RHEUMATOLOGY

Original article

Public priorities for joint pain research: results from a general population survey

Vicky Y. Strauss[1], Pam Carter[1], Bie Nio Ong[1], John Bedson[1], Kelvin P. Jordan[1], Clare Jinks[1] in collaboration with the Arthritis Research UK Research Users' Group

Abstract

Objective. We aimed to identify the priorities for joint pain research from a large general population survey and identify characteristics associated with these priorities.

Methods. A question about research priorities was developed in collaboration with the Arthritis Research UK Primary Care Centre's Research Users' Group. The question was embedded in a postal survey to an existing cohort of adults with self-reported joint pain, aged $\geqslant$56 years, in North Staffordshire. Respondents were asked to rank their top three priorities for research. Factor mixture modelling was used to determine subgroups of priorities.

Results. In all, 1756 (88%) people responded to the survey. Of these, 1356 (77%) gave three priorities for research. Keeping active was rated the top priority by 38%, followed by research around joint replacement (9%) and diet/weight loss (9%). Two clusters of people were identified: 62% preferred lifestyle/self-management topics (e.g. keeping active, weight loss) and 38% preferred medical intervention topics (e.g. joint replacement, tablets). Those who preferred the medical options tended to be older and have hip or foot pain.

Conclusion. This study has provided population data on priorities for joint pain research expressed by a large cohort of older people who report joint pain. The most popular topics for research were linked to lifestyle and self-management opportunities. Pharmaceutical and invasive interventions, despite being common topics of research, are of less importance to these respondents than non-medical topics. Specific research questions will be generated from this study with collaboration of the patient's group.

Key words: patient priority, joint pain, survey, logistic regression, latent class analysis, factor analysis.

CLINICAL SCIENCE

Introduction

Identifying topics for health research, and prioritizing them, is one area where patients/health care users/consumers and the public can become active in the research process [1]. Information on public priorities for research is useful for researchers, as subsequent research proposals can be more patient centred and relevant to patients'

experiences, and therefore should be more likely to result in patient benefit.

Researchers have used a variety of mechanisms to determine priorities of the general public. These include, for example, Citizens' Juries [2–4], Delphi studies [5], nominal groups [6–8], focus groups [9–13], surveys [14] and mixed methods [15, 16]. A systematic review found 87 examples of studies that made specific efforts to include the public in identifying or prioritizing research topics [17]. This work has been further expanded with the publication of a bibliography and systematic map of research reports about patients', clinicians' and researchers' priorities for new research [18, 19]. This study, funded by the James Lind Alliance, found that patients are less likely to be consulted about their research priorities than clinicians, and despite policy support for

patient and public involvement in health research, involvement rarely extends to influencing health research agendas.

Organizations [e.g. the National Institute for Health Research (NIHR) Health Technology Assessment programme] have developed processes to involve patients in deciding research topics and prioritizing them. A systematic review of patient and public involvement within health technology assessment internationally found only two studies that focused on public participation in priority setting [20].

Few studies have sought to identify public priorities for joint pain research [8, 14, 15, 21–24]. This is surprising considering the burden of joint pain in the population and its impact on health care consumption. For example, it is estimated that nearly one-quarter of adults are affected by long-standing musculoskeletal problems, such as arthritis, that limit everyday activities [25]. Musculoskeletal conditions are one of the most common reasons for general practitioner consultations, with one in seven consultations being related to musculoskeletal problems [26].

Patients are invited to participate in setting research priorities for systematic reviews undertaken by the Cochrane Musculoskeletal Group. Arthritis Research UK has also established a joint initiative with the NIHR Health Technology assessment programme to invite research suggestions via their website.

