Supplementary Material

Copy of electronic survey to patients

Assembling the data jigsaw: Improving MSK research using patient-generated health data (PGHD)

<u>Prevalence Survey</u>

Thank you for being willing to take part in this survey about medication and social care use, led by researchers at The University of Manchester in partnership with the rheumatology team at Salford Royal.

We are keen to understand two things. First, what types of pain relievers and supplements are being taken by people living with arthritis and other musculoskeletal diseases, and second, whether the same group of people get help with day-to-day activities (for example from family and friends or more formal help from care services).

After collecting some brief information about you, the survey will ask about your medication use **in the last week.** Once complete, the survey results will be posted in the waiting area of the rheumatology department in order that you can see what we have learnt.

The survey should take no more than 5 minutes. Your responses will be seen by the research team only and will not be shared with the clinical team.

About you

1. Please tell us your year of birth   [numerical, range 1900-2005]
2. Please tell us your gender
3. Please tell us the first half of postcode   [one or two letters, then one or two numbers]
4. Please tell us your ethnicity
5. Please indicate your rheumatic and musculoskeletal conditions
   Select all that apply

Rheumatoid arthritis	[Box]
Psoriatic arthritis	[Box]
Axial spondyloarthopathy/ ankylosing spondyloarthritis	[Box] etc
Other inflammatory arthritis	
Osteoarthritis	
Gout	
Fibromyalgia/ chronic widespread pain	
Systemic sclerosis	
Myositis	
Lupus	
Sjogren's syndrome	
Vasculitis	
Osteoporosis	
Other	[Free text] _____

6. Please indicate any other health conditions
   Include here as tick box
   Heart disease, cancer (previous), cancer (current) recurrent infections, gastrointestinal disease, osteoporosis, depression, anxiety

Other   [Free text – ideally allow one line per other additional health condition]_____

Part 1: Your medications

We are interested in learning about what medication and supplements you took **in the last week**.

7) Have you taken any pain relievers* such as paracetamol, non-steroidal anti-inflammatory or opioid drugs, **in the last week**? We are interested in prescription medicines, drugs you have purchased over the counter or non-prescription drugs. **Non-prescription drugs maybe those that are bought from the internet or borrowed from a family member.**

*For a list of pain relieving and opioid medications, please see below.
        Yes/No

If yes:
Please choose all those that apply and add any others that are not listed, marking whether the medication is provided by prescription or not.

7a) Non-opioid pain relievers (for example, paracetamol, ibuprofen)

	Prescription	**over the counter**	**non-prescription**
Paracetamol	[Box]	[Box]	[Box]

Non-steroidal anti-inflammatory drugs

Ibuprofen	[Box]	[Box]	[Box]
Naproxen			
Diclofenac			
Celecoxib			
Mefenamic acid			
Etoricoxib			
Indomethacin			
Other _____(please specify)			

7b) Opioid pain-relievers
For the opioid drugs, in addition to marking whether the medication is provided by prescription or not, please enter some additional details on how much you have taken on average **in the last week** for each medication you take. For example, taking codeine 30mg tablets 4 times a day, you might enter Dose= 30, Units= mg, frequency= 4/ day.

	Prescription	**Over the counter**	**Non-prescription**
	Dose/tablet strength (numerical value)	*Units (mg/ mcg)*	*Frequency (x per day/week)*

Tablets
Codeine
Dihydrocodeine
Cocodamol
Codydramol
Tramadol

Morphine
Oromorph
Oxycodone
Patches
Buprenorphine
Fentanyl
Other _____(please specify)

8) Have you taken any sleep aids or cannabidiol (CBD) oils or similar **in the last week**, either purchased over the counter or via the internet?   Yes/No

If yes:
Please choose all those that apply and add any others that are not listed

8a) Sleep aids:	Prescription	Over the counter	Non-prescription/
Antihistamines for sleep (Benadryl, Nytol)	[Box]	[Box]	[Box]
Melatonin			
Zopiclone			
Zolpidem			
Benzodiazepine (e.g. diazepam [Valium], alprazolam [Xanax], lorazepam, temazepam)			
Other _____(list what)			

	Over the counter	Non-prescription
8b) Cannabidiol (CBD) oil or similar	[Box]	[Box]

If CBDs ticked:
8c) What CBD product do you use? _____

8d) What do you use it for? Please tick all that apply:
Sleep, anxiety, pain, acne   [One box per option, allow multiple responses]
Other (please describe) _____

