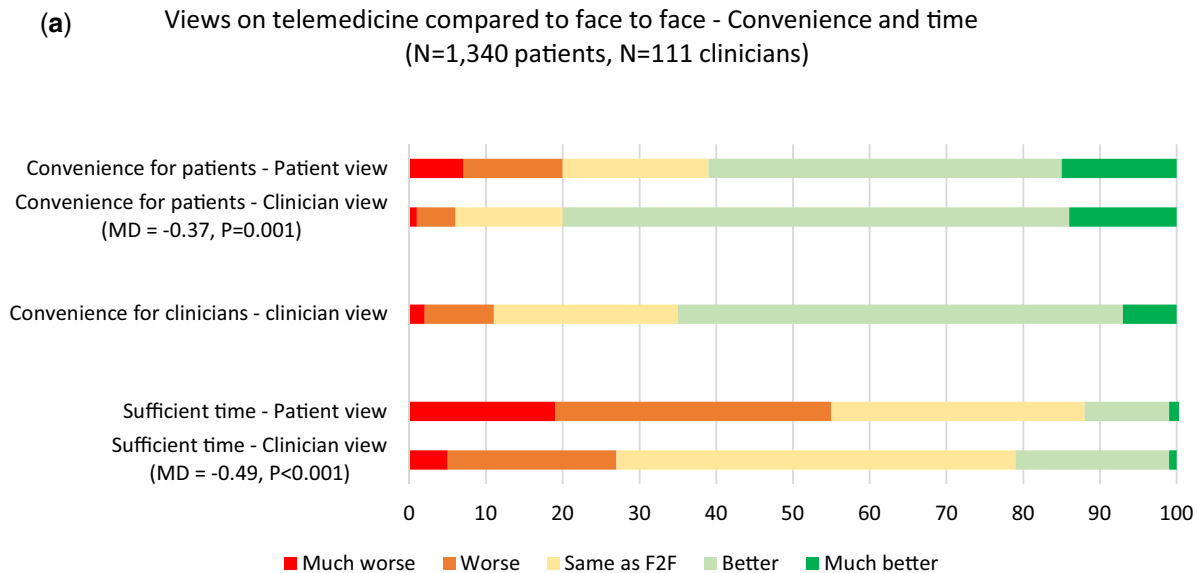
TABLE 2 Illustrative participant quotes on the advantages and disadvantages of telemedicine

Category	Advantages of telemedicine	Disadvantages of telemedicine
Building a trusting relationship	<i>It's nice that my GP has called me. This way I didn't have to go to her Practice. She has also called me to check if I'm having flares. Small things like this really kept me going during lockdown. (Patient 1063, lupus)</i>	<i>It's definitely harder to build trust over the phone, and you're picking up that they're not saying everything, so much of that for me on my side is that I use very open body language, eye contact, that kind of stuff, and showing empathy. (Clinician 11, Registrar)</i>
Clinicians' listening and taking symptoms seriously	<i>Medics listened to symptoms because they couldn't see me. More so than in person. (Patient 517, Sjögrens)</i>	<i>All the time he was interrupting and my words were falling on deaf ears . . . 'How's your skin?' Me, 'starting to flare'. Again no advice or reaction . . . I felt like I was on a very long patient list he had to get through and he was taking no prisoners. I decided I didn't want to see him again and was greatly upset by his abruptness and attitude (Patient 23, lupus)</i>
Patients' feeling anxious due to previous adverse medical experiences	<i>I get huge anxiety just walking into the doctor's office because I feel like I'm not going to be heard. Also, I've had so many bad experiences, I don't feel like doctors are interested enough. So, in that regard, telemedicine is awesome. I'm in my home, on my territory and they can't harm me. (Patient 892, RA)</i>	<i>It is always different on the phone whereas if you see them you can see how they're actually feeling . . . often feel like I'm not being believed . . . makes me report it less on the phone definitely. (Patient 80, lupus)</i>
Accuracy of assessment	No advantages in this category specified by clinicians or patients.	<i>Telemedicine sucks and kills people. Might be good for administrative stuff, like questions about medications etc but dangerous for if you are actually unwell. Easy to dismiss a patient over the phone and impossible to physically exam them. And idiotic to make the patient and their family behave like medical professionals. (Patient 836, mixed/multiple)</i>
Reporting of symptoms, including mental health	<i>I like them . . . honestly I feel more listened to and less dismissed . . . Maybe it's changed how I present myself too as I'm more confident in my own space and not so aware of being judged visually. (Patient 890, systemic sclerosis)</i>	<i>It's quite easy to hide how you're really feeling. I've done this when my anxiety was having a wobble . . . needed more support than I let on. It's much easier to put a brave face on when on a phone call. (Patient 578, dermatomyositis)</i>
Remembering what to report	<i>It's helpful being able to make notes before and during the appointment when it's by phone . . . so you don't forget to ask about all pertinent issues . . . I don't feel confident doing that in a face-to-face appointment. I think doctors hate it when you produce a list at an appointment. (Patient 310, RA)</i>	<i>It's harder for them to remember . . . they're thinking about what's going on in the background and in the house. They don't actually then think so much and focus than if they were sitting in your office and there were no distractions . . . And they are not then as mentally prepared. (Clinician 5, GP)</i>
Convenience	<i>We are a tertiary centre and most of our patients travel for h to get to us and it does seem bonkers at times when they do that and stay for 5 min . . . clearly a role for patients like that and I know a lot of them have really liked it. (Clinician 11, Registrar)</i>	<i>If we knew a time slot it would really improve telemedicine. I'm a teacher and can't take a call in class. (Patient 1385, vasculitis)</i>