Two patient representatives were involved in international consensus development work to identify research priorities for future trials in non-pharmacological therapies for common musculoskeletal therapies [8]. Kirwan *et al.* [23] investigated the patient's perspectives on outcomes to be measured in research of treatments for patients with RA and developed a research agenda based on consensus work with patients and clinicians. Tallon *et al.* [15] highlighted a mismatch between research evidence and consumer views on what should be researched in relation to treatment of OA of the knee. They found that 50% of published research focused on pharmaceutical interventions, whereas only 4% of patients wanted research in this area. Similarly only 3% of published research focused on education and advice, whereas 21% of patients wanted research in this area. A recent Scandinavian study used web surveys to ask members of the Norwegian Rheumatism Association and the Swedish Rheumatism Association to prioritize research topics [14]. They found that patients with different arthritis diagnoses had different research priorities. Patients with RA preferred research on medication, whereas patients with OA wanted research on exercise.

Patient and public involvement in research priority setting for joint pain has tended to be small scale, to rely on the membership of support groups or has been undertaken in service users. The objectives of this study were therefore to determine priorities for joint pain research from a large general population survey and to explore differences in priorities by socio-demographic characteristics and site of joint pain. The future aim is to work collaboratively with a group of lay people to identify research questions based on priorities identified in this study.

Methods

Development of the research priority question

The Arthritis Research UK Primary Care Centre at Keele University established a Research User's Group (RUG) in 2006. The group has eight members with experience of living with musculoskeletal pain and meets four times a year to discuss research proposals in collaboration with researchers. In 2007 the centre recognized the role that patients and members of the public can play much earlier in the research process and was keen to identify public priorities for joint pain and OA research.

An initial literature review was undertaken to identify previous relevant population-based studies around priorities, and resources from INVOLVE and the James Lind Alliance were also searched (bibliography of priority setting by patients and clinicians, 2006). One researcher in our team (C.J.) then worked collaboratively with the RUG to devise a survey question to include in a population-based survey instrument.

The RUG chose to develop a two-part question with an open and closed response category. The format of this closed question was derived from Tallon's study (with permission) [15]. First, six topics appeared exactly as they had in Tallon's study (physical therapy, complementary therapy, tablets, removal of fluid/debris, aids and adaptations, education and advice). Secondly, two topics were adapted to remove references to specific joint sites (e.g. knee replacement changed to joint replacement). Thirdly, Tallon's question included another priority option. The RUG discussed the topics that were chosen by responders to this other section. They considered it important to ask the wider general population of people with joint pain their view on four topics (counselling, improved mobility, reduced swelling and diet); therefore these topics were added to our list of choices. We also used the phrases and words that were reported by Tallon *et al.* [15], as these were patient derived and also made sense to members of the RUG. Finally, the RUG also thought that it was important to distinguish informal types of exercise or physical activity from more formal physical therapy. Therefore keeping active was added as a specific new topic. The closed question used in our study contained a total of 13 topics. The open question allowed respondents to choose topics not already listed and write any other comments. The final format of the question is displayed in supplementary data appendix 1, available at *Rheumatology* Online.

Postal survey

The question was embedded in a self-completion postal survey within one cohort of the North Staffordshire Osteoarthritis Project. This is a prospective (baseline, 3 years and 6 years) general population-based cohort study of joint pain in all adults registered at three general practices aged $\geqslant$50 years at baseline [27]. At baseline,

7878 (71%) people responded. In 2008, a 6-year follow-up health questionnaire was mailed to the 3410 people who had responded to the 3-year survey and were still registered at the practices. Of these, 2831 (adjusted response 84%) completed the health questionnaire and, of these, 2002 participants who self-reported joint pain (in the hand, hip, knee or foot) and had agreed to further contact were sent a second questionnaire focusing on joint pain, which included the research priority question. The study was approved by the North Staffordshire Local Research Ethics Committee.

Analysis

Top priority

Descriptive statistics were used to summarize the topics ranked as first priority for research. Multinomial logistic regression analysis was then used to identify associations of the most selected top priority topics with patient characteristics. Patient characteristics included age group at 6-year follow-up (56–64, 65–74, >75), gender, socio-economic status based on job performed for most of life (managerial/professional, intermediate and routine) [28] and BMI [normal or underweight (<25), overweight (≥25–29.99) and obese (≥30)]. The association of top priority with location of pain was assessed for each of the four locations: hip, knee, foot and hand. Odds ratios (ORs) with 95% CIs were calculated. Multinomial logistic regression analysis was conducted using PASW statistic 18.