Supplements
9) Do you take any over the counter supplements, including vitamins and minerals, herbal supplements and nutritional supplements?   Yes/No

9a) If yes, please tick all those that apply and add any others that are not listed
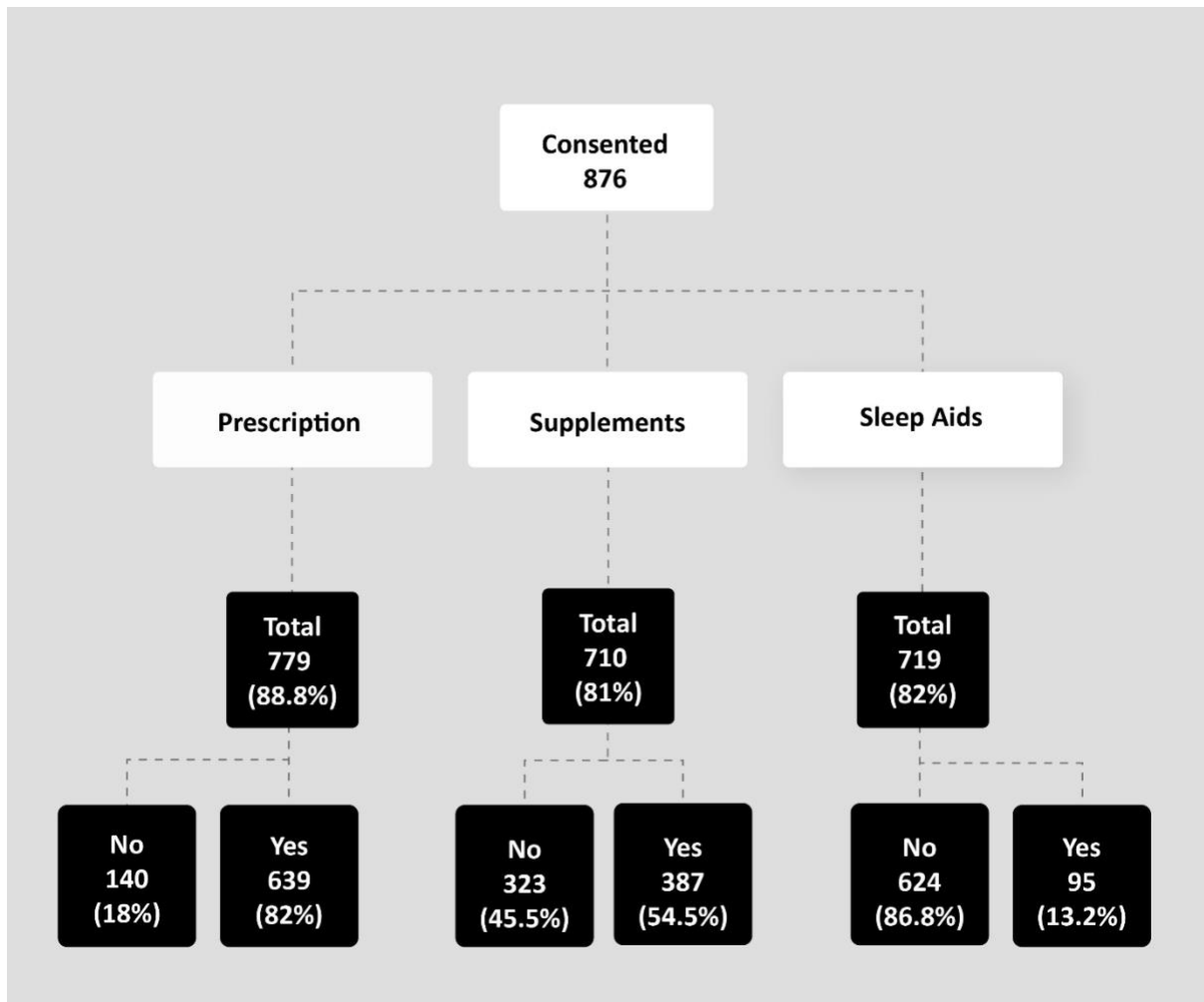
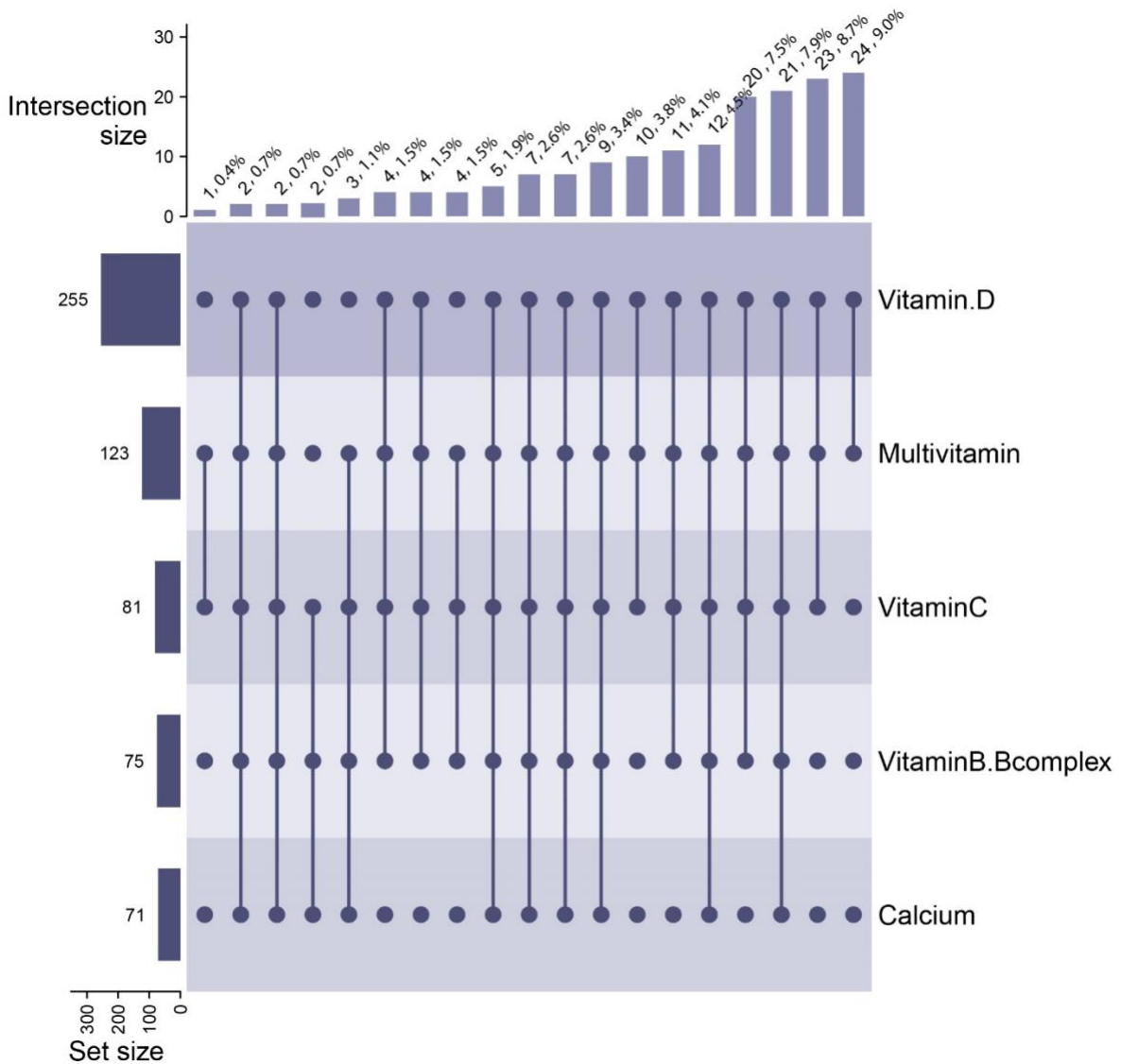| Vitamins & Minerals	Herbal/ food Supplements	Specialty Supplements	Sports nutrition & weight management
Vitamin D	Echinacea	CBD oil	Protein supplement
Calcium	Turmeric	Omega-3	Green tea extract
Vitamin C	St John's wort	Omega-6	Fat binder tablets
Zinc	Valerian	Probiotics	Keto supplements
Vitamin B/ Bcomplex	Ginseng	Glucosamine	Creatine
Multivitamin	Ginkgo biloba	Chondroitin	Other_____
Magnesium	Cranberry	Coenzyme- Q10	
	Chamomile		
	Feverfew		
	Garlic		
	Ginger		
	Goldseal		
	Kava		
	Senna		