they weren't given appointment times for telemedicine in the same way as for face-to-face, leading to greater inconvenience for some. In addition, remote appointments did not always save clinicians' time (Fig. 2b). Telemedicine involves more administration, including sending blood forms and prescriptions that would have been handed to the patient in a face-to-face appointment. Patients were often 'double-seen' by clinicians

who arranged a face-to-face appointment for any they were concerned about. Administrative errors meant that patients were sometimes not informed as to whether their appointment was face-to-face or telemedicine. Although some clinicians reported an improved work-life balance through remote working, others found their workload expanding as a result of the increase in direct patient communication (such as by email).

Fig. 2 Views of telemedicine compared with F2F—Convenience and time



(b)

Category	Advantages of telemedicine	Disadvantages of telemedicine
Work/life balance	<i>Able to work from home intermittently has lessened the stress of daily travel</i> (Clinician 81, Nurse)	<i>Inundated with emails from patients...yesterday spent 2 or 3 hours just dealing with patient emails.</i> (Clinician 4, Consultant)
Time	<i>More efficient use of time for self and patient when they are in remission</i> (Clinician 53, Nurse)	<i>Sometimes we double see patients because we're trying to deal with the problem on the telephone and then you end up trying to schedule them again to come in, and you're talking about pressured waiting lists already</i> (Clinician 1, Registrar)
Productivity	<i>Makes things easier for clinicians as we can more easily multi-task, check results...while speaking to the patient without having to make eye contact</i> (Clinician 77, Registrar)	<i>If you don't answer then they keep calling...keep on being interrupted by all these phonecalls... then answering an email and then lots of calls that nobody is taking...interrupts me when maybe I'm maybe checking bloods and things can then go a bit wrong...it's distractions all the time</i> (Clinician 23, Consultant)

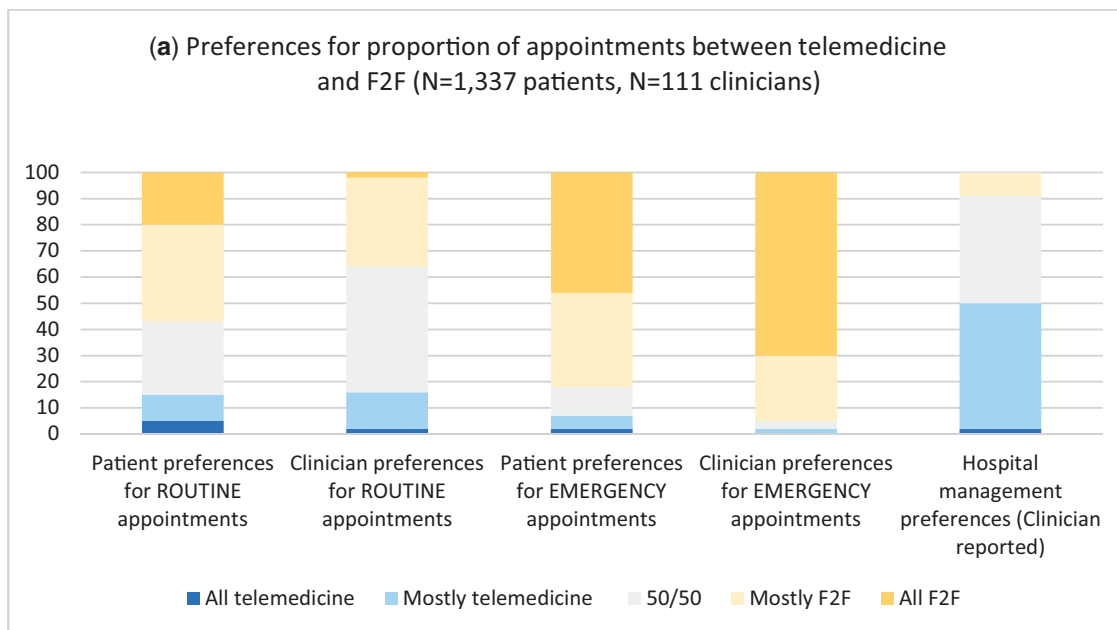
(a) Views on telemedicine compared with face to face – convenience and time ($n = 1340$ patients, $n = 111$ clinicians). Note: T-tests comparing means of ratings from 1 (much worse) to 5 (much better) from clinicians and patients regarding views of telemedicine compared to F2F. MD: mean difference between scores of patients and clinicians assessed by t test. If $P > 0.05$, it is reported as non-significant. **(b)** Common clinician views of advantages and disadvantages of telemedicine for convenience.