Top three priorities

Factor mixture analysis (FMA) was used to assess whether there were distinct groups of people with different priorities based on their top three research priorities [29]. FMA is a combination of factor analysis and latent class analysis. A small number of latent (i.e. unobserved) continuous variables (factors) that describe the majority of the variation in the selection of the top 3 of the 13 research topics is first derived. This resulted in a reduced number of variables (called factors) from the original 13, with each factor being a linear weighted combination of the 13 variables. These factors were then used in a further stage to identify distinct groups (clusters) of people, with people within the same group having similar priorities. People were allocated to a cluster based on their highest posterior probability of belonging to each cluster. A detailed description of the FMA analysis is given in supplementary data appendix 2, available at *Rheumatology* Online.

Differences in patient characteristics between cluster memberships were then modelled using multinomial logistic regression. FMA was conducted using Mplus version 6.1. Logistic regression was performed using PASW statistics 18.

Results

Response

Of the 2002 people who were sent the joint pain questionnaire, 1756 people responded (adjusted response 88%). Of these, 1396 (79%) gave a top priority for research and

1356 (77%) gave three priorities for research. The characteristics of people who stated a top priority (responders) and those who did not (non-responders) are given in Table 1. There was little difference in age between non-responders and responders (mean difference 1.2; 95% CI 0.4, 2.0). Non-responders were more likely to be male and in a manual occupation. There was some difference in the prevalence of hand problems/pain and foot pain between responders and non-responders, but not knee or hip pain.

Top priority

Keeping active was the top priority for 38% of responders (Fig. 1). Next was joint replacement and research into weight loss/diets (both 9%) and research into education and advice (8%). The least popular topics for research were aids and adaptations, removal of fluids from joints and counselling (all 1%).

Results of the multinomial logistic regression comparing the characteristics of respondents who selected keeping active as their top priority with those of respondents who selected the other most frequently chosen six priorities are shown in Table 2. Gender had no association with the topic chosen as first priority for research. People aged ≥65 years were more likely to choose joint replacement over keeping active compared with those <65 years: OR (95% CI) 2.69 (1.60, 4.50) and 2.13 (1.29, 3.83) for those aged 65–74 years and ≥75 years, respectively, compared with those aged <65 years. People aged ≥65 years were also more likely to select tablets as their first choice (65–74 years: OR 1.82; 95% CI 1.04, 3.18), but were less likely to choose weight loss and diet than those <65 years (≥75 years: OR 0.36; 95% CI 0.18, 0.72).

Obese respondents were more likely to choose weight loss and diet (OR 2.99; 95% CI 1.74, 5.14) and improved mobility (OR 2.14; 95% CI 1.19, 3.87) than those of normal weight. There was no difference in patient characteristics between those selecting keeping active and those selecting education as the first priority for research. People with knee or foot pain were more likely to choose research on improving mobility than those without pain in these sites. Foot pain was also associated with selecting tablets as the first priority for research, whereas those with hip pain were more likely to select joint replacement.

Top three priorities

Based on the top three priorities of participants (*n* = 1356), research into lifestyle options for self-management (e.g. keeping active, weight loss/diet) were more popular than research on more medical or invasive treatments (e.g. tablets, injection). Keeping active was the most popular choice, with 70% of responders ticking this as either a first, second or third choice. Research on weight loss and education were the other two most popular topics with 33% and 32% of responders selecting these, respectively, in their top three priorities, followed by physical therapy (29%) and improved mobility (28%). Research on tablets and joint replacement were prioritized by 22% each.