Cost
10) On average, how much do you spend **per month** on
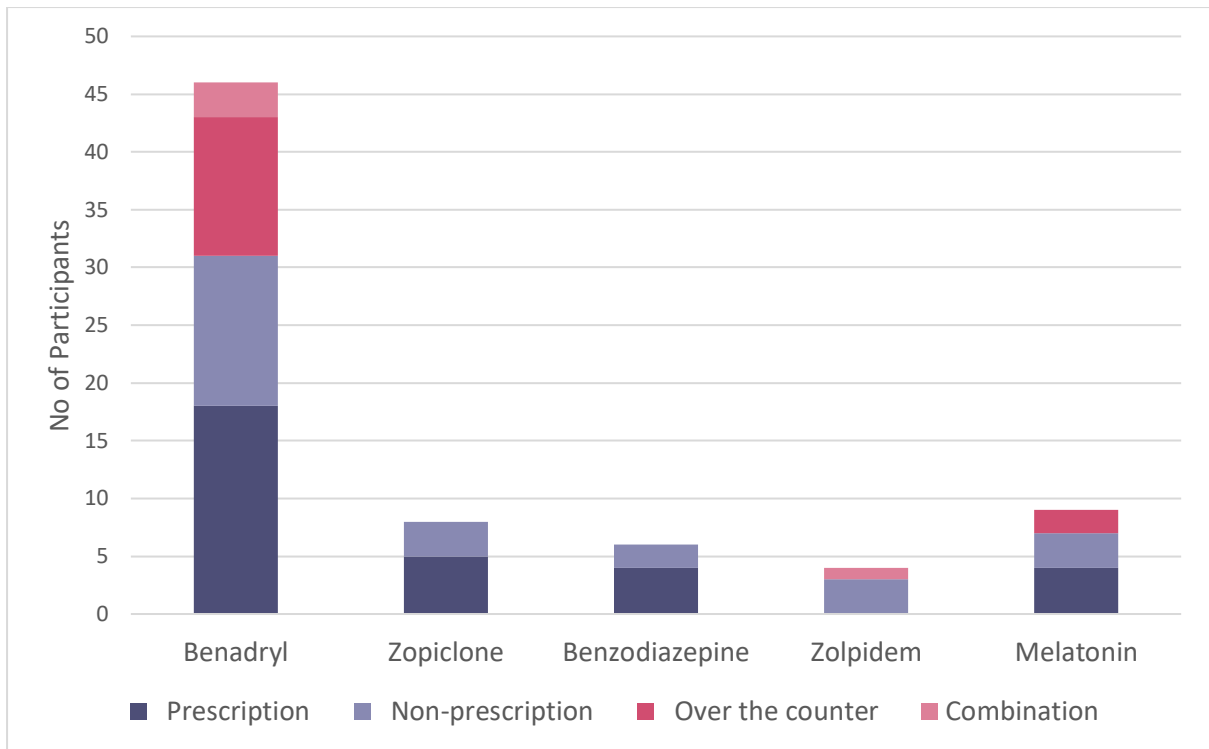**10a)** Prescription medication : £(Numerical value)
10b) Over the counter medications, sleep aids, CBD products and supplements: £(Numerical value)