NHS technology and organisation were sometimes spoken of in strongly negative terms, such as being 'embarrassingly primitive' (Clinician 82, Consultant); although several clinicians reported rapid pandemic-induced improvements in technology. Despite sometimes 'fierce opposition' (Clinician 4, Consultant) to

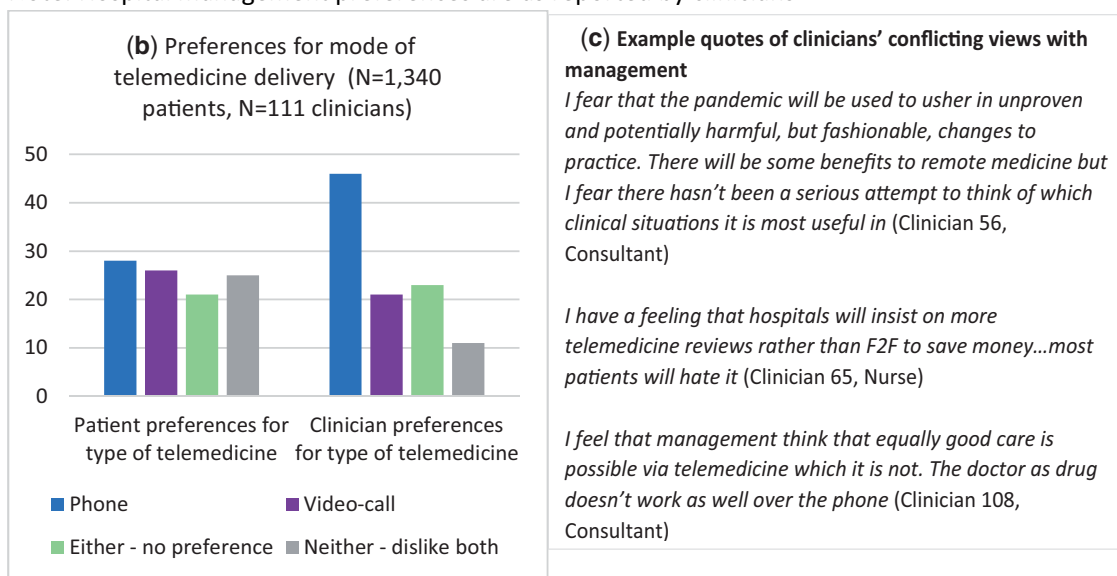
change initially from some clinicians, hospitals with existing integrated technology for communication between clinicians and patients had an easier transition to telemedicine and greater patient satisfaction:

The addition of the 'MyChart' app . . . has really helped me. I can send a message without battling to pick up the phone, I can attach

FIG. 3 Preferences for mode of appointment delivery



Note: Hospital management preferences are as reported by clinicians



(c) Example quotes of clinicians' conflicting views with management

I fear that the pandemic will be used to usher in unproven and potentially harmful, but fashionable, changes to practice. There will be some benefits to remote medicine but I fear there hasn't been a serious attempt to think of which clinical situations it is most useful in (Clinician 56, Consultant)

I have a feeling that hospitals will insist on more telemedicine reviews rather than F2F to save money...most patients will hate it (Clinician 65, Nurse)

I feel that management think that equally good care is possible via telemedicine which it is not. The doctor as drug doesn't work as well over the phone (Clinician 108, Consultant)

(a) Preferences for proportion of appointments between telemedicine and F2F ($n=1337$ patients, $n=111$ clinicians). Note: Hospital management preferences are as reported by clinicians **(b)** Preferences for mode of telemedicine delivery ($n=1340$ patients, $n=111$ clinicians). **(c)** Example quotes of clinicians' conflicting views with management.

photos which can then be shown to my rheumatologist, and I receive all my blood test results quickly too (Patient 825, mixed/multiple)

Clinicians and patients felt that the medical relationship and the quality of care would benefit from improved patient telemedicine skills: 'once my daughter had taught me how to email photos I sent some flare pictures in' (Patient 1424, Sjögren's), and also for clinicians:

I have taught telemedicine myself as a clinical subject. What is apparent in the current situation is the lack of preparedness in the

NHS to train clinical staff in telemedicine in terms of: demonstrating empathy, active listening, summarising and checking, formulating a shared management plan and provision of signposting, care and worsening advice (Patient 1250, lupus)