Based on the FMA (supplementary data appendix 2, available at *Rheumatology* Online), two distinct clusters

TABLE 1 Characteristics of responders and non-responders to survey of priorities for research

Characteristic	Responders n = 1396 (%)	Non-responders n = 606(%)
Gender		
Male	568 (41)	279 (46)
Female	828 (59)	327 (54)
Age		
Mean (s.d.)	67.6 (8.8)	68.9 (8.0)
Live alone		
Yes	364 (26)	178 (30)
No	1024 (74)	416 (70)
Marital status		
Married	918 (66)	390 (65)
Single/separated/ divorced/windowed	471 (34)	206 (35)
BMI		
Normal/underweight	483 (36)	194 (34)
Overweight	578 (43)	221 (39)
Obese	298 (22)	158 (27)
Social class		
Managerial/professional	342 (25)	130 (23)
Intermed/self-employed	335 (25)	121 (22)
Routine/manual	666 (50)	309 (55)
Having hand pain/problem	909 (65)	358 (60)
Having hip pain	720 (52)	304 (51)
Having knee pain	964 (69)	396 (66)
Having foot pain	722 (52)	347 (58)

of people were identified. Cluster 1 consisted of 512 (38%) people, with 844 (62%) in cluster 2. Table 3 shows the frequency of choosing each topic by cluster. Those in cluster 1 tended to be more likely to choose medical or invasive topics. Of the 214 people who chose research into joint injections, 87% were assigned to cluster 1, and the majority of those who chose research into reducing swelling (60%), tablets (61%), joint replacement (69%) and fluid removal (86%) were also in cluster 1. Cluster 2 included the majority of people who chose lifestyle options, including diet/weight loss (97% of those who chose this option), education/advice (92%) and counselling (93%).

Table 4 displays the most common selection of the top three priorities for each cluster. To aid interpretation, injection, swelling, tablets, joint replacement and fluid removal were combined into a count of medical-related topics. The most common selections for people in cluster 1 included at least one medical topic, and often two or three medical topics. The most common selections for people in cluster 2 were combinations of keeping active with other lifestyle topics, particularly diet/weight loss, education/advice and physical therapy.

The difference in characteristics between those in the two clusters is shown in Table 5. Cluster 1 was more likely to include people with foot pain (OR 1.58; 95% CI 1.25, 2.02) compared with cluster 2. Those in cluster 1 also tended to be older (aged 65–74 years: OR 1.59; 95% CI 1.22, 2.02; aged ⩾75 years: OR 1.73; 95% CI 1.26, 2.37).

Discussion

We have provided, for the first time, population-based data on public priorities for joint pain research. Working
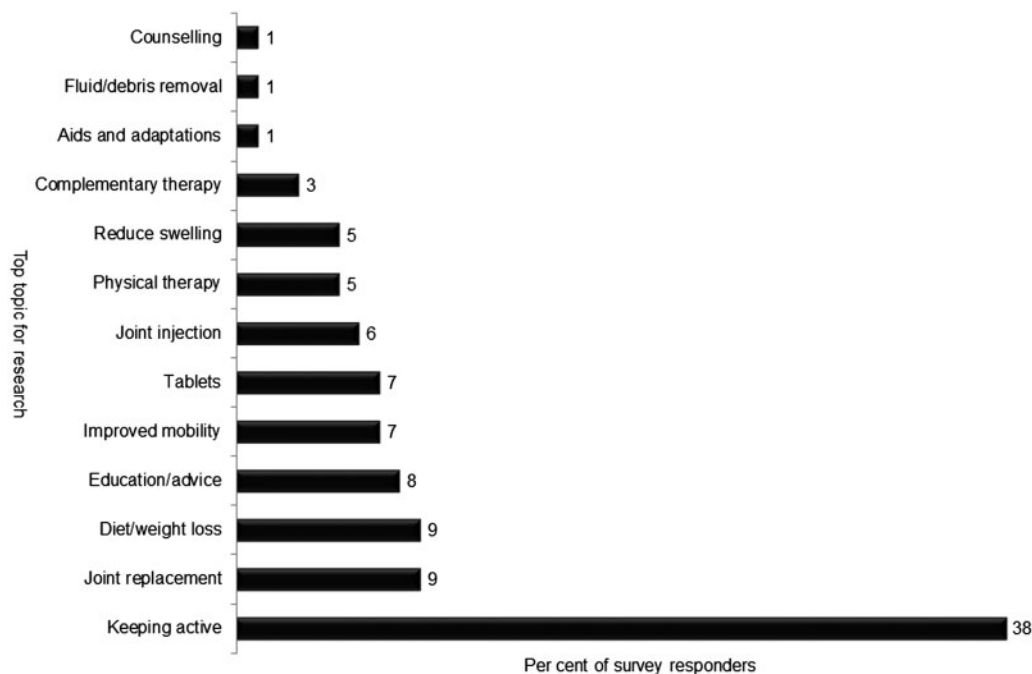
FIG. 1 Top priority for joint pain research in 1396 survey responders aged ⩾56 years.