Supplementary Figure S1: Cohort diagram of the final number of patients included in the survey
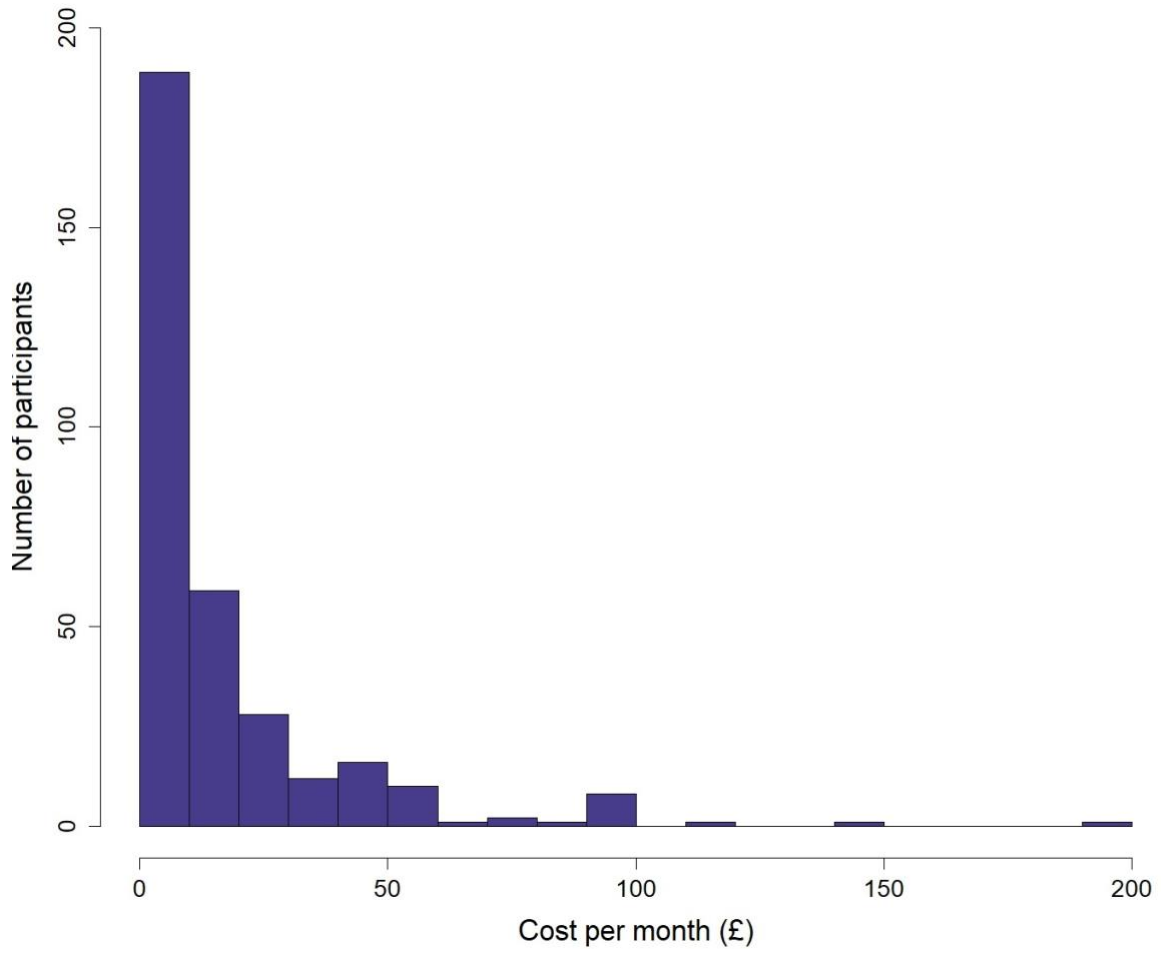
Supplementary Figure S2: Upset plot showing the distinct overlap between the five most common supplements. *The upset plot shows a bar chart with the number of people in the data who reported some combination or overlap of supplement use. Each bar is a different, mutually exclusive combination. Underneath it is a graphical table showing what those combinations are. Each row is one of our top five most reported supplements: Vitamin D, Multivitamin, Vitamin C, Vitamin B, and Calcium. The black dots and lines show the combination of supplements that comprise each cluster or subset of supplements overlap. Reading from right to left, we can see that the most common subset of supplement overlap is the combination of vitamin D and multivitamins. This shows the unconditional frequency count of each supplement across all subsets. Please note this plot represents a two-way overlap only: for instance, 4 patients (1.5%) overlap between just multivitamins and Vitamin B; however, the overall proportion of this overlap alongside other supplements was n=19 (4.9%).*

Supplementary Figure S3: Types of sleep aids used reported by rheumatology patients
Non-prescription use was defined in the survey as those medicines borrowed from a family member or purchased over the internet.

Supplementary Figure S4: Distribution of Cost: histogram of how much participants spend per month on over-the-counter medications, sleep aids, CBD products, and supplements.

