




## Original article

# The effect of COVID-19 public health restrictions on the health of people with musculoskeletal conditions and symptoms: the CONTAIN study

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## Abstract

**Objective.** To quantify the change in quality of life, disease-specific indicators, health and lifestyle before and during the COVID-19 pandemic among people with musculoskeletal diagnoses and symptoms.

**Methods.** We undertook an additional follow-up of two existing UK registers involving people with axial spondyloarthritis (axSpA) or psoriatic arthritis (PsA) and participants in a trial in the UK who had regional pain and were identified at high risk of developing chronic widespread pain. Participants completed the study questionnaire between July and December 2020, throughout which time there were public health restrictions in place.

**Results.** The number of people taking part in the study was 1054 (596 axSpA, 162 PsA, 296 regional pain). In comparison with their previous (pre-pandemic) assessment, there was an age-adjusted significant, small decrease in quality of life measured by EQ-5D [−0.020 (95% CI −0.030, −0.009)] overall and across all population groups examined. This was primarily related to poorer mental health and pain. There was a small increase in fibromyalgia symptoms, but a small decrease in sleep problems. There was a small deterioration in axSpA disease activity, and disease-specific quality of life and anxiety in PsA participants. Predictors of poor quality of life were similar pre- and during the pandemic. The effect of lockdown on activity differed according to age, gender and deprivation.

**Conclusion.** Important lessons include focusing on addressing anxiety and providing enhanced support for self-management in the absence of normal health care being available, and awareness that all population groups are likely to be affected.

**Key words:** COVID-19, axial spondyloarthritis, psoriatic arthritis, pain, quality of life

### Rheumatology key messages

- Lockdown has resulted in decreased self-reported quality of life amongst people with musculoskeletal conditions and symptoms.
- Deterioration in some disease-specific measures and impacts on health were noted across most population sub-groups.
- There were negative and positive effects on ability to take physical activity (variable by group).

## Introduction

The COVID-19 pandemic resulted in unprecedented changes to the life of people throughout the world during 2020. Although specific measures varied according

to country, generally public health measures were put in place across a very short space of time around March, to reduce the spread of the virus. In the United Kingdom, from 23 March 2020 measures were put in place that confined most people to their home and

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Submitted 17 March 2021; accepted 19 April 2021

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meant they were only able to leave for a limited number of reasons and people identified as ‘vulnerable’ were advised to ‘shield’ in their home. Subsequent to the national lockdown, there was a gradual easing of restrictions beginning in May 2020, but with a rise in the number of cases of infection due to COVID-19 at the end of August 2020 there was then a series of local and national (specific to England, Scotland, Wales and Northern Ireland) public health restrictions put in place which have remained into 2021.

Musculoskeletal health can be supported and maintained by physical activity and getting an adequate duration and quality of sleep. Related to these factors, poor mental health is an important determinant of reduced health-related quality of life [1] and a marker for poor disease outcome in both pain [2, 3] and inflammatory arthritis [4]. Individuals’ mental health may have been affected by the amount of time required to be spent at home and the resulting social isolation, as well as anxiety around the pandemic and concerns about health. Most people in work will have experienced important changes: some working in stressful circumstances, others making the transition to home working while some may either have been furloughed or lost their job. An interim report of a survey by the Institute of Employment Studies, involving 500 people working at home, reported a significant increase in musculoskeletal complaints [5]. More than half of respondents said they were exercising less, while around two-thirds reported loss of sleep due to worry.

While many research studies chose to undertake *ad hoc* surveys of convenience samples of people, we undertook additional follow-ups of well-characterized groups with musculoskeletal conditions and symptoms. Future reports from the study will consider impact on health service usage and experience of healthcare received, and impact on work. This analysis is focused on the health of respondents during the public health restrictions associated with the pandemic and specifically how this had changed since they were previously surveyed.

## Methods

The CONTAIN (COvid-19 aNd musculoskeletal health during lockdown) study re-surveyed three cohorts of patients with musculoskeletal disease or symptoms using a questionnaire comprising existing validated instruments and questions specific to their experience during the COVID-19 pandemic. The cohorts were patients with axial spondyloarthritis (BSRBR-AS) [6], psoriatic arthritis (BSR-PsA) (protocol: <https://osf.io/jzs8n>) and patients with regional musculoskeletal pain who were at risk of chronic widespread pain and enrolled in the MAmMOTH randomized controlled trial [7]. Further details of the study cohorts are given in the [Supplementary text](#), available at *Rheumatology* online.

All potential participants received a letter by post (or an email if details were available) over the period June–

July 2020. Those who received an email but did not respond were then sent a letter by post. The communication explained about the study and invited recipients to go online to access the patient information sheet, consent to participate and complete the study questionnaire, which was specific to their cohort. For those people who wished to participate but were unable to complete the questionnaire online, we provided email and telephone contact details to request a mailed questionnaire. When we were able to do so (from mid-July 2020), these were sent out. Reminder letters were sent by post from September 2020.

The questionnaire asked about demographic and employment information, and deprivation was computed with reference to the population of either Scotland [8], England [9] or Wales [10], and, along with the classification of residence as urban or rural, was determined by participants’ post codes. Common across all three cohorts, the questionnaire collected health information including quality of life (EQ-5D-5L) [11], sleep problems [12], quantitative measurement of fibromyalgia symptoms through the fibromyalgia severity (FS) score from the 2011 research criteria [13] and questions in relation to COVID-19. There were also specific questionnaires for individual cohorts:

BSRBR-AS: quality of life (ASQoL) [14], disease activity (BASDAI) [15] and function (BASFI) [16]; and

BSR-PsA: quality of life (PsAQoL) [17], depression and anxiety (PROMIS) [18], and physical activity (IPAQ) [19].

Details of the instruments and scoring is given in the [Supplementary text](#), available at *Rheumatology* online.