Table 2 Association of characteristics with topic selected[a] as the first priority (OR; 95% CI)

Characteristic	Joint replacement	Diet/weight loss	Education/advice	Improved mobility	Tablets
Gender					
Male	1	1	1	1	1
Female	0.65; 0.42, 1.01	1.12; 072,1.76	1.29; 0.81, 2.06	1.51; 0.93, 2.46	1.00; 0.61, 1.63
Age, years					
56–64	1	1	1	1	1
65–74	2.69; 1.60, 4.50[b]	0.63; 0.39, 1.00	0.94; 0.59, 1.49	0.84; 0.51, 1.38	1.82; 1.04, 3.18[b]
⩾75	2.13; 1.19, 3.83[b]	0.36; 0.18, 0.72[b]	0.60; 0.32, 1.12	0.82; 0.44, 1.51	1.52; 0.80, 2.90
BMI					
Normal/underweight	1	1	1	1	1
Overweight	1.29; 0.80, 2.08	1.09; 0.64, 1.87	0.94; 0.59, 1.52	1.41; 0.82, 2.45	0.94; 0.55, 1.63
Obese	1.39; 0.78, 2.50	2.99; 1.74, 5.14[b]	1.23; 0.69, 2.18	2.14; 1.18, 3.87[b]	1.05; 0.55, 2.02
Social class					
Managerial/professional	1	1	1	1	1
Intermed/self-employed	0.92; 0.52, 1.64	1.41; 0.75, 2.62	1.03; 0.56, 1.90	0.96; 0.52, 1.79	0.74; 0.36, 1.53
Routine/manual	0.81; 0.49, 1.34	1.54; 0.90, 2.63	1.00; 0.60, 1.68	0.98; 0.56, 1.72	1.20; 0.67, 2.14
Hand pain/problem					
No	1	1	1	1	1
Yes	0.67; 0.43, 1.04	1.35; 0.82, 2.21	0.67; 0.43, 1.03	1.08; 0.65, 1.81	1.09; 0.65, 1.84
Hip pain					
No	1	1	1	1	1
Yes	1.76; 1.14, 2.70[b]	0.96; 0.62, 1.49	1.04; 0.68, 1.59	0.95; 0.61, 1.48	1.25; 0.79, 2.00
Knee pain					
No	1	1	1	1	1
Yes	0.79; 0.51, 1.23	1.26; 0.79, 1.99	1.13; 0.72, 1.77	2.20; 1.25, 3.87[b]	0.98; 0.59, 1.65
Foot pain					
No	1	1	1	1	1
Yes	1.15; 0.75, 1.76	0.83, 0.54, 1.29	0.84; 0.55, 1.29	1.68; 1.06, 2.68[b]	2.00; 1.23, 3.24[b]

[a]The six most selected topics only compared with selecting keeping active; [b]statistically significant at the 5% level.