Supplementary Table S1: Baseline characteristics of patients

	Sleep aids			Pain relievers		
	All (719)	Yes (95)	No (624)	All (779)	Yes (639)	No (140)
Age, mean [SD]	58.3 (14.4)	52.4 (15.5)	59.2 (14.0)	58.4 (14.5)	58.5 (14.2)	57.5 (15.7)
18-39	93 (12.9%)	26 (27.4%)	67 (10.7%)	100 (12.9%)	76 (11.9%)	25 (17.9%)
40-54	175 (24.3%)	20 (21.1%)	155 (24.8%)	188 (24.1%)	160 (25.0%)	28 (20.0%)
55-69	278 (38.6%)	36 (37.9%)	242 (38.7%)	304 (38.9%)	249 (38.9%)	55 (39.3%)
70+	173 (24.2%)	13 (13.7%)	160 (25.8%)	187 (24.1%)	154 (24.2%)	32 (22.9%)
Gender						
Female	529 (73.6%)	71 (74.7%)	458 (73.4%)	577 (74.0%)	486 (76.1%)	91 (65.0%)
Male	186 (25.8%)	21 (22.1%)	165 (26.4%)	197 (25.2%)	147 (23.0%)	49 (35.0%)
Other	4 (0.6%)	3 (3.2%)	1 (0.2%)	5(0.8%)	6 (0.9%)	0 (0%)
Ethnicity						
White British	672 (93.4%)	87 (91.5%)	585 (93.7%)	725 (93.0%)	606 (94.8%)	119 (85.0%)
Other/Mixed/Multiple ethnic groups	28 (3.8%)	5 (5.2%)	23 (3.6%)	31 (3.9%)	18 (2.8%)	13 (9.2%)
Asian/Asian British	12 (1.6%)	2 (2.1%)	10 (1.8%)	14 (1.7%)	8 (1.2%)	6 (4.2%)
Black/African/Caribbean/Black/British	7 (0.9%)	1 (1.05%)	6 (0.9%)	9 (1.1%)	7 (1.0%)	2 (1.4%)
Diagnoses						
MSK Conditions						
Osteoarthritis	230 (31.9%)	37 (38.9%)	193 (30.9%)	263 (33.7%)	240 (37.5%)	23 (16.4%)
Rheumatoid arthritis	227 (31.5%)	30 (31.5%)	197 (31.5%)	247 (31.7%)	212 (33.1%)	35 (25.0%)
Fibromyalgia/ Chronic Widespread Pain	174 (24.2%)	34 (35.7%)	140 (22.4%)	192 (24.6%)	178 (27.8%)	14 (10.0%)
Osteoporosis	92 (12.7%)	13 (13.6%)	79 (12.6%)	99 (12.7%)	86 (13.4%)	13 (9.2%)
Psoriatic arthritis	82 (11.4%)	8 (8.4%)	74 (11.8%)	87 (11.1%)	70 (10.9%)	17 (12.1%)
Other inflammatory condition	63 (8.7%)	16 (16.8%)	47 (7.5%)	67 (8.6%)	59 (9.2%)	8 (5.7%)
Axial spondyloarthropathy ankylosing spondylarthritis	58 (8.0%)	13 (13.6%)	45 (7.2%)	65 (8.3%)	53 (8.2%)	12 (8.5%)
Myositis	47 (6.5%)	4 (4.2%)	43 (6.8%)	50 (6.4%)	32 (5.0%)	18 (12.8%)
Comorbidities						
Other health conditions	234 (32.5%)	36 (37.8%)	198 (31.7%)	255 (32.7%)	207 (32.1%)	48 (34.2%)
Anxiety	189 (26.2%)	35 (36.8%)	154 (24.6%)	209 (26.8%)	182 (28.4%)	27 (19.2%)
Depression	155 (21.5%)	35 (36.8%)	120 (19.2%)	173 (22.2%)	159 (24.8%)	14 (10.0%)
Gastrointestinal disease	93 (12.9%)	11 (11.5%)	82 (13.1%)	100 (12.8%)	84 (13.1%)	16 (11.4%)
Heart Disease	69 (9.5%)	5 (5.2%)	64 (10.2%)	77 (9.8%)	63 (9.8%)	14 (10.0%)
Systemic sclerosis	63 (8.7%)	10 (10.5%)	53 (8.4%)	70 (8.9%)	59 (9.2%)	11 (7.8%)
Previous Cancer	50 (6.9%)	8 (8.4%)	42 (6.7%)	58 (7.4%)	51 (7.9%)	7 (5.0%)
Sjogren s Syndrome	48 (6.6%)	9 (9.4%)	39 (6.2%)	51 (6.5%)	42 (6.5%)	9 (6.4%)
Townsend deprivation scores (quintiles)						
1	105 (14.6%)	6 (6.3%)	99 (15.8%)	145 (18.6%)	120 (18.7%)	25 (17.8%)
2	63 (8.7%)	13 (13.6%)	50 (8.01%)	48 (6.1%)	40 (6.2%)	8 (5.7%)
3	127 (17.6%)	16 (16.8%)	111 (17.7%)	243 (31.1%)	197 (30.8%)	46 (32.8%)
4	110 (15.2%)	11 (11.5%)	99 (15.8%)	119 (15.2%)	94 (14.7%)	25 (17.8%)
5	314 (43.6%)	49 (51.5%)	265 (42.4%)	224 (28.7%)	188 (29.4%)	36 (25.7%)