Theme 4: Barriers to safe and effective telemedicine

Although most clinicians acknowledged that problems had occurred with patient-initiated access during earlier stages of the pandemic, the majority felt that their own

TABLE 3A Patient types/groups, some of whom expressed a preference for telemedicine

Characteristic	Example quote
Employed	<i>Telemedicine has been great for convenience as someone who works full time. F2F appointments in the NHS are frustrating as they are literally never on time. So have to allocate 2–3 h for travel and waiting for a 10 min appointment. (Patient 71, inflammatory arthritis)</i>
Stable, quick check-in	<i>I like the fact that if my condition is stable I don't have to waste 3 h of my day to tell the consultant that. I have never felt rushed over the phone. (Patient 942, RA)</i>
Experienced patients	<i>I know my disease and my body. My RA team know that if I say I'm ready for infusion they accept that. (Patient 1237, RA)</i>
High fatigue/pain or physical disability	<i>I also feel like it's more convenient as if I am having a bad fatigue day, I can still speak to someone whereas I may have had to cancel an in person slot. (Patient 97, mixed)</i>

TABLE 3B Patient and physician characteristics that may make telemedicine less acceptable/effective

Characteristic	Example quote
Undiagnosed	<i>With my initial appointment first postponed and then moved to a phone call it took almost a whole year longer to be diagnosed, a whole year was lost without medication. I think for a first appointment this was terrible. (Patient 989, inflammatory arthritis)</i>
Newly diagnosed	<i>GP telemedicine was difficult during early diagnosis as everything felt rushed and emotional support was lacking. I found my diagnosis very scary whilst trying to cope with a lot of pain and with very restricted mobility. This element was lost during a telephone appointment whereas at a face-to-face it would have been very apparent just how difficult I was finding it to cope. (Patient 1218, RA)</i>
The more complex diseases	<i>I think a lot of us want to do more face-to-face, in particular with something like lupus . . . For other diseases you just can look at the blood tests and do an adequate job but in something like lupus where blood tests don't always correlate with symptoms and activity you're then going on the only kind of assessment you can do on the telephone which is essentially doing it blind. (Clinician 24, Registrar)</i>
Communication – Accents	<i>Several of the Drs have accents that I find very hard to understand over the phone and as I have a slight hearing loss I find the experience frustrating and uncomfortable. (Patient 16, Sjögrens)</i>
Elderly and/or deaf	<i>All telemedicine is hard for the elderly. I am very deaf and even with two hearing aids, get stressed talking on the phone about important things. (Patient 605, vasculitis)</i>
Hearing and/or cognitive difficulties	<i>My hearing isn't the best and it's much easier face to face. I like to have my wife with me to corroborate and amplify and remind me if I forget anything, which is difficult on the phone. (Patient 1422, lupus)</i>
Less technologically able (clinicians and patients)	<i>My younger colleagues . . . they are much better than me at managing online and connection . . . I end up making the mistakes . . . a lot of time wasted in trying to get these online functioning properly as well. (Clinician 23, Consultant)</i>
Socio-economically disadvantaged	<i>In terms of support and living in stressful, over-crowded environments . . . won't get what they need or learn easily from a remote consultation . . . need more support because there's less support at home and they have less background knowledge. (Clinician 2, Consultant)</i>

department/GP surgery was currently responding promptly. Several highlighted the importance of a quick response to patients experiencing flares:

If a patient phones up a department, even if we're working remotely, a lupus patient should be responded to on the same day, there's no doubt about that (Clinician 25, Consultant)

A minority of patients reported that increased use of telemedicine had ensured quicker responses:

The GPs are much more efficient using telephone appointments and when I've needed them they've seemed much more responsive and engaged. The NHS has benefitted from changing how they work (Patient 890, systemic sclerosis)

However, emergency access remained highly variable and many patients felt 'insecure' due to continued difficulties in obtaining emergency care/advice. Overall patient medical security ratings (from 0 = totally medically abandoned to 100 = totally medically secure) were lower for patient recalled pre-pandemic levels (66.7) compared with during (48.1) the pandemic (mean difference 18.6, $P < 0.001$). Differences between disease groups' ratings of medical security increased during the pandemic. For example, recalled pre-pandemic medical security ratings were 68.9 for participants with inflammatory arthritis and 66.0 for participants with lupus (with a non-significant mean difference of 2.9,

$P = 0.06$). These had dropped to 51.8 (inflammatory arthritis) and 46.3 (lupus) in April 2021 (MD of 5.5, $P = 0.004$). Medical security was lowest in Sjögren's patients (42.2 in April 2021).