Ethical approval for CONTAIN was obtained through applying for substantial amendments to the ethical approvals for each original study. The ethics approval for MAmMOTH was from NRES Committee South West (Cornwall and Plymouth, Reference 16/SW/0019), for BSRBR-AS from NRES Committee North East (County Durham and Tees Valley, Reference 11/NE/0374) and for BSR-PsA from West of Scotland REC 3 (Reference 18/WS/0126). Informed consent was given by participants. Patient and patient organization input was obtained in relation to items asked in the questionnaire and through review of study documentation.

## Analysis

To examine the change in measures from the last survey time point, mixed effects regression models were used, with individual participant as a random effect. Only participants who had the measure available at each time point were included in these analyses. For EQ-5D-5L, the Jenkins Sleep Problem Scale, fibromyalgia severity, ASQoL, BASDAI, BASFI, PROMIS Anxiety, PROMIS Depression and PSAQOL, mixed effects linear regression was used. For changes in the individual items of the EQ-5D-5L and in IPAQ category, mixed effects ordinal logistic regression and mixed effects multinomial logistic regression were used, respectively. Analyses were first carried out for the whole sample, then stratified by demographic characteristics and clinical

characteristics. Analyses were adjusted for age at time of data collection, and appropriate effect sizes reported with 95% CIs: mean difference for linear regression, odds ratios (ORs) for logistic and ordinal logistic regression, and multinomial odds ratios (MORs) for multinomial logistic regression. In order to examine for the effects of non-participation by age, gender, deprivation and study cohort, a weighted analysis was run with weights determined by the inverse of the probability of people in these population sub-groups participating in the CONTAIN study.

To examine predictors of EQ-5D-5L, two linear regression models were run, one for pre-pandemic predictors of pre-pandemic EQ-5D-5L and the other for pre-pandemic predictors of current EQ-5D-5L. Regression coefficients with 95% CIs were reported. To provide an estimate of the size of the difference in association between these time points, a mixed effects linear regression was carried out for each predictor with an interaction between the predictor and the time point (previous time point or current survey). The interaction term is reported with 95% CIs.

The analysis uses the 14 December 2020 version of the database; all analyses were conducted using Stata SE 15.1 (StataCorp, College Station, TX, USA).

## Results

A total of 1054 people who filled in a study questionnaire were included in the analysis (596 from BSRBR-AS, 162 from BSR-PsA and 296 from MAmMOTH), representing 29% of those invited (27% from BSRBR-AS, 26% from BSR-PsA and 33% from MAmMOTH). Among the respondents 43% completed the questionnaire in July 2020, 25% in August–September and 32% in October–December. The median time since last follow-up was 1002 days for BSRBR-AS participants, 249.5 days for BSR-PsA and 635 days for MAmMOTH. Overall, the median age of participants was 59 years (inter-quartile range: 47–69 years), 55% were male, while 50% reported that they were in full- or part-time work and 34% were retired. Thirty per cent of the sample were (based on their postcode) resident in an area classified as rural while the sample over-represented those with low levels of deprivation (58% were in the lowest two quintiles of deprivation). Of the 523 respondents who reported that they were in paid employment, 205 identified themselves as a ‘key worker’, while a total of 390 (37%) respondents indicated that they had been advised to shield. Only 1.6% of respondents stated that they had had COVID-19, a further 8.4% reported that they had had COVID-19-related symptoms and 10.1% were unsure if they had had COVID-19-related symptoms; the vast majority of respondents (75.2%) reported that they had not had COVID-19-related symptoms.

In comparison with the previous assessment, there was an age-adjusted significant decrease in quality of life [EQ-5D-5L age-adjusted mean difference (MD)  $-0.020$  (95% CI:  $-0.030$ ,  $-0.009$ )]. This was noted

across all age groups, among males and females, and across all levels of deprivation, time periods of completion and work status, although not all were statistically significant (Table 1). Analysis of the individual components of EQ-5D-5L demonstrated different effects across domains. There was no difference in relationship to mobility and self-care but, after age-adjustment, respondents were significantly more likely to report higher levels of pain/discomfort and anxiety/depression in comparison with the previous follow-up [age-adjusted OR 1.63 (95% CI: 1.35, 1.96) and 1.79 (95% CI: 1.46, 2.18), respectively] (Table 2). Over all respondents there was a worsening of fibromyalgia severity score [age-adjusted MD 0.42 (95% CI: 0.18–0.66)], and this worsening was noted in both males and females, among those resident in areas of low and high deprivation, with the largest change in the early period of follow-up (Table 3). In contrast there was a small but significant reduction in sleep problems over all respondents [age-adjusted MD  $-0.52$  (95% CI:  $-0.81$ ,  $-0.22$ )]. This was noted in both males and females, across all age groups, deprivation categories, study cohort and time period of completion (Table 4).

In the two disease cohorts, we examined additional disease-specific measures as follows.

### Axial spondyloarthritis

There were no consistent or important age-adjusted differences in terms of disease-specific quality of life (as measured by ASQoL) [age-adjusted MD 0.02 (95% CI:  $-0.28$ , 0.33)]. There was also no consistent changes in population sub-groups although it was noted that there was relative improvement of disease-specific quality of life over the period of the study (Table 5A). Disease activity increased by a small amount [BASDAI age-adjusted MD 0.13 (95% CI:  $-0.03$ , 0.29)], with the largest increase in those resident in areas with the highest levels of deprivation [0.31 (95% CI:  $-0.09$ , 0.71)] and in those followed up at the earliest time point [0.23 (95% CI: 0.01, 0.46)], although only the latter was statistically significant (Supplementary Table A, available at *Rheumatology* online). There were no important changes in function [BASFI age-adjusted MD  $-0.05$  (95% CI:  $-0.19$ , 0.09)] overall or in any population sub-group (Supplementary Table B, available at *Rheumatology* online).