Table 3 Frequency of selecting research topic in top three priorities by cluster

Topic	Number selecting topic (%)	n (%) of all selecting topic by cluster	
		Cluster 1	Cluster 2
n	1356	512 (38)	844 (62)
Lifestyle/self-management			
Keeping active	943 (70)	236 (25)	707 (75)
Diet/weight loss	443 (33)	13 (3)	430 (97)
Education/advice	438 (32)	34 (8)	404 (92)
Physical therapy	388 (29)	104 (7)	284 (73)
Improved mobility	382 (28)	225 (59)	157 (41)
Complementary therapy	208 (15)	68 (33)	140 (67)
Aids and adaptations	114 (8)	83 (73)	31 (27)
Counselling	57 (4)	4 (7)	53 (93)
Medical			
Joint replacement	299 (22)	206 (69)	93 (31)
Tablets	297 (22)	182 (61)	115 (39)
Joint injection	214 (16)	186 (87)	28 (13)
Reduce swelling	187 (14)	113 (60)	74 (40)
Fluid/debris removal	93 (7)	80 (86)	13 (14)

TABLE 4 Most common top three priorities[a] by cluster

	n (%)
Cluster 1	
1 × medical, keeping active, improved mobility	85 (17)
2 × medical, keeping active	77 (15)
3 × medical	51 (10)
2 × medical, improved mobility	47 (9)
1 × medical, keeping active, physical therapy	24 (5)
1 × medical, keeping active, aids/adaptations	24 (5)
1 × medical, physical therapy, improved mobility	22 (4)
2 × medical, physical therapy	19 (4)
1 × medical, improved mobility, complementary therapy	18 (4)
1 × medical, physical therapy, complementary therapy	15 (3)
Cluster 2	
Keeping active, diet/weight loss, education/advice	112 (13)
Keeping active, diet/weight loss, 1 × medical	112 (13)
Keeping active, education/advice, 1 × medical	79 (9)
Keeping active, education/advice, physical therapy	56 (7)
Keeping active, physical therapy, 1 × medical	47 (6)
Keeping active, diet/weight loss, physical therapy	46 (5)
Keeping active, education/advice, improved mobility	41 (5)
Keeping active, diet/weight loss, improved mobility	41 (5)
Keeping active, physical therapy, improved mobility	35 (4)
Keeping active, physical therapy, complementary therapy	31 (5)

Medical = injection, swelling, tablets, joint replacement or fluid removal. [a]Actual ranking ignored.

TABLE 5 Associations of clusters with people characteristics

Characteristic	Cluster 1 n (%)	Cluster 2 n (%)	OR[a] (95% CI)
Hip pain			
No	218 (43)	430 (51)	1
Yes	291 (57)	410 (49)	1.22; 0.97, 1.55
Knee pain			
No	142 (28)	268 (32)	1
Yes	368 (72)	575 (68)	1.22; 0.94, 1.58
Foot pain			
No	207 (41)	444 (53)	1
Yes	301 (59)	396 (47)	1.58; 1.25, 2.02[b]
Hand pain/problem			
No	164 (32)	304 (36)	1
Yes	348 (68)	539 (64)	1.06; 0.82, 1.36
Gender			
Male	203 (40)	349 (41)	1
Female	309 (60)	495 (59)	1.07; 0.84, 1.36
BMI			
Normal	171 (34)	293 (36)	1
Overweight	226 (46)	334 (41)	1.10; 0.84, 1.44
Obese	100 (20)	193 (23)	0.76; 0.55, 1.06
Age, years			
56–64	179 (35)	395 (47)	1
65–74	211 (41)	288 (34)	1.59; 1.22, 2.02[b]
≥75	122 (24)	161 (19)	1.73; 1.26, 2.37[b]
Social class			
Managerial/professional	118 (23)	220 (27)	1
Intermed/self-employed	126 (25)	201 (25)	1.13; 0.81, 1.58
Routine/manual	248 (48)	393 (48)	1.10; 0.83, 1.48

[a]Adjusted for other presented variables, cluster 2 is the reference category; [b]statistically significant at the 5% level.

collaboratively with research users, a new question for a postal survey was developed and administered to adults living in the community. Overall the new question was well completed and the majority of survey responders completed the question as intended by identifying their three top priorities for joint pain research.