Great difficulties in accessing support were frequently reported, sometimes from the departments that clinicians felt were responding promptly:

Waiting for a call back after 4 voicemails . . . feel sad and scared knowing that when I really need medical help I have no-one (Patient 132, lupus)

Administrative staff triaging and 'gate-keeping' was particularly disliked; and there were reports of being made to feel 'like I was making a fuss' or being refused access, sometimes with life-threatening consequences:

You have to go through reception, she . . . didn't think I should bother GP . . . hung up on me . . . it was 3 or 4 days that she agreed that actually a doctor did need to see me . . . my lovely GP who was like it's too late, straight to A&E . . . kidney infection. I was in hospital for a week . . . If I had seen the GP in real life this would not have happened (Patient 9, lupus)

Perceptions of continuing barriers to prompt care were also reflected in the quantitative findings, with for example only 48% confident that a GP would respond within 24 hours, and only 55% confident that their rheumatology department would respond within 48 h. Patients with inflammatory arthritis were significantly more confident ($P = 0.002$) of getting a prompt response from their rheumatology department than those with lupus. Restricted methods of access were felt to disproportionately impact the most disadvantaged:

We've had some local Practices only allowing contact through econsult, so that means that if you can't use it, you're elderly, English not your first language, you've got learning difficulties . . . it's not fair. They're doing that whole barrier to protect their time (Clinician 7, GP)

Multiple barriers to safe and effective remote appointments were identified, with these barriers appearing to place certain groups at a disadvantage, particularly patients at an early stage of the disease journey. There were reports of greater diagnostic delays, less support at diagnosis, and less chance to build a supportive medical relationship with telemedicine than with face-to-face appointments: 'With new patients it is really important to meet F2F and build up a rapport and confidence' (Clinician 20, Nurse). These disadvantages were reflected statistically in that the newly diagnosed (<1 year) gave significantly lower ratings ($P = 0.009$) for telemedicine (compared with face-to-face) for relationship building than those diagnosed >10 years ago.

Telemedicine was also reported by clinicians and patients to disadvantage (Table 3b):

- Patients without English as a first language; those with hearing, cognitive or speech difficulties; or when the accent of the patient or clinician was felt to be difficult to understand.
- Patients with more complex, multi-system, potentially life-threatening diseases, particularly vasculitis or SLE.
- Those in need of urgent care or with MH difficulties.

- Older patients; although the only statistically significant differences in views of telemedicine between age groups was in terms of convenience (a low negative correlation between age and convenience of -0.14 , $P = 0.01$).
- Clinicians and patients experiencing difficulties with access to/ability with telemedicine-related technology.
- Socio-economically or educationally disadvantaged patients.

Theme 5: Cost-cutting, clinical need or choice?

Although there was an overall preference for face-to-face appointments, most participants supported a mixture of face-to-face and telemedicine (Fig. 3a). A significantly ($P < 0.01$) higher proportion of clinicians (70%) than patients (46%) wanted all emergency appointments to be face-to-face. This disparity may be partially explained by clinicians being very concerned about the difficulties of diagnosing and treating a flare remotely, including medico-legal considerations, while patients appreciated the option of telemedicine if feeling too unwell to physically attend. There were no significant differences in patient preference between the mode of telemedicine (phone or video), or between disease groups, in views of telemedicine's acceptability. Clinicians had a strong preference (over twice as many) for telephone appointments over videocalls (Fig. 3b). Male clinicians and rheumatology registrars were the most negative clinician sub-groups on the relative merits of telemedicine over face-to-face both quantitatively and qualitatively, and rheumatology nurses were the most positive.

Concerns were expressed that telemedicine would be overused by the NHS and hospital management (Fig. 3a and c) as a cost and time-saving measure rather than in patients' best interests. Clinicians (only 3% of whom felt telemedicine overall was better than face-to-face) and patients had rarely been consulted as to their preferences:

We've got a top-down system where the view on consultation has been taken at a different level than purely a clinical one (Clinician 1, Registrar)

The importance of assessing individual suitability – for example, by pre-consultation questionnaires – and allowing clinician and patient choice were frequently highlighted:

The rapid digitalisation and use of telemedicine must stay but appropriate patient selection is key, it is perfect for some but disastrous for others (Clinician 40, Consultant)

Discussion

This is the first mixed methods telemedicine study we are aware of that compares the views of rheumatology patients, rheumatology clinicians and GPs. The findings identified a place for telemedicine for certain patients, yet a strong overall preference for face-to-face

consultations on the part of both clinicians and patients. Telemedicine was widely perceived to reduce the accuracy of assessments and to impede the building of trusting medical relationships. Consistent with other studies [16], our study indicated that telemedicine was particularly unsuitable for initial rheumatological diagnoses. Contributing factors to the inaccurate assessments and multiple misdiagnoses reported with telemedicine included: no examinations, limited testing, increased patient reticence to report symptoms, and increased clinician difficulty in eliciting and identifying unspoken concerns without non-verbal cues. The importance of non-verbal communication in medical relationships has been widely reported [23–25], including eye-contact [26], expressive (to reassure or comfort) touch [27] and smiling [28]. In agreement with other studies [29] this lack of non-verbal interaction was found to be particularly detrimental to the eliciting and reporting of mental health concerns, although a minority of our participants (both clinician and patient) found it easier to discuss mental health and sensitive issues remotely. Demonstrations of listening and empathy, identified as of key importance to rheumatology patients in terms of satisfaction and behaviours [30–32], were perceived by our participants to be limited with telemedicine. This is in contrast to another study reporting that very few (<10%) clinicians and patients felt tele-rheumatology had a negative impact on the medical relationship [33].