### Psoriatic arthritis

There was a significant worsening of quality of life, as measured by the PsAQoL, with an age-adjusted mean difference of 0.75 (95% CI: 0.19, 1.30); the worsening was mainly observed in those who were advised to, and followed, shielding guidance and those living in urban settings (Table 5B). There were no important or significant changes in depression since the last follow-up either overall [PROMIS Depression age-adjusted MD 0.7 (95% CI:  $-0.6$ , 1.9)] or in population subgroups (Supplementary Table C, available at *Rheumatology*

TABLE 1 Changes in EQ-5D-5L

Domain and categories	<i>n</i>	Previous time point, mean (s.d.)	CONTAIN survey, mean (s.d.)	Mean difference (95% CI)	Age-adjusted mean difference (95% CI)
All participants	1020	0.684 (0.209)	0.664 (0.219)	<b>-0.021 (-0.032, -0.009)</b>	<b>-0.020 (-0.030, -0.009)</b>
Year of birth					
1924–1945	125	0.664 (0.221)	0.625 (0.253)	<b>-0.039 (-0.060, -0.009)</b>	
1946–1964	477	0.685 (0.208)	0.668 (0.203)	-0.017 (-0.033, 0.002)	
1965–1980	292	0.693 (0.210)	0.677 (0.221)	-0.016 (-0.036, 0.004)	
1981–2001	126	0.685 (0.199)	0.658 (0.239)	-0.026 (-0.065, 0.013)	
Gender					
Female	461	0.695 (0.197)	0.666 (0.200)	<b>-0.029 (-0.045, -0.012)</b>	<b>-0.029 (-0.045, -0.013)</b>
Male	557	0.676 (0.218)	0.662 (0.234)	-0.014 (-0.029, 0.001)	-0.013 (-0.028, 0.002)
Study cohort					
BSRBR-AS	578	0.659 (0.224)	0.652 (0.231)	-0.007 (-0.023, 0.009)	-0.004 (-0.021, 0.012)
MAMMOTH	288	0.744 (0.159)	0.701 (0.190)	<b>-0.043 (-0.059, -0.026)</b>	<b>-0.040 (-0.057, -0.023)</b>
BSR-PsA	154	0.667 (0.210)	0.639 (0.220)	<b>-0.029 (-0.054, -0.003)</b>	<b>-0.030 (-0.056, -0.005)</b>
Deprivation					
1 (most deprived)	90	0.578 (0.256)	0.580 (0.262)	0.003 (-0.038, 0.043)	0.003 (-0.039, 0.044)
2	129	0.642 (0.237)	0.609 (0.254)	-0.033 (-0.068, 0.001)	-0.028 (-0.063, 0.007)
3	205	0.687 (0.209)	0.660 (0.220)	-0.026 (-0.054, 0.001)	-0.024 (-0.052, 0.004)
4	307	0.702 (0.180)	0.677 (0.210)	<b>-0.025 (-0.042, -0.007)</b>	<b>-0.024 (-0.042, -0.006)</b>
5 (least deprived)	289	0.716 (0.195)	0.703 (0.184)	-0.013 (-0.033, 0.006)	-0.014 (-0.033, 0.007)
Employment					
Full-time	361	0.717 (0.181)	0.707 (0.180)	-0.010 (-0.029, 0.009)	-0.015 (-0.034, 0.004)
Part-time	145	0.703 (0.186)	0.679 (0.195)	-0.024 (-0.050, 0.002)	-0.024 (-0.050, 0.003)
Retired	356	0.698 (0.192)	0.680 (0.202)	<b>-0.018 (-0.035, -0.0002)</b>	-0.014 (-0.032, 0.005)
Other	150	0.555 (0.274)	0.506 (0.288)	<b>-0.049 (-0.084, -0.015)</b>	<b>-0.047 (-0.082, -0.011)</b>
Urban/rural					
Urban	713	0.678 (0.218)	0.654 (0.227)	<b>-0.024 (-0.037, -0.011)</b>	<b>-0.023 (-0.036, -0.009)</b>
Rural	307	0.700 (0.186)	0.688 (0.199)	-0.012 (-0.032, 0.007)	-0.013 (-0.033, 0.007)
Shielding					
Advised and followed	337	0.624 (0.228)	0.604 (0.226)	-0.021 (-0.043, 0.002)	-0.021 (-0.044, 0.001)
Not advised or not followed	647	0.718 (0.189)	0.697 (0.209)	<b>-0.021 (-0.033, -0.008)</b>	<b>-0.021 (-0.034, -0.008)</b>
Date of completion					
July	436	0.698 (0.205)	0.675 (0.199)	<b>-0.022 (-0.038, -0.007)</b>	<b>-0.024 (-0.040, -0.009)</b>
Aug–Sep	257	0.662 (0.220)	0.639 (0.245)	-0.023 (-0.048, 0.001)	-0.022 (-0.047, 0.004)
Oct–Dec	327	0.684 (0.203)	0.669 (0.223)	-0.015 (-0.034, 0.004)	-0.013 (-0.032, 0.007)

Values in bold are statistically significant.

online). In contrast there was a significant increase in anxiety overall [PROMIS anxiety age-adjusted MD 1.7 (95% CI: 0.5, 2.9)], with the greatest increases in anxiety noted in the oldest age group (over 75 years), those resident in the most affluent areas and in the last follow-up period (Supplementary Table D, available at *Rheumatology* online). Since their previous assessment, while there was a small increase in the number of participants who had low levels of physical activity or were inactive as assessed by the IPAQ [37% vs 32%, age-adjusted OR vs moderate activity 1.78 (95% CI: 0.78, 4.11)], there was a much larger (and statistically significant) increase in the proportion classified as highly active [31% vs 20%, age-adjusted OR 2.54 (95% CI: 1.14, 5.67)]. In comparison with previous assessments, high levels of activity were particularly noted in females [age-adjusted MOR 3.88 (95% CI: 1.17, 12.85)] and low

levels of activity in those resident in areas with the greatest levels of deprivation [age-adjusted MOR 5.27 (95% CI: 1.27, 21.97)] and in the earliest follow-up period (Supplementary Table E, available at *Rheumatology* online).