Keeping active was the topic chosen as a top priority for research in our survey. Similarly, the study of Kjeken *et al.* [14] in Scandinavia also found that exercise (one form of keeping active) was prioritized by participants with OA. They also pointed out that despite the existence of rich evidence on the benefit of exercise for patients with musculoskeletal disorders, there is little agreement on which types of exercise are effective for patients. Other priorities included research into weight loss and education. These topics are aligned with guidelines for the management of OA in adults and are core recommended treatments [30]. Topics for research identified by the public thus generally match with scientific evidence about risk factors and recommended treatment for OA.

The findings from our study also partly echo Tallon's survey with regards to public preferences for education and advice research. However, in Tallon's survey, knee replacement was the top priority for research, while in our study only 9% of responders ranked joint replacement as first priority, and 22% selected it in their top three priorities. This is likely to be related to differences in the samples. Our study included people with hand and foot pain where joint replacement surgery is not an option, and it is noticeable that hip pain was related to choosing joint replacement surgery in our study.

People in the youngest age groups prioritized research into weight loss and diet more than older age groups. People in older age groups tended to prioritize more medical and invasive topics, e.g. joint replacement. This finding is consistent with rates of joint replacement, which tend to increase with age, although slightly decrease in those aged ≥85 years [31].

When analysing the top three priorities, there appears to be a clear divide in priority topics for research between those wanting research into more medical areas (joint replacement, reducing swelling, tablets, fluid removal and joint injections) and those preferring more lifestyle or self-management areas (keeping active, diet/weight loss, education and advice). Overall, only a third of respondents

predominantly wanted research in medical topics. This partly reflects the location of the joint problem, with those with foot problems more likely to prefer such research, but also age, as those in the older age group wanted research in medical areas, especially tablets, compared with the youngest groups. Garrow *et al.* [32] identified that few people with foot pain received treatment, and this may explain why people with foot pain prioritized medical treatment. Older patients are more likely to have more severe joint pain where medical treatment is most beneficial.

This preference for lifestyle or self-management topics is in agreement with previous studies that suggested there was a mismatch between public and professional interests in areas for research [6, 12, 15, 16, 24, 33]. People with joint pain prioritize research that focuses on helping patients to manage their condition rather than drug and surgical treatments. Qualitative studies have previously highlighted that the primary concern for many people experiencing chronic pain is to maintain valued activities [34, 35].

The survey was mailed to a large sample of people living in the community and achieved a high response rate. Opinion surveys have previously given limited data on research priorities because of the methods used for analysis [15, 16, 36]. This study is the first to employ advanced statistical techniques to study patients' priorities, whereas previous studies described findings based on descriptive analyses and ignored other topics except the individual's most preferred one. We have shown that priorities for research into joint pain vary, with distinct preferences for lifestyle/self-management or medical topics characterized by age and site of pain. However, medical topics, despite being common topics of research, are of less importance for research from the patient's perspective.

This study has some limitations. There was some non-response, and those who did respond may be considered a select group who had responded to two previous surveys. They were also recruited from a particular geographical area. The topic keeping active is very broad and may have several meanings. Some free-text responses gave added specificity to the topic of keeping active, e.g. specific forms of exercise, such as yoga and swimming, tailored activity for exclusive pain sites such as physical therapy treatment or valued activity such as dancing and gardening with mental and overall well-being.

However, the findings provided information for discussion in the next stage of our study. Our aim now is to continue to collaborate with patient groups, assess the relevant evidence base and discuss and agree a study proposal that will take forward the findings of this population survey.

> ### Rheumatology key messages
>
> - This is the first study to use a large-scale survey to obtain public perspectives of joint pain research.
> - Members of the public who suffer from joint pain prioritize research in lifestyle and self-management topics.

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