Our study participants were mainly UK-based (96%), where telemedicine to date has been reported as often being the substitution of a face-to-face appointment with a telephone call [34], or less frequently a video call. This may partially explain why our findings were more negative towards telemedicine than studies on medical systems that utilize more visual telemedicine and/or integrate multiple remote methods of assessing and supporting patients [35, 36]. Indeed, Leggett *et al.* found a much higher level of diagnostic accuracy and satisfaction with video compared with telephone consultations [37], although interestingly our rheumatology clinicians had a strong preference for telephone over video consultations, possibly influenced by technology constraints and familiarity. Patients did not have an overall preference for whether remote consultations were by telephone or video.

The benefits of digital technology and integrated systems allowing prompt access to health data and communication between patients and clinicians across multiple disciplines and NHS trusts have yet to be realized in many areas. This is a source of inefficiency and frustration currently in the UK [38], and addressing it would greatly improve patient empowerment, satisfaction and self-management. Greater use of patient-initiated follow-up (PIFU) [39] may also reduce existing inefficiencies and sub-optimal care from the current dominant model of reviewing rheumatology patients according to timescales rather than disease activity. However, this study has demonstrated that a move towards further PIFU urgently requires improved

administrative systems in some rheumatology departments to ensure a prompt, appropriate response to the vast increase in patient-initiated contact. This is currently generating difficulties in managing work–life balance for some clinicians, and endangering and upsetting the many patients who report being unable to access care when required, as also found in studies at earlier stages of the pandemic [40, 41]. Our results indicate that telemedicine may have increased existing barriers to accessing medical support [42], such as inappropriate telephone triaging, and difficulties navigating administrative and reception systems [43]. The importance of prompt accessibility in a flare identified in our previous study [38] was repeatedly reiterated by senior rheumatologists in this study, as delays can cause permanent organ/joint damage and be fatal in the more severe cases [9].

We found no differences in preferences for telemedicine between disease groups. However, our participants with inflammatory arthritis had significantly higher confidence in a prompt response from their rheumatology department, higher ratings for medical security, and lower reductions in medical security during the pandemic than patients with lupus or other rare autoimmune rheumatic diseases, such as Sjögren's. This adds credence to the clinician participants' and authors' concerns that there are inequalities in care between rare and more common rheumatic diseases, and that telemedicine may increase these, and other inequalities. It is particularly important that proactive efforts [44] through policy ensure telemedicine does not increase existing health inequalities [45] and further disadvantage groups such as the elderly and those with communication challenges.

Aside from the obvious benefits of telemedicine reducing the risks of infection, additional benefits were identified. With a patient population often suffering from pain and fatigue [31, 46, 47], and long journeys to hospital, especially for tertiary care, the option of a telemedicine appointment was felt to be equally/more acceptable in some cases. This included for medication reviews or administrative queries, and for stable patients who are knowledgeable and secure in their pre-existing medical relationship(s). As previous studies also advise, individual choice [16] and careful patient selection for telemedicine will be essential to ensure safety and acceptability, and to alleviate concerns that telemedicine in the NHS is being instituted primarily as a cost and time-saving measure.

It is important to emphasize that our study patients all had autoimmune inflammatory rheumatic diseases and these patients often have more severe and/or unpredictable disease that may be less suited to telemedicine. A limitation of this study is that those with technological, communication or socio-economic barriers to accessing telemedicine are also less likely to participate in an online survey. This study's great strength was in eliciting multiple viewpoints from all sides of patient–clinician relationships, including patients with a variety of rheumatological

diseases. This, and combining of qualitative and quantitative data at each stage of the research, allowed for triangulation and helped address threats to validity and reliability. The many studies reporting the authors' own patients' high levels of satisfaction should be viewed with some caution due to the power differential and high risk of social desirability bias. Further strengths and limitations are summarized in [Supplementary Data S1](#), available at *Rheumatology* online.