#### Weighted analysis

Taking account of non-participation by age, gender and deprivation had little effect on the estimates of change. Specifically, the deterioration in EQ-5D [-0.021 (95% CI: -0.035, -0.008)], increase in fibromyalgia severity [0.38 (95% CI: 0.11, -0.64)] and PROMIS anxiety score [1.57 (95% CI: 0.20, 2.95)] remained and were of a similar magnitude, as was the reduction in sleep problems [-0.57 (95% CI: -0.89, -0.25)]. The worsening of disease activity in patients with axSpA was marginally

TABLE 2 Changes in EQ-5D-5L domains

EQ-5D domain	Previous assessment, n (%)	CONTAIN survey, n (%)	OR (95% CI)	Age-adjusted OR (95% CI)
Mobility				
No problems	472 (46.0)	487 (47.5)	1.02 (0.84, 1.24)	0.93 (0.76, 1.13)
Slight problems	310 (30.2)	277 (27.0)		
Moderate problems	167 (16.3)	176 (17.2)		
Severe problems	71 (6.9)	80 (7.8)		
Unable to walk	6 (0.6)	6 (0.6)		
Self-care				
No problems	751 (73.2)	752 (73.3)	1.08 (0.84, 1.39)	1.03 (0.80, 1.33)
Slight problems	184 (17.9)	178 (17.4)		
Moderate problems	77 (7.5)	71 (6.9)		
Severe problems	10 (1.0)	23 (2.2)		
Unable to wash and dress	4 (0.4)	2 (0.2)		
Usual activities				
No problems	431 (41.9)	452 (44.0)	1.01 (0.84, 1.22)	0.97 (0.80, 1.17)
Slight problems	368 (35.8)	332 (32.3)		
Moderate problems	177 (17.2)	176 (17.1)		
Severe problems	41 (4.0)	57 (5.5)		
Unable to do	11 (1.1)	11 (1.1)		
Pain/discomfort				
No pain or discomfort	130 (12.7)	96 (9.3)	1.65 (1.37, 1.99)	<b>1.63 (1.35, 1.96)</b>
Slight pain or discomfort	498 (48.4)	464 (45.1)		
Moderate pain or discomfort	303 (29.5)	343 (33.4)		
Severe pain or discomfort	85 (8.3)	104 (10.1)		
Extreme pain or discomfort	12 (1.2)	21 (2.0)		
Anxiety/depression				
Not anxious or depressed	518 (50.4)	437 (42.6)	1.65 (1.36, 2.00)	<b>1.79 (1.46, 2.18)</b>
Slightly anxious or depressed	332 (32.3)	373 (36.3)		
Moderately anxious or depressed	141 (13.7)	178 (17.3)		
Severely anxious or depressed	28 (2.7)	30 (2.9)		
Extremely anxious or depressed	8 (0.8)	9 (0.9)		

OR: odds ratio. Values in bold are statistically significant.

higher and the deterioration was statistically significant [0.18 (95% CI: 0.01, 0.36)].

### Predictors of poor quality of life during the pandemic

Three analyses in relation to poor quality of life are reported in Table 6: using pre-pandemic data to predict pre-pandemic quality of life; using pre-pandemic and pandemic data to predict pandemic quality of life; and an analysis looking at the change of strength of association between a factor and pre-pandemic and pandemic quality of life. The relationship of factors with poor quality of life is very similar pre- and during the pandemic: sleep problems, living in areas with high levels of deprivation, and low levels of physical activity (which could be examined only in PsA). In the mixed effects model (model 3 in Table 6), which included an interaction term for strength of relationship, the only factor showing a change in relationship

was that being a member of the MAMMOTH cohort (i.e. being at risk of developing chronic widespread pain) was associated with relatively poorer quality of life during the pandemic.

### Discussion

There was a small detrimental effect on quality of life for people with musculoskeletal conditions and symptoms during the period of public health restrictions in the UK due to COVID-19. The decrease in quality of life was principally related to mental health and pain, and in the cohort for which more detailed information was available on mental health (participants with PsA), this was specifically related to higher levels of anxiety. Participants with PsA reported a decrease in disease specific quality of life while there was an increase in disease activity in participants with axSpA. Factors influencing poor quality of life, and their importance, were similar pre- and