N/A – not applicable, SD – Standard deviation, MSk – musculoskeletal. * Some participants reported more than one diagnosis. ∞ includes MSK diseases above and the following chronic diseases listed in the questionnaire: angina, heart attack, heart disease, anxiety, gastrointestinal disease, stroke, COPD, diabetes, cancer, multiple sclerosis, depression, and other health conditions (participants asked to specify).

Supplementary Table S2 (A): Univariate analysis

	Supplements		Sleep aids		Pain relievers	
	unadjusted		unadjusted		unadjusted	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Age						
18-39	Referent	Referent	Referent	Referent	Referent	Referent
40-54	0.96	0.62, 1.47	**0.3**	**0.15, 0.58**	1.84	1.00, 3.38
55-69	0.81	0.55, 1.18	**0.39**	**0.22, 0.69**	1.5	0.86, 2.55
>70	0.95	0.57, 1.58	**0.21**	**0.10, 0.42**	1.59	0.88, 2.87
Sex						
Female	Referent	Referent	Referent	Referent	Referent	Referent
Male	1.27	0.90, 1.78	0.84	0.49, 1.39	0.56	0.38, 0.84
Other	2.65	0.34, 53.8	19.8	2.49, 403	-	NA
Ethnicity						
Non-White	Referent	Referent	Referent	Referent	Referent	Referent
White	0.89	0.43, 1.79	2.35	0.69, 14.7	1.71	0.70, 3.79
Townsend deprivation scores						
1	Referent	Referent	Referent	Referent	Referent	Referent
2	1.12	0.70, 1.80	1.46	0.70, 3.09	1.08	0.47, 2.73
3	0.92	0.57, 1.47	1.25	0.59, 2.69	0.92	0.53, 1.57
4	1.19	0.74, 1.91	1.47	0.72, 3.10	0.84	0.45, 1.56
5	0.84	0.53, 1.35	1.74	0.86, 3.61	1.13	0.64, 1.96
Rheumatoid. Arthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.01	0.73, 1.38	0.8	0.49, 1.28	**1.49**	**0.99, 2.29**
Lupus						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.69	0.30, 1.57	0.95	0.22, 2.83	0.87	0.35, 2.66
Fibromyalgia						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.1	0.77, 1.55	**1.91**	**1.19, 3.02**	**3.49**	**2.02, 6.48**
Osteoarthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.1	0.80, 1.51	1.2	0.75, 1.87	**3.58**	**2.22, 6.05**
Other inflammatory condition						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.19	0.71, 2.04	**2.54**	**1.34, 4.61**	1.68	0.83, 3.88
Sjogren s Syndrome						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.93	0.52, 1.70	1.6	0.71, 3.28	1.02	0.51, 2.29
Gout						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.99	0.42, 2.38	**0**	—	1.55	0.53, 6.64
Myositis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.71	0.39, 1.29	0.6	0.18, 1.54	**0.36**	**0.20, 0.67**
Systemic sclerosis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.08	0.64, 1.84	1.29	0.60, 2.54	1.19	0.63, 2.46
Psoriatic arthritis						

	No	Referent	Referent	Referent	Referent	Referent	Referent
	Yes	0.74	0.47, 1.18	0.7	0.30, 1.41	0.89	0.52, 1.61
Axial spondylarthritis							
	No	Referent	Referent	Referent	Referent	Referent	Referent
	Yes	0.85	0.49, 1.47	**2.08**	**1.04, 3.92**	0.97	0.52, 1.94
Osteoporosis							
	No	Referent	Referent	Referent	Referent	Referent	Referent
	Yes	0.65	0.42, 1.02	1.11	0.57, 2.04	1.52	0.85, 2.93
Vasculitis							
No		Referent	Referent	Referent	Referent	Referent	Referent
Yes		0.82	0.28, 2.43	**0**	—	0.65	0.22, 2.36
Multimorbidity							
	0	Referent	Referent	Referent	Referent	Referent	Referent
	1	0.88	0.61, 1.26	0.84	0.47, 1.49	0.81	0.53, 1.24
	2	0.74	0.48, 1.13	1.44	0.78, 2.64	1.6	0.92, 2.85
	≥3	0.89	0.51, 1.54	1.68	0.76, 3.64	**2.87**	**1.12, 8.11**