It is probable that some of the negative perceptions of telemedicine, particularly relating to some access barriers and clinicians having less time, are partly influenced by ongoing Covid-19 pressure and the huge backlog of rheumatology patients requiring appointments, rather than telemedicine itself. Concerns and risks may lessen as remote consultation systems are improved, and the identified benefits for select patients are realized. However, it is unlikely that the serious concerns expressed by our participants regarding assessing complex rheumatological conditions remotely will be fully resolvable. This has implications for the telemedicine ambitions and plans of the UK and other health systems, and highlights the need for ongoing assessment and mitigation of the clinical risks associated with a telemedicine strategy.

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Data availability statement

Additional anonymized data may be made available on request.

Supplementary data

[Supplementary data](#) are available at *Rheumatology* online.

References

- Sharma E, Meade S, D'Errico F *et al*. The effects of COVID-19 on IBD prescribing and service provision in a UK tertiary centre. *GastroHep* 2020;2:318–26.
- Bateman J, Cleaton N. Managing patients using telerheumatology: lessons from a pandemic. *Best Pract Res Clin Rheumatol* 2021;35:101662.
- Bos WH, van Tubergen A, Vonkeman HE. Telemedicine for patients with rheumatic and musculoskeletal diseases during the COVID-19 pandemic; a positive experience in the Netherlands. *Rheumatol Int* 2021;41:565–73.
- Alexander GC, Tajanlangit M, Heyward J *et al*. Use and content of primary care office-based vs telemedicine care visits during the COVID-19 pandemic in the US. *JAMA Netw Open* 2020;3:e2021476.
- Cavagna L, Zanframundo G, Codullo V *et al*. Telemedicine in rheumatology: a reliable approach beyond the pandemic. *Rheumatology* 2021;60:366–70.
- NHS. 2021/22 priorities and operational planning guidance. <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0468-nhs-operational-planning-and-contracting-guidance.pdf> (26 June 2021, date last accessed).
- So H, Szeto C, Tam L. Patient acceptance of using telemedicine for follow-up of lupus nephritis in the COVID-19 outbreak. *Ann Rheum Dis* 2020;80:e97.
- Bozzalla Cassione E, Zanframundo G, Biglia A *et al*. Telemedicine: a useful tool but not the holy grail. Response to: 'Telemedicine will not keep us apart in the COVID-19 pandemic' by Perniola *et al*. *Ann Rheum Dis* 2020. doi: 10.1136/annrheumdis-2020-218071.
- Vymetal J, Skacelova M, Smrzova A *et al*. Emergency situations in rheumatology with a focus on systemic autoimmune diseases. *Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub* 2016;160:20–9.
- Sloan M, Bosley M, Blane M *et al*. 'But you don't look sick': a qualitative analysis of the LUPUS UK online forum. *Rheumatol Int* 2021;41:721–32.
- McDougall JA, Ferucci ED, Glover J, Fraenkel L. Telerheumatology: a systematic review. *Arthritis Care Res* 2017;69:1546–57.
- Santos-Moreno P, Chavez-Chavez J, Hernández-Zambrano SM *et al*. Experience of telemedicine use in a big cohort of patients with rheumatoid arthritis during COVID-19 pandemic. *Ann Rheum Dis* 2020; doi: 10.1136/annrheumdis-2020-218193
- Fardanesh A, Byravan S, Moorthy A, Tahir H. COVID-19 and rheumatology: reflecting on the first wave and preparing for the second wave. *Int J Rheum Dis* 2021;24:7–9.
- Piga M, Cangemi I, Mathieu A, Cauli A. Telemedicine for patients with rheumatic diseases: systematic review and proposal for research agenda. *Semin Arthritis Rheum* 2017;47:121–8.
- Matsumoto RA, England BR, Mastarone G *et al*. Rheumatology clinicians' perceptions of telerheumatology within the Veterans Health Administration: a national survey study. *Mil Med* 2020;185:e2082–e2087.