TABLE 3 Change in fibromyalgia severity score

Domain and categories	n	Previous time point, mean (s.d.)	CONTAIN survey, mean (s.d.)	Mean difference (95% CI)	Age-adjusted mean difference (95% CI)
All participants	952	8.55 (5.29)	8.84 (5.08)	<b>0.29 (0.05, 0.52)</b>	<b>0.42 (0.18, 0.66)</b>
Year of birth					
1924–1945	116	7.48 (5.01)	8.02 (4.63)	0.53 (–0.04, 1.11)	
1946–1964	440	8.00 (4.93)	8.49 (4.86)	<b>0.48 (0.15, 0.82)</b>	
1965–1980	272	8.83 (5.15)	9.08 (5.16)	0.25 (–0.22, 0.72)	
1981–2001	124	10.9 (6.35)	10.3 (5.72)	–0.56 (–1.24, 0.11)	
Gender					
Female	434	9.32 (5.24)	9.59 (5.17)	0.27 (–0.07, 0.61)	<b>0.41 (0.06, 0.75)</b>
Male	516	7.90 (5.26)	8.20 (4.92)	0.30 (–0.02, 0.63)	<b>0.41 (0.07, 0.74)</b>
Study cohort					
BSRBR-AS	527	9.26 (5.55)	9.09 (5.15)	–0.17 (–0.50, 0.16)	–0.03 (–0.37, 0.31)
MAMMOTH	280	6.61 (3.87)	7.66 (4.18)	<b>1.05 (0.69, 1.42)</b>	<b>1.10 (0.73, 1.46)</b>
BSR-PsA	145	9.72 (5.76)	10.19 (5.90)	0.47 (–0.17, 1.11)	0.53 (–0.12, 1.17)
Deprivation					
1 (most deprived)	84	10.55 (6.40)	10.74 (6.10)	0.19 (–0.62, 1.01)	0.41 (–0.42, 1.25)
2	113	8.95 (5.08)	9.39 (5.11)	0.44 (–0.28, 1.16)	0.40 (–0.34, 1.13)
3	197	9.29 (5.44)	9.10 (5.05)	–0.19 (–0.73, 0.34)	–0.08 (–0.63, 0.46)
4	289	8.12 (5.13)	8.57 (4.86)	<b>0.46 (0.05, 0.86)</b>	<b>0.58 (0.16, 0.99)</b>
5 (least deprived)	269	7.68 (4.83)	8.10 (4.79)	0.42 (–0.02, 0.86)	<b>0.59 (0.15, 1.04)</b>
Employment					
Full-time	343	8.76 (5.30)	8.64 (4.88)	–0.13 (–0.53, 0.28)	0.13 (–0.29, 0.55)
Part-time	134	8.91 (4.92)	9.32 (4.85)	0.41 (–0.22, 1.04)	0.48 (–0.17, 1.14)
Retired	331	7.14 (4.73)	7.75 (4.50)	<b>0.61 (0.24, 0.98)</b>	<b>0.61 (0.21, 1.00)</b>
Other	134	11.13 (5.98)	11.62 (6.06)	0.49 (–0.16, 1.14)	0.61 (–0.05, 1.28)
Urban/Rural					
Urban	667	8.64 (5.40)	8.98 (5.26)	<b>0.34 (0.06, 0.62)</b>	0.46 (0.17, 0.74)
Rural	285	8.34 (5.04)	8.50 (4.62)	0.16 (–0.27, 0.59)	0.36 (–0.08, 0.79)
Shielding					
Advised and followed	307	10.12 (5.56)	10.21 (5.14)	0.09 (–0.36, 0.54)	0.28 (–0.17, 0.74)
Not advised or not followed	611	7.72 (5.02)	8.11 (4.89)	<b>0.39 (0.11, 0.67)</b>	<b>0.52 (0.24, 0.80)</b>
Date of completion					
July	403	7.94 (5.02)	8.53 (4.58)	<b>0.59 (0.25, 0.94)</b>	<b>0.74 (0.39, 1.09)</b>
Aug–Sep	238	9.77 (5.72)	9.78 (5.87)	0.00 (–0.48, 0.49)	0.17 (–0.32, 0.67)
Oct–Dec	311	8.41 (5.16)	8.51 (4.95)	0.11 (–0.32, 0.54)	0.21 (–0.22, 0.64)

Values in bold are statistically significant.

during the pandemic. In contrast there were small improvements in sleep reported overall, while there were both improvements (in females, and at older ages) and deterioration (those resident in areas of high deprivation) in the amount of exercise reported during the restrictions.

Many studies of ill-health during COVID-19 were conducted by means of *ad hoc* internet surveys promoted through social media (e.g. [20, 21]). Although these can provide useful information [22], it is difficult for them to assess the magnitude of effects due to recall and being highly selective in terms of people participating. Our study had the advantage of prospective collection of information before the COVID-19 pandemic and during restrictions. Nevertheless, the time period since last follow-up varied considerably between and

within studies. Secondly, the 6 months over which the study was conducted represented different levels of restrictions and also varied depending on where participants lived. Thus, our data need to be interpreted in the general context of restrictions over this period. Thirdly, our patient and patient organization partners commented to us at the time of designing the survey that there was a perceived ‘survey fatigue’ among patients because of the number of internet surveys that were being conducted during the course of the pandemic—and indeed this proved to be the case as participation was relatively low and caused us to issue an (initially unplanned) reminder. This was an issue experienced by others such as Smith *et al.* [23] who reported a 19% participation rate among patients registered in the Norfolk Arthritis Register (NOAR) when approached

TABLE 4 Changes in Jenkins sleep problem scale score

Domain and categories	n	Previous time point, mean (s.d.)	CONTAIN survey, mean (s.d.)	Mean difference (95% CI)	Age-adjusted mean difference (95% CI)
All participants	927	9.01 (5.52)	8.39 (4.70)	<b>-0.62 (-0.91, -0.033)</b>	<b>-0.52 (-0.81, -0.22)</b>
Year of birth					
1924–1945	103	8.08 (5.32)	6.99 (3.92)	<b>-1.09 (-1.98, -0.20)</b>	
1946–1964	424	8.88 (5.58)	8.24 (4.70)	<b>-0.64 (-1.07, -0.21)</b>	
1965–1980	272	9.23 (5.62)	8.94 (4.97)	-0.29 (-0.81, 0.24)	
1981–2001	128	9.68 (5.22)	8.23 (4.47)	<b>-0.85 (-1.65, -0.05)</b>	
Gender					
Female	422	9.51 (5.33)	9.03 (4.61)	<b>-0.48 (-0.91, -0.05)</b>	-0.41 (-0.84, 0.03)
Male	503	8.58 (5.66)	7.87 (4.72)	<b>-0.71 (-1.11, -0.32)</b>	<b>-0.61 (-1.01, -0.21)</b>
Study cohort					
BSRBR-AS	528	8.99 (5.83)	8.31 (4.83)	<b>-0.68 (-1.07, -0.29)</b>	<b>-0.53 (-0.94, -0.13)</b>
MAMMOTH	264	8.71 (4.96)	8.19 (4.45)	-0.53 (-1.07, 0.02)	-0.49 (-1.03, 0.06)
BSR-PsA	135	9.62 (5.34)	9.07 (4.66)	-0.55 (-1.23, 0.14)	-0.50 (-1.19, 0.19)
Deprivation					
1 (most deprived)	79	10.19 (5.99)	9.05 (5.19)	<b>-1.14 (-2.24, -0.03)</b>	-0.90 (-2.02, 0.21)
2	122	9.28 (5.98)	8.30 (4.86)	<b>-0.99 (-1.84, -0.13)</b>	<b>-1.00 (-1.86, -0.13)</b>
3	190	9.62 (5.47)	8.96 (4.79)	<b>-0.66 (-1.27, -0.05)</b>	<b>-0.62 (-1.24, -0.004)</b>
4	278	8.83 (5.35)	8.23 (4.36)	-0.51 (-1.04, 0.03)	-0.37 (-0.91, 0.17)
5 (least deprived)	258	8.25 (5.29)	7.88 (4.73)	-0.37 (-0.90, 0.16)	-0.28 (-0.81, 0.26)
Employment					
Full-time	332	8.95 (5.49)	8.51 (4.78)	-0.45 (-0.94, 0.04)	-0.40 (-0.90, 0.11)
Part-time	135	9.41 (5.41)	8.81 (4.37)	-0.60 (-1.35, 0.15)	-0.49 (-1.25, 0.27)
Retired	306	8.04 (5.23)	7.20 (4.14)	<b>-0.84 (-1.35, -0.34)</b>	<b>-0.74 (-1.26, -0.21)</b>
Other	139	11.06 (5.85)	10.34 (5.19)	<b>-0.72 (-1.44, -0.003)</b>	-0.64 (-1.38, 0.09)
Urban/rural					
Urban	646	8.99 (5.68)	8.28 (4.81)	<b>-0.71 (-1.06, -0.36)</b>	<b>-0.62 (-0.97, -0.27)</b>
Rural	281	9.04 (5.15)	8.64 (4.45)	-0.40 (-0.93, 0.13)	-0.27 (-0.80, 0.27)
Shielding					
Advised and followed	297	9.75 (5.75)	8.99 (4.85)	<b>-0.76 (-1.26, -0.26)</b>	<b>-0.59 (-1.09, -0.08)</b>
Not advised or not followed	595	8.61 (5.37)	8.08 (4.61)	<b>-0.53 (-0.90, -0.15)</b>	<b>-0.46 (-0.84, -0.08)</b>
Date of completion					
July	395	8.69 (5.52)	8.31 (4.78)	-0.38 (-0.82, 0.06)	-0.22 (-0.66, 0.22)
Aug–Sep	234	9.46 (5.47)	8.94 (4.60)	-0.52 (-1.11, 0.07)	-0.42 (-1.02, 0.17)
Oct–Nov	298	9.07 (5.57)	8.06 (4.66)	<b>-1.01 (-1.53, -0.49)</b>	<b>-0.99 (-1.52, -0.47)</b>

Values in bold are statistically significant.

for a COVID-19-related survey. We conducted a weighted analysis to take account of socio-demographic factors and reassuringly they showed similar magnitude of change although with a slightly higher estimate for change in BASDAI among participants with axSpA. Finally, while we generally saw less impact of lockdown on health over time, it is not possible to disentangle this time period effect from the methodological issue of people who were most severely affected responding earlier. Nevertheless, the interpretation of lessening impact with time is generally supported by longitudinal surveys conducted in the general population, for example on mental health [24]. This also emphasizes that in interpreting the results from the current study we are not concluding that the changes in health were “because of participants” musculoskeletal conditions.

There have been several reports about the effect of COVID-19 on health in the UK population. An additional sweep of the UK Household Survey in April 2020 showed increased levels of psychological distress (compared with the previous pre-pandemic survey) particularly affecting younger people and women [24]. Poor mental health is a key factor influencing quality of life among people with musculoskeletal conditions [1] and also is an independent predictor of response to therapy [25]. Therefore the effect of the pandemic on mental health in patients with musculoskeletal symptoms and conditions is of relevance to their management, and addressing increasing levels of anxiety is likely to be key to maintaining quality of life. An analysis of >12 000 people with inflammatory arthritis in the DANBIO register in Denmark reported that females, people with comorbidities, not working, with lower levels of education, on

**TABLE 5A** Changes in disease specific measures: quality of life (ASQoL) in participants with axial spondyloarthritis

Domain and categories	n	Previous time point, mean (s.d.)	CONTAIN survey, mean (s.d.)	Mean difference (95% CI)	Age-adjusted mean difference (95% CI)
All participants	578	6.26 (5.19)	6.22 (5.16)	-0.04 (-0.34, 0.25)	0.02 (-0.28, 0.33)
Year of birth					
1924–1945	57	6.33 (4.99)	6.16 (4.91)	-0.18 (-0.85, 0.49)	
1946–1964	260	6.17 (5.16)	6.11 (5.04)	-0.06 (-0.47, 0.35)	
1965–1980	174	6.04 (5.45)	5.96 (5.33)	-0.08 (-0.68, 0.52)	
1981–2001	87	6.97 (4.86)	7.12 (5.35)	0.16 (-0.69, 1.00)	
Gender					
Female	197	7.16 (5.20)	6.87 (5.15)	-0.29 (-0.82, 0.24)	-0.21 (-0.76, 0.34)
Male	380	5.79 (5.13)	5.88 (5.15)	0.09 (-0.27, 0.44)	0.10 (-0.27, 0.47)
Deprivation					
1 (most deprived)	58	8.34 (5.35)	8.45 (5.07)	0.10 (-0.79, 1.00)	0.23 (-0.69, 1.16)
2	88	7.13 (5.67)	7.46 (5.70)	0.33 (-0.48, 1.14)	0.26 (-0.57, 1.10)
3	107	6.82 (5.01)	6.19 (4.99)	-0.63 (-1.42, 0.15)	-0.60 (-1.41, 0.20)
4	162	5.69 (4.91)	5.71 (4.95)	0.02 (-0.46, 0.50)	0.05 (-0.46, 0.56)
5 (least deprived)	163	5.27 (4.95)	5.29 (4.91)	0.02 (-0.53, 0.58)	0.16 (-0.42, 0.73)
Employment					
Full-time	226	5.53 (4.81)	5.40 (4.73)	-0.13 (-0.61, 0.36)	0.20 (-0.31, 0.71)
Part-time	86	5.70 (5.19)	6.18 (5.31)	0.48 (-0.33, 1.29)	0.54 (-0.32, 1.39)
Retired	172	5.84 (4.96)	5.39 (4.80)	-0.45 (-0.94, 0.04)	<b>-0.63 (-1.20, -0.5)</b>
Other	91	9.49 (5.44)	9.99 (5.18)	0.49 (-0.27, 1.25)	0.59 (-0.20, 1.39)
Urban/rural					
Urban	423	6.41 (5.20)	6.50 (5.30)	0.09 (-0.25, 0.43)	0.13 (-0.22, 0.48)
Rural	155	5.86 (5.14)	5.46 (4.69)	-0.41 (-1.02, 0.20)	-0.27 (-0.90, 0.37)
Shielding					
Advised and followed	219	7.51 (5.26)	7.53 (5.16)	0.01 (-0.55, 0.57)	0.16 (-0.41, 0.73)
Not advised or not followed	347	5.45 (5.02)	5.35 (5.03)	-0.10 (-0.44, 0.24)	-0.05 (-0.41, 0.31)
Date of completion					
Jul	251	6.02 (5.03)	6.36 (5.12)	0.34 (-0.12, 0.79)	<b>0.51 (0.04, 0.98)</b>
Aug–Sep	174	6.32 (5.20)	6.21 (5.13)	-0.11 (-0.61, 0.39)	-0.12 (-0.65, 0.40)
Oct–Dec	153	6.59 (5.42)	6.00 (5.30)	-0.60 (-1.19, 0.001)	<b>-0.64 (-1.26, 0.02)</b>

Values in bold are statistically significant.

biologic treatment and with lower quality of life were more likely both to be anxious and self-isolate [26].

How do we interpret the magnitude of decrease in quality of life? There has been debate about whether a minimal clinically important difference (MCID) is relevant to EQ-5D and where it has been calculated (for EQ-5D-3L) in the context of musculoskeletal conditions, estimates vary between 0.03 and 0.54 across 12 studies [27]. For comparison with the decrease in EQ-5D-5L of 0.02 noted here, in the MAmMOTH trial, the cognitive behaviour therapy intervention (which was shown to be highly cost effective) resulted in an *improvement* of quality of life (using the EQ-5D-5L) over usual care of roughly similar magnitude, 0.024 [7]. There have been no estimates of MCID for PsAQoL, but again for context, a study of 28 patients with PsA followed up after a change in disease modifying therapy showed an average improvement of 2.96 in PsAQoL at 6 months [28], in comparison with the worsening here over follow-up of 0.75. It might have been reasonably expected that there could have been an increase in fibromyalgia-related

symptoms, particularly given the effect of the pandemic on mental health, and this indeed was the case. One particular area of interest in the current analysis is whether particular population sub-groups' health was more affected by the restrictions than others. There is no consistent evidence across the conditions and domains of such—worsening of domains have affected both males and females, people of different ages and across levels of deprivation. It was of particular note that the influences on poor quality of life were similar (and of similar magnitude) both before and during the pandemic. However, it was noted that the deterioration in quality of life was greatest among the cohort who had markers for risk of developing chronic widespread pain.

One surprising result is the lower level (on average) of sleep problems. The magnitude of change was small but was noted overall and for all population sub-groups examined. In an environment of uncertainty and increasing anxiety it might have been expected that there would be detrimental effects on sleep [29]. However, sleep problems remained an important influence on quality of



**TABLE 5B** Changes in disease specific measures: quality of life (PsAQoL) in participants with psoriatic arthritis

Domain and categories	n	Previous time point, mean (s.d.)	CONTAIN survey, mean (s.d.)	Mean difference (95% CI)	Age-adjusted mean difference (95% CI)
All participants	132	6.96 (5.42)	7.63 (5.72)	<b>0.67 (0.11, 1.22)</b>	<b>0.75 (0.19, 1.30)</b>
Year of birth					
1924–1945	7	5.86 (2.54)	6.74 (4.42)	0.86 (–1.14, 2.85)	
1946–1964	59	5.97 (5.32)	6.36 (5.47)	0.39 (–0.34, 1.12)	
1965–1980	53	7.57 (5.70)	8.68 (6.12)	<b>1.11 (0.15, 2.08)</b>	
1981–2001	13	9.62 (5.01)	9.62 (4.75)	0.00 (–1.90, 1.90)	
Gender					
Female	79	7.90 (5.35)	8.70 (5.35)	<b>0.80 (0.02, 1.57)</b>	<b>0.82 (0.04, 1.60)</b>
Male	53	5.57 (5.26)	6.04 (5.92)	0.47 (–0.28, 1.22)	0.62 (–0.14, 1.38)
Deprivation					
1 (most deprived)	16	8.00 (6.10)	9.25 (6.68)	1.25 (–0.29, 2.79)	1.33 (–0.22, 2.89)
2	15	6.87 (5.07)	7.73 (4.95)	0.87 (–0.75, 2.49)	0.75 (–0.87, 2.38)
3	34	7.79 (5.79)	7.76 (5.74)	–0.03 (–1.17, 1.11)	0.08 (–1.06, 1.23)
4	29	6.24 (4.91)	6.72 (5.52)	0.48 (–0.86, 1.82)	0.49 (–0.86, 1.83)
5 (least deprived)	38	6.37 (5.39)	7.47 (5.84)	<b>1.11 (0.26, 1.95)</b>	<b>1.26 (0.40, 2.11)</b>
Urban/rural					
Urban	99	6.74 (5.54)	7.69 (5.85)	<b>0.95 (0.32, 1.58)</b>	<b>1.02 (0.39, 1.66)</b>
Rural	33	7.64 (5.07)	7.45 (5.37)	–0.18 (–1.27, 0.91)	–0.07 (–1.16, 1.03)
Shielding					
Advised and followed	59	8.12 (5.92)	9.29 (6.29)	<b>1.17 (0.28, 2.05)</b>	<b>1.29 (0.40, 2.17)</b>
Not advised or not followed	68	6.07 (4.88)	6.19 (4.71)	0.12 (–0.57, 0.81)	0.18 (0.52, 0.87)
Date of completion					
Jul	42	5.48 (4.82)	6.36 (5.63)	0.88 (–0.13, 1.89)	0.93 (–0.08, 1.94)
Aug–Sep	47	8.06 (5.14)	8.70 (5.33)	0.64 (–0.32, 1.59)	0.70 (–0.26, 1.66)
Oct–Dec	43	7.21 (6.03)	7.70 (6.08)	0.49 (–0.42, 1.40)	0.65 (–0.27, 1.57)

Values in bold are statistically significant.

life during the pandemic. Positive effects on sleep during the pandemic have been reported—principally around duration of sleep and reduced variability of sleep patterns. In a study of almost 3 million users of a smartphone app in five metropolitan areas across the Americas, Europe and Asia, there was an increase in sleep duration between April 2019 and April 2020 of 22.3 min (95% CI: 21.5–23.1) [30]. In a study of 1021 participants in a sleep survey in Argentina who had measurements of sleep made both prior to and during the pandemic, sleep duration was longer during lockdown; only 37% did not reach the recommended 7 h of sleep on weekdays during the pandemic compared with 62% pre-pandemic. However, there was no difference in sleep quality pre- and during the pandemic [31]. Retrospective studies asking people to recall sleep patterns have tended to find people reporting worsening as opposed to improvement of sleep during the pandemic (e.g. [32]). Other ‘benefits’ noted in the results include significant (positive) changes in the likelihood of respondents being classified as taking high levels of physical activity compared with previously—particularly for older respondents and females. However, it is noteworthy that these positive effects were not uniformly seen; indeed respondents living in areas with higher levels of deprivation were significantly more likely to be classed as having low levels

of physical activity compared with the previous follow-up. We could not find any other large-scale study of people with musculoskeletal conditions that had examined the impact on physical activity during the pandemic.

In summary, this study provides evidence of only a small average decrease in quality of life reported by people with musculoskeletal symptoms or diagnoses during restrictions caused by the COVID-19 pandemic, with the main issues being pain and anxiety. There was also some deterioration noted in average disease specific measures, again of small magnitude, an increase in fibromyalgia-related symptoms but a small reduction in sleep problems. Changes were not restricted to particular population groups. The results taken as a whole are generally reassuring but provide some lessons for future similar situations: focusing on addressing anxiety is important, providing enhanced support for self-management (including in relation to pain) in the absence of normal health services being available, and being aware that all patients regardless of circumstances can be affected.

### Acknowledgements

We are grateful to help from staff at the National Ankylosing Spondylitis Society and specifically to patient partners Lynne Laidlaw (for help with designing questionnaire) and Susan Davis (for commenting on the

**TABLE 6** Predictors of EQ-5D (pre-pandemic and during lockdown)

Domain and categories	Coefficient (95% CI)		
	Pre-pandemic (model 1)	During lockdown (model 2)	Mixed effects model with interaction (model 3)
Gender			
Male	Reference	Reference	Reference
Female	0.018 (−0.008, 0.045)	0.002 (−0.025, 0.030)	−0.015 (−0.037, 0.007)
Cohort			
BSRBR-AS	Reference	Reference	Reference
MAMMOTH	0.092 (0.062, 0.122)	0.054 (0.023, 0.086)	<b>−0.036 (−0.062, −0.011)</b>
BSR-PsA	0.009 (−0.028, 0.045)	−0.014 (−0.053, 0.025)	−0.023 (−0.055, 0.009)
Pre-pandemic sleep problems			
0–3	Reference	Reference	Reference
4–8	−0.064 (−0.100, −0.028)	−0.059 (−0.097, −0.020)	0.006 (−0.027, 0.038)
9–20	−0.178 (−0.211, −0.146)	−0.166 (−0.200, −0.131)	0.013 (−0.017, 0.043)
Year of birth			
1924–1945	−0.032 (−0.087, 0.023)	−0.062 (−0.120, −0.004)	−0.021 (−0.057, 0.014)
1946–1964	Reference	Reference	Reference
1965–1980	0.020 (−0.033, 0.074)	0.032 (−0.024, 0.089)	0.001 (−0.025, 0.027)
1981–2001	0.021 (−0.067, 0.109)	0.031 (−0.062, 0.124)	−0.009 (−0.044, 0.026)
Deprivation			
1 (most deprived)	−0.113 (−0.164, −0.062)	−0.084 (−0.138, −0.030)	0.029 (−0.015, 0.074)
2	−0.046 (−0.091, −0.000)	−0.053 (−0.100, −0.005)	−0.007 (−0.046, 0.033)
3	Reference	Reference	Reference
4	0.016 (−0.020, 0.053)	0.018 (−0.202, 0.056)	0.002 (−0.030, 0.033)
5 (least deprived)	0.030 (−0.007, 0.066)	0.042 (0.003, 0.081)	0.0.13 (−0.019, 0.045)
Urban/rural			
Urban	Reference	Reference	Reference
Rural	0.024 (−0.005, 0.052)	0.036 (0.06, 0.066)	0.012 (−0.012, 0.036)
Pre-pandemic physical activity (BSR-PsA cohort only)			
Low	−0.085 (−0.172, 0.002)	−0.147 (−0.240, −0.055)	−0.062 (−0.131, 0.007)
Moderate	Reference	Reference	Reference
High	0.035 (−0.066, 0.136)	0.008 (−0.100, 0.115)	−0.028 (−0.108, 0.053)

Values in bold are statistically significant.

manuscript). G.J.M. conceived the idea for the study and all authors were involved in the detailed planning. M.H., K.K., E.M.-B. and M.B. were responsible for obtaining ethics and research governance approvals. M.B. undertook the analysis, which was independently verified by G.T.J. G.J.M., with input from M.B., drafted the manuscript, and all authors contributed important intellectual content via written comments. We thank Linda Dean for comments on the manuscript.

**Funding:** This work was supported by Versus Arthritis [Grant No.: 20748] and the British Society for Rheumatology. The funding for the original studies included were from Versus Arthritis (MAMMOTH) and the British Society for Rheumatology (BSRBR-AS and BSR-PsA). D.W. is supported by a Versus Arthritis Foundation Fellowship [Grant No. 21742].

**Disclosure statement:** The authors do not report any conflicts of interest.

## Data availability statement

The data within the article that relate to the collection of BSR register data are owned by the BSR—access to these data are subject to application being made to the BSR: Registers ([rheumatology.org.uk](http://rheumatology.org.uk)). For other data in the article, application can be made for access to the data by contacting the corresponding author.

## Supplementary data

Supplementary data are available at *Rheumatology* online.

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