Supplementary Table S2 (B): Factors associated with administering supplements, sleep aids, and pain relievers adjusted for age and sex.

	Supplements		Sleep aids		Pain relievers	
	adjusted		adjusted		adjusted	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Age						
18-39	Referent	Referent	Referent	Referent	Referent	Referent
40-54	1.04	0.62, 1.73	**0.31**	**0.16, 0.61**	**1.96**	**1.06, 3.62**
55-69	0.87	0.54, 1.40	**0.42**	**0.24, 0.77**	1.57	0.90, 2.69
>70	1.04	0.62, 1.75	**0.23**	**0.11, 0.48**	1.79	0.97, 3.27
Sex						
Female	Referent	Referent	Referent	Referent	Referent	Referent
Male	1.28	0.90, 1.82	0.81	0.46, 1.37	0.55	0.37, 0.83
Other	2.5	0.31, 51.2	12.4	1.43, 266	-	NA
Ethnicity						
Non-White	Referent	Referent	Referent	Referent	Referent	Referent
White	0.9	0.43, 1.82	2.56	0.74, 16.1	1.71	0.69, 3.84
Townsend deprivation scores						
1 (Least deprived)	Referent	Referent	Referent	Referent	Referent	Referent
2	1.07	0.67, 1.73	1.34	0.63, 2.89	0.98	0.42, 2.49
3	0.89	0.55, 1.42	1.29	0.60, 2.79	0.93	0.54, 1.60
4	1.15	0.71, 1.85	1.4	0.67, 3.00	0.82	0.43, 1.54
5	0.82	0.51, 1.31	1.73	0.85, 3.65	1.1	0.62, 1.94
Rheumatoid. Arthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.03	0.74, 1.42	0.85	0.51, 1.38	**1.58**	**1.04, 2.44**
Lupus						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.73	0.31, 1.67	0.76	0.17, 2.34	0.81	0.31, 2.51
Fibromyalgia						
No	Referent	Referent	Referent	Referent	Referent	Referent

Yes	1.17	0.82, 1.69	**1.81**	**1.10, 2.97**	**3.44**	**1.95, 6.48**
Osteoarthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.16	0.83, 1.63	1.64	0.99, 2.73	**3.34**	**2.03, 5.75**
Other inflammatory condition						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.23	0.73, 2.11	**2.62**	**1.36, 4.85**	1.69	0.83, 3.93
Sjogren s Syndrome						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.01	0.55, 1.86	1.58	0.68, 3.33	0.89	0.44, 2.03
Gout						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.93	0.39, 2.25	**0**	—	1.86	0.61, 8.11
Myositis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.71	0.39, 1.29	0.55	0.16, 1.43	**0.38**	**0.20, 0.71**
Systemic sclerosis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	1.14	0.67, 1.97	1.25	0.56, 2.55	1.03	0.54, 2.14
Psoriatic arthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.73	0.46, 1.17	0.71	0.30, 1.46	0.96	0.55, 1.76
Axial spondylarthritis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.79	0.45, 1.38	**2.32**	**1.13, 4.52**	1.12	0.59, 2.28
Osteoporosis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.66	0.42, 1.05	1.44	0.71, 2.74	1.36	0.75, 2.66
Vasculitis						
No	Referent	Referent	Referent	Referent	Referent	Referent
Yes	0.75	0.25, 2.23	**0**	—	0.69	0.23, 2.55
Multimorbidity						
0	Referent	Referent	Referent	Referent	Referent	Referent
1	0.86	0.60, 1.24	0.95	0.53, 1.72	0.8	0.51, 1.23
2	0.72	0.47, 1.10	1.38	0.74, 2.57	1.71	0.97, 3.08
≥3	0.88	0.50, 1.53	1.48	0.66, 3.26	**2.78**	**1.10, 8.20**