- 16 Matsumoto RA, Barton JL. Telerheumatology: before, during, and after a global pandemic. *Curr Opin Rheumatol* 2021;33:262–9.
- 17 Zhang Y, Wang J, Zhao L, Xiao J, Shi Z. Online management of rheumatoid arthritis during COVID-19 pandemic. *Ann Rheum Dis* 2021;80:e4.
- 18 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 19 Cresswell J, Clark V. Designing and conducting mixed methods research. London, UK: Sage, 2017.
- 20 Seale C. The quality of qualitative research. London: SAGE Publications Ltd, 1999: doi:10.4135/9780857020093.
- 21 Birt L, Scott S, Cavers D, Campbell C, Walter F. Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qual Health Res* 2016;26:1802–11.
- 22 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 23 Henry BW, Block DE, Ciesla JR, McGowan BA, Vozenilek JA. Clinician behaviors in telehealth care delivery: a systematic review. *Adv Health Sci Educ Theory Pract* 2017;22:869–88.
- 24 Giroldi E, Timmerman A, Veldhuijzen W *et al*. How doctors recognise that their patients are worried: a qualitative study of patient cues. *Patient Educ Couns* 2020;103:220–5.
- 25 Riess H, Kraft-Todd G. E.M.P.A.T.H.Y.: a tool to enhance nonverbal communication between clinicians and their patients. *Acad Med* 2014;89:1108–12.
- 26 MacDonald K. Patient-clinician eye contact: social neuroscience and art of clinical engagement. *Postgrad Med* 2009;121:136–44.
- 27 Kelly MA, Gormley GJ. In, but out of touch: connecting with patients during the virtual visit. *Ann Fam Med* 2020;18:461–2.
- 28 Beamish AJ, Foster JJ, Edwards H, Olbers T. What's in a smile? A review of the benefits of the clinician's smile. *Postgrad Med J* 2019;95:91–5.
- 29 Liberati E, Richards N, Parker J *et al*. Remote care for mental health: qualitative study with service users, carers and staff during the COVID-19 pandemic. *BMJ Open* 2021;11:e049210.
- 30 Sloan M, Lever E, Gordon C *et al*. Medication decision-making and adherence in lupus: patient-physician discordance and the impact of previous 'Adverse Medical Experiences'. *Rheumatology* 2021; keab534.
- 31 Sloan M, Harwood R, Sutton S *et al*. Medically explained symptoms: a mixed methods study of diagnostic, symptom and support experiences of patients with lupus and related systemic autoimmune diseases. *Rheumatol Adv Pract* 2020;4:rkaa006.
- 32 Georgopoulou S, Prothero L, D'Cruz DP. Physician-patient communication in rheumatology: a systematic review. *Rheumatol Int* 2018;38:763–75.
- 33 Kernder A, Morf H, Klemm P *et al*. Digital rheumatology in the era of COVID-19: results of a national patient and physician survey. *RMD Open* 2021; 7:e001548.
- 34 Murphy M, Scott LJ, Salisbury C *et al*. Implementation of remote consulting in UK primary care following the COVID-19 pandemic: a mixed-methods longitudinal study. *Br J Gen Pract* 2021;71:e166–e177.
- 35 Müskens W, Rongen-van Dartel S, Vogel C *et al*. Telemedicine in the management of rheumatoid arthritis: maintaining disease control with less health-care utilization. *Rheumatol Adv Pract* 2021;5:rkaa079.
- 36 Hasson SP, Waissengrin B, Shachar E *et al*. Rapid implementation of telemedicine during the COVID-19 pandemic: perspectives and preferences of patients with cancer. *Oncologist* 2021;26:e679–e685.
- 37 Leggett P, Graham L, Steele K *et al*. Telerheumatology—diagnostic accuracy and acceptability to patient, specialist, and general practitioner. *Br J Gen Pract* 2001;51:746–8.
- 38 Sloan M, Naughton F, Harwood R *et al*. Is it me? The impact of patient-physician interactions on lupus patients' psychological well-being, cognition and health-care-seeking behaviour. *Rheumatol Adv Pract* 2020;4:rkaa037.
- 39 Bech B, Lykkegaard JJ, Lundbak T *et al*. Patient-Initiated Follow-Up (PIFU) as reorganized support for increased patient involvement - focus group discussions among patients' with inflammatory arthritis. *BMC Rheumatol* 2020;4:44.
- 40 RAIRDA. Chronic crisis. The impact on COVID-19 on people with rare autoimmune rheumatic diseases. The Rare Autoimmune Rheumatic Disease Alliance. rairdaorg.files.wordpress.com.
- 41 Sloan M, Gordon C, Harwood R *et al*. The impact of the COVID-19 pandemic on the medical care and health-care behaviour of patients with lupus and other systemic autoimmune diseases: a mixed methods longitudinal study. *Rheumatol Adv Pract* 2021;5:rkaa072.
- 42 Ford JA, Turley R, Porter T *et al*. Access to primary care for socio-economically disadvantaged older people in rural areas: A qualitative study. *PLoS One* 2018;13: e0193952.
- 43 Arber S, Sawyer L. The role of the receptionist in general practice: a 'dragon behind the desk'? *Soc Sci Med* 1985;20:911–21.
- 44 Nouri S, Khoong EC, Lyles CR, Karliner L. Addressing equity in telemedicine for chronic disease management during the covid-19 pandemic. *NEJM Catalyst* 2020 <https://catalyst.nejm.org/doi/full/10.1056/CAT.20.0123>.
- 45 Sirolich E, Hausmann JS. Removing barriers and disparities in health: lessons from the COVID-19 pandemic. *Nat Rev Rheumatol* 2021;17:125–6.
- 46 Gudu T, Gossec L. Quality of life in psoriatic arthritis. *Expert Rev Clin Immunol* 2018;14:405–17.
- 47 Pope JE. Management of fatigue in rheumatoid arthritis. *RMD Open* 2020;6:e001084.