

BMJ Open Elbow conditions: research priorities setting in partnership with the James Lind Alliance

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ABSTRACT

Objective To undertake a UK-based James Lind Alliance (JLA) Priority Setting Partnership for elbow conditions and be representative of the views of patients, carers and healthcare professionals (HCPs).

Setting This was a national collaborative study organised through the British Elbow and Shoulder Society.

Participants Adult patients, carers and HCPs who have managed or experienced elbow conditions, their carers and HCPs in the UK involved in managing of elbow conditions.

Methods The rigorous JLA priority setting methodology was followed. Electronic and paper scoping surveys were distributed to identify potential research priority questions (RPQs). Initial responses were reviewed and a literature search was performed to cross-check categorised questions. Those questions already sufficiently answered were excluded and the remaining questions were ranked in a second survey according to priority for future elbow conditions research. Using the JLA methodology, responses from HCP and patients were combined to create a list of the top 18 questions. These were further reviewed in a dedicated multistakeholder workshop where the top 10 RPQs were agreed by consensus.

Results The process was completed over 24 months. The initial survey resulted in 467 questions from 165 respondents (73% HCPs and 27% patients/carers). These questions were reviewed and combined into 46 summary topics comprising: tendinopathy, distal biceps pathology, arthritis, stiffness, trauma, arthroplasty and cubital tunnel syndrome. The second (interim prioritisation) survey had 250 respondents (72% HCP and 28% patients/carers). The top 18 ranked questions from this survey were taken to the final workshop where a consensus was reached on the top 10 RPQs.

Conclusions The top 10 RPQs highlight areas of importance that currently lack sufficient evidence to guide diagnosis, treatment and rehabilitation of elbow conditions. This collaborative process will guide researchers and funders regarding the topics that should receive most future attention and benefit patients and HCPs.

BACKGROUND

Elbow conditions encompass a wide range of pathologies, including trauma and its

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Use of established and transparent methods for conducting research priorities surveys using James Lind Alliance methodology.
- ⇒ The process and study have produced the top 10 research treatment uncertainties in relation to common elbow problems.
- ⇒ Survey responses were received from across the UK and from a range of patients and healthcare providers.
- ⇒ The SARS-CoV-2 pandemic limited the use of patients and volunteers for face-to-face meetings to gather responses.

sequelae, tendinopathy, arthritis, sports injuries and nerve compression disorders.¹ The primary role of the elbow is to position the hand in space in order to facilitate all activities whether they involve reaching or are performed close to the body. Dysfunction of the elbow, particularly those pathologies that restrict motion and/or cause pain, can result in significant functional restriction.^{2 3} The most common elbow conditions include tendinopathies such as tennis elbow, golfers elbow, arthritis and cubital tunnel syndrome.^{1 4} Research and innovation regarding the elbow has been neglected relative to conditions affecting other large joints, although in recent years there has been growing impetus to improve our understanding and treatment of elbow conditions.

The dearth of high-quality evidence related to the optimal management of elbow conditions is in part due to small scale research focused on answering narrow questions posed by healthcare professionals (HCPs), which may not always align with patients' priorities.⁵

The James Lind Alliance (JLA) is an independent initiative hosted by the National Institute for Health Research (NIHR). Established in 2004 the JLA has an established

**Table 1** Time frame of priority setting partnership (PSP)

November 2019	Initial face-to-face meeting to determine the protocol and scope of the PSP, and the terms of reference (TOR).
November to December 2019	Regular videoconference to finalise protocol, scope, TOR and initial survey design.
January to August 2020	Initial survey distribution and promotion.
August 2020	Videoconference to finalise total initial questions and agree on themes and wording of summary questions.
August 2020 to February 2021	Videoconference to finalise the phrasing of summary questions.
February to April 2021	Literature search to review potential 'answered' summary questions. Design of interim survey agreed.
April to August 2021	Interim prioritisation of summary questions.
August 2021	Videoconference to finalise the top 18 questions to put forward to the final workshop.
November 2021	Final workshop and conclusion of 'Top 10' research priorities.

method to identify priorities for future research through collaboration between patients, carers and HCPs working together as equals. In doing so, the JLA priority settings partnerships (PSPs) provide a unique opportunity for members of the public to influence the national research agenda. Previous successful PSPs in a variety of fields have helped guide funders of research to support studies that have ultimately answered the questions important to both patients and HCPs.^{6 7} This article describes the process and results of this UK based PSP for elbow conditions using the rigorous JLA priority setting methodology.

METHODS

The 'elbow conditions' PSP was conducted in accordance with the JLA guidelines.⁶ The preparation for the PSP began in November 2019 and was undertaken over a 24-month period (table 1).

The process is summarised in figure 1.

Steering group and partner organisations

The first step of the PSP was to establish a steering group to direct the process. The steering group included a diverse range of stakeholders, including patients, carers and HCPs. The HCPs comprised surgeons and physiotherapists from across the UK. Each member of the group had a connection to an elbow condition, either as someone with a lived experience of the condition or a professional who treated patients with elbow conditions. The steering group information can be found on JLA website <https://leicestershoulderunit.co.uk/elbow-bsp/steering-group/>.

An independent JLA adviser (JG) facilitated the PSP steering group with local administrative support.

This was to ensure that each member had an equal opportunity to participate in discussion and decision making, resulting in a fair and transparent process. The information specialists developed the surveys, managed data, conducted the analysis and presented the findings in the form of an infographic and a report. The steering group oversaw and advised on each task. The PSP steering group met in person for the first meeting, followed by a number of

videoconferences during the COVID-19 pandemic. Before any decisions were made, a minimum number of patients (two) and clinical representatives (two) had to be present.

Stage 1: Establishing the PSP Steering Group

- Formation of Steering Group
- Protocol and scope agreed



Stage 2: Initial Survey Design and Dissemination

- Distribution of electronic and paper surveys
- 165 respondents - 118 healthcare professionals, 40 patients, 4 family members/friends/carers, 3 unspecified.
- 467 uncertainties collected



Stage 3: Creation of Summary Questions

- Thematic analysis by information specialist
- Meeting with the steering group
- 467 questions combined into 46 summary questions under 7 main themes.



Stage 4: Literature Review

- MEDLINE, EMBASE, CINAHL, Cochrane central database, Cochrane Library, and NICE Guidelines.
- Titles and abstracts reviewed by three information specialists
- Relevant systematic reviews and guidelines assessed for relevance and quality
- None deemed to fully answer the uncertainties.



Stage 5: Interim prioritisation

- Distribution of electronic and paper surveys
- Top 18 questions ranked by 250 respondents (181 healthcare professionals, 61 patients, 4 family/friends/carers, 4 unspecified)



Stage 6: Final workshop prioritisation

- 31 participants (19 healthcare professionals, 12 patients/carers)
- Consensus reached on Top 10 priorities

Figure 1 Flow chart summarising the priority setting process for elbow conditions in line with James Lind Alliance methodology. PSPs, priority settings partnerships; NICE, National Institute for Health and Care Excellence.

Definition of scope

Any potential questions about elbow conditions were considered in the scope of this PSP.

The steering group recognised the need to include both traumatic and chronic elbow conditions. Hence, this PSP covered the following conditions affecting the elbow: osteoarthritis, inflammatory arthritis, elbow stiffness, tendinopathy (including tennis elbow, golfers elbow, biceps and triceps tendinopathy), chronic elbow instability, ulnar nerve pathology, biceps tendon rupture, acute elbow fracture, dislocations and congenital elbow conditions. It was further agreed that both the surgical and non-surgical treatment of these conditions were within the scope of the PSP.

Acute fractures of the elbow were considered in previous JLA PSPs on 'Research Priorities for the Management of Broken Bones of the Upper Limb in People over 50' and 'Complex Fractures', and the steering group agreed that these injuries would still be included in the present PSP given their potential for disability. The steering group initially felt that paediatric elbow injuries and congenital elbow problems should also be included in the PSP, despite acknowledgement that these may be included in other future PSPs.

Initial survey design and dissemination

The steering group created a survey questionnaire in which patients, carers and HCPs were asked for their input on the topics that mattered most to them about elbow conditions.

The survey was created in both a paper (online supplemental appendix 1) and an online format using Online Surveys (previously Bristol Online Surveys).⁸ The steering group agreed on the survey design and phrasing to ensure that it was user-friendly for the general public and that it did not bias responses. Basic demographic information was gathered, including age, gender, role, initial postcode section and consent to continue participating in the PSP.

The primary survey question was:

- ▶ What questions about elbow conditions would you like to be answered by research?

Using the steering group's collective expertise and resources, the survey was advertised and publicised through multiple channels.

While the survey was live, responses were tracked and additional promotion was targeted at any under-represented stakeholder groups to ensure balanced and representative distribution of responses. The following are a few examples of public relations and promotional activities:

- ▶ A dedicated social media account (Twitter, Facebook) called 'Elbow PSP' was created to promote the survey.
- ▶ The survey was promoted by individual members of the steering group via emails to professional networks, social media and 'word of mouth'.
- ▶ Professionally designed JLA posters were created for mounting in outpatient clinics setting.

- ▶ Relevant organisations were contacted to bring the survey to the attention of their members. These included specialty organisations (eg, Royal College of General Practice, Royal College of Emergency Medicine, British Society for Rheumatology, British Elbow and Shoulder Society, The Faculty of Sport and Exercise Medicine), patient bodies (eg, Arthritis UK, Patient UK) and sports organisations (eg, Tennis UK, Golf Organisations UK).

Collection of questions and classifying research suggestions

The survey began on 1 January 2020 and ended on 15 August 2020. The initial survey responses were gathered and recorded in their raw form. The steering group agreed on a classification system based on elbow conditions and, when applicable, a subcategory of topic (surgical, non-surgical, rehabilitation, investigation or general). Two information specialists (PR and HHC) classified the responses and responses that were submitted as general comments or out-of-scope questions were separated.

Creation of summary questions

The information specialists combined the list of classified questions into a set of 'summary questions', which reflected the original submissions and were broader in scope than any of the original survey questions.

These were decided on by consensus to include all the individual questions from the initial survey and were worded to be easily understandable by the general public without a medical background. This was carried out with input from the patient members of the steering group. For example, 'What are the long-term outcomes of conservative management strategies for golfers and tennis elbow in terms of seeking further treatments/surgery and cost effectiveness?' and 'Do we have strong evidence about the best treatment for elbow tendinopathies?' were both included under the summary question, 'What is the effectiveness of surgery for elbow tendinopathies (eg, tennis/golfer's elbows) compared with non-surgical management?'.

Literature review

Following the formulation of the summary questions, the existing literature was examined to see whether any of the questions had been addressed previously. According to JLA guidelines, a question is considered unanswered if either (1) no recent (within the past 3 years) reliable systematic reviews of research evidence addressing the question exist or (2) up-to-date systematic reviews of research evidence show that uncertainty still persists.^{6 7} The steering group agreed to increase the timeframe from 'past 3 years' to 'past 5 years' due to paucity of literature on elbow conditions.

Literature searches were conducted by one of the information specialists (PD) and her clinical librarian team. For published systematic reviews relevant to each summary question, the following databases were searched: MEDLINE, EMBASE, CINAHL, Cochrane



central database, Cochrane Library and National Institute for Health and Care Excellence (NICE) guidelines. Two other information specialists (PR and HHC) verified the summary questions against the relevant systematic reviews to make sure the uncertainty had not been addressed previously by systematic review or existing guidelines.

Interim prioritisation

With the remaining unanswered summary questions, an interim prioritisation survey was produced following the evidence-checking step. From the summary questions, respondents were asked to choose the ten most important questions from their perspective. This survey was available for 5 months in either online or print version (April to August 2021). It was promoted via similar channels as the first survey.

After compiling all the responses, they were scored according to a template devised by the JLA. The summary questions were ranked according to the number of times they had been picked in two separate groups: (1) responses from HCPs and (2) responses from the patients/carers. The information specialists combined the 13 most highly ranked questions from each group which resulted in 18 final questions (because of overlap between the groups) that the steering group agreed on, for presentation in the final workshop.

Final Workshop: deciding the 'top 10' priorities

For a 1-day virtual meeting, HCPs, patients and carers came together to determine the final 'top 10' research questions for elbow conditions. Participants were recruited through the steering group invitation, social media, outpatient clinics and respondents who participated in the first and interim surveys. Places were assigned on a first-come, first-served basis, with efforts made to guarantee a similar number of participants (the patients, HCPs) and also to get a range of demographics, conditions, HCP specialties.

The videoconference workshop took place on 24 November 2021. To reach consensus on the final 'top 10' priorities, the workshop used a modified nominal group methodology. Stakeholders were split into four groups, with equivalent proportions of HCPs and patient/carers. With the help of the JLA facilitators, each group explored the 18 questions within their group and ranked them in order of priority by consensus. The rankings from the four groups were then combined and presented back to the workshop participants. Participants were then reassigned to new groups, preserving a similar balance and the combined rankings from the first session were discussed and ranked again. The rankings from each of the four groups were then combined again to produce a final ranked order (from 1 to 18) which was presented to the whole group. The 'top 10' priorities were highlighted and participants were given the opportunity to comment on the order which had been reached through this consensus-building process.

Dissemination of results

The steering group discussed and decided on the PSP's dissemination strategy, which will primarily consist of the publication of this report. It will be distributed to funding and research agenda-setting organisations, such as the NIHR, as well as partner organisations. The findings will be presented at specialty conferences and on social media. It will also be made available to the public via the JLA website.

Patient and public involvement

Patient and public involvement was a core part of the study. The steering group lay members included those with lived experience of elbow conditions. Both the initial survey and the interim prioritisation survey were answered by the public, the majority of whom had lived experience of elbow conditions. Participants at the final prioritisation workshop included equal proportions of lay members (elbow conditions) and HCPs.

RESULTS

Initial survey

During the initial survey, 165 people contributed 467 original questions. Most of the respondents (85%) were between the ages of 30 and 69, with a male predominance (88, 56%). One hundred and eighteen respondents (71%) were HCPs, 40 (24%) were patients with elbow conditions and 4 (3%) were family members, friends or carers. Three (2%) respondents did not specify their background. Sixty-seven (41%) suffered from elbow conditions, the majority of whom were between the ages of 30–49 (52%). In this cohort, 39 (58%) were patients, 1 (1%) was carer and 27 (42%) were HCPs. [Figure 2](#) depicts the distribution of participants by age, gender and background.

Classification

Twenty-one responses were subsequently excluded from the list after agreement among the steering group, leaving 446 responses classified as shown in [figure 3](#). Reasons for exclusion were 'duplication' (13 responses), 'unclear suggestion' (2 responses), 'out-of-scope' (1 response) and 'no discernible questions' (5 responses).

Summary questions and literature reviews

The steering group agreed on 46 summary questions under seven broad topics after analysing each of the initial questions: tendinopathy, biceps tendon pathology, arthritis, stiffness, trauma, arthroplasty and cubital tunnel syndrome. All of the summary questions were determined to be of genuine uncertainty after the literature review.

Interim prioritisation

A total of 250 people responded to the interim survey. Similar to the initial survey, the vast majority (87%) were between the ages of 30 and 69, with a male predominance (150, 60%). In comparison to patients, family, friends or carers (65, 26%), the majority of responses (181, 72%)

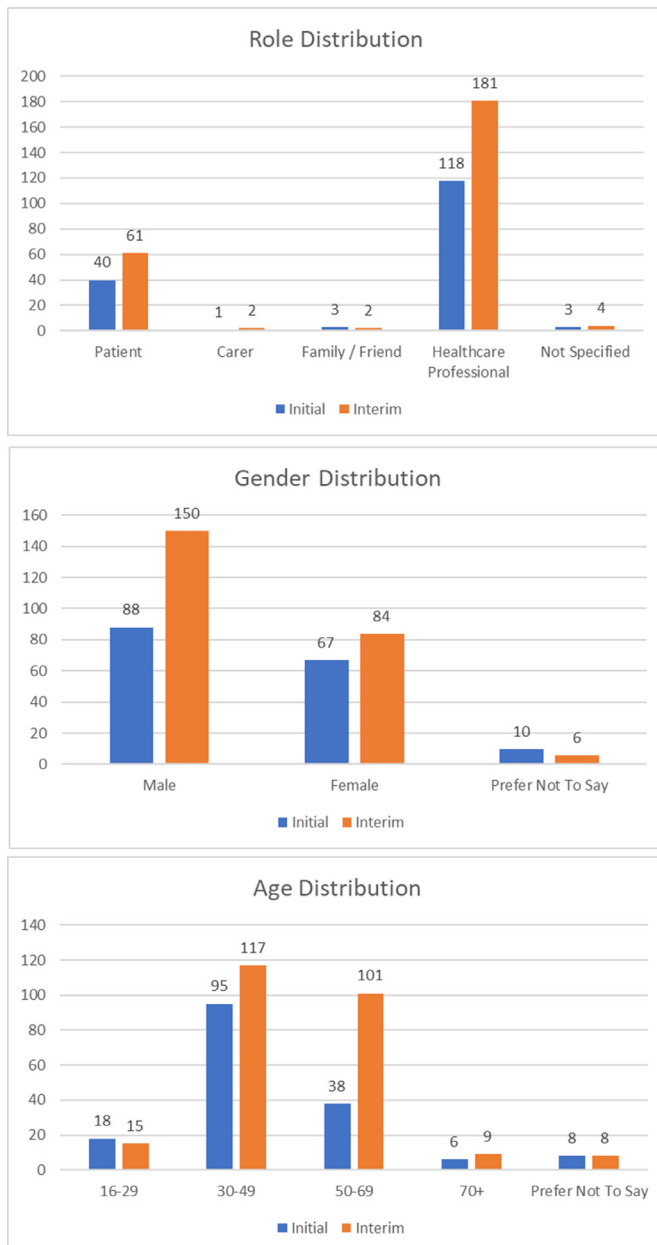


Figure 2 Demographic background (role, gender, age distribution) of survey respondents.

were HCPs, with 4 (2%) respondents did not specify. **Figure 2** illustrates a demographic summary. Using the described ranking method, top eight ranked questions overlapped between HCPs and the patients/carers and further top five questions were selected from both groups. In total, the top 18 questions were identified for the final workshop.

Final workshop

The final workshop was attended by 19 HCPs (including surgeons, rheumatologist and allied health professionals) and 12 patients with elbow conditions or carers) (2 patients were not able to attend). It was facilitated by four JLA representatives. The final 'top 10' research priorities (see [table 2](#)) was agreed and signed off by all stakeholder

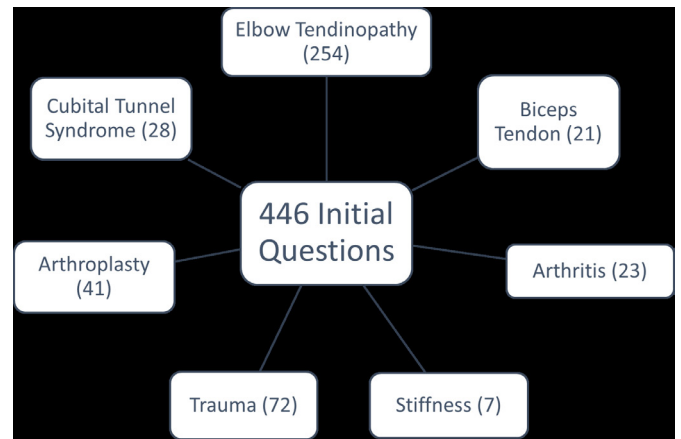


Figure 3 Classification of research questions submitted during initial survey.

representatives. The full list of the top 18 priorities can be viewed in online supplemental appendix 2.

DISCUSSION

Through the rigorous JLA process, this UK PSP has delivered the 'top 10' research priorities for elbow conditions. These research priorities represent the collective shared views of the multiple stakeholders including patients, carers, family and friends and HCPs. The top 10 research priority questions encompass broad elements across management (surgical and non-surgical), prognosis and rehabilitation for elbow conditions. Through the process, we have highlighted that there are clear need for further research for many of these questions. We found that some questions including management options are only partly answered, but in many areas, there are no clear answers to inform care pathways or management of the elbow conditions. This paper outlines the efforts taken by the steering group, with the help of key stakeholders to identify the most pressing research priorities in patients with elbow conditions.

Key messages

In the top 10 priorities of elbow conditions, arthritis, tendinopathy, stiffness and arthroplasty were the most frequently occurring themes, broadly encompassing management (surgery or non-surgical) and rehabilitation regimens. Within the top 18 priorities, tendinopathies continue to receive the most inquiries. The steering group believed that the priorities had been in line with the current, poor-quality evidence regarding elbow conditions through the JLA process and evidence checking.

This PSP employs similar JLA methodology to earlier PSP conducted in this field, either on 'complex fracture'⁹ or 'upper limb fracture'.¹⁰ This PSP's primary distinction is that it focuses on all elbow pathology, including paediatric cohort in elbow trauma. In comparison to Bretherton *et al*⁹ and Sheehan *et al*,¹⁰ the 'top 10' research priorities identified in this PSP were more 'chronic' conditions.¹⁰

**Table 2** Top 10 research priorities for elbow conditions (November 2021)

Rank	Questions
1	What is the best treatment (surgery or conservative management) for elbow arthritis in young/active patients?
2	Which factors affect the outcome and longevity of elbow replacements?
3	What is the best rehabilitation programme for prevention of stiffness following elbow trauma or surgery?
4	What is the best treatment approach (surgery or without surgery) in management of early or persistent elbow tendinopathies (such as tennis/golfer's elbow)?
5	Comparing non-surgical treatments (such as medications, therapy interventions, injections etc), which is most effective in elbow arthritis?
6	What is the outcome of surgery (including open or key-hole surgery) in the management of elbow arthritis?
7	What is the best treatment (including surgical and non-surgical) for non-arthritic elbow stiffness?
8	How to manage pain (early/persistent) in elbow conditions?
9	What and when is the best treatment option for distal biceps tendon ruptures (surgical or non-surgical)?
10	What are the best pre and post-op rehabilitation regimens for total elbow replacements, including advice on long term physical restrictions?

Strengths and limitations

This study has a number of strengths. This is the first study to report national research priorities in elbow conditions in partnership with the JLA. By using the established JLA methodology, we ensured a robust and transparent study with a fair and representative outcome. Patients and carers were actively involved at all stages of the process, from the initial scoping survey to the final workshop, to ensure that the patient voice was clearly captured and remained at the centre of our efforts alongside the views of health professionals.

For transparency, all recorded responses have been logged and available for review in online supplemental appendix 1. The formulation of summary questions was performed with discussion and agreement of all stakeholders and each stage involved all steering group members' input ensuring robust and fair consensus. This also aided to ensure that interpretations were consistent and not misrepresented. Responses have been submitted from widely across the UK, and we are therefore confident that this work represents a national viewpoint.

The study does have some limitations. First, the PSP was impacted by the COVID-19 pandemic and as highlighted by another PSP,⁹ which encountered similar issues, this impacted heavily on any face-to-face aspects of the JLA methodology. Previous PSPs have often relied on patients to disseminate surveys and steering group discussions were also to try to recruit from outpatient clinics, however, both of which were impeded by the pandemic. This can partly explain why the responses were not quite split evenly among HCP and non-healthcare responses as desired. However, to limit this bias, combining separate rankings from the two groups, through the JLA methodology, enabled this to be taken into account. The initial survey scoping responses were a little lower than would have been anticipated due to the impact of the COVID-19 pandemic, however, the number of scoping questions was sufficient and additionally the responses to the interim survey were much better and the number of responses depend on the

condition. Use of virtual meeting enabled facilitation of steering group meetings and the all-important workshop discussions, break out rooms through this format could also be used to enable running for the final workshop. Participation in steering committee meetings and the final workshop, using videoconferencing was different to the suggested methods by the JLA but the alterations to workshop and meetings methodology enabled participants attendance easier and facilitation by trained JLA advisers enabled everybody to contribute equally.

Implications and dissemination of this PSP

The results of the top 10 questions for elbow conditions are due to be presented at the annual national conferences in 2022. The top 10 have also been circulated on a variety of social media platforms including Twitter, Facebook and Instagram as well as advertised on the PSP website and funding bodies' websites. They are also further now being disseminated through formal publication and reporting to funding and research agenda setting organisations such as the NIHR and the Medical Research Council, as well as the major research funding charities.

Our hope is that these research priority questions will help to direct and shape research in this area and provide clear and definitive answers to the top 10 to help improve the care provided by health professionals to benefit patients suffering with elbow conditions.

CONCLUSION

Through this PSP we have successfully outlined the key research priorities for elbow conditions that are important for patients, carers and HCPs. This work should help guide the prioritisation, funding and future research for elbow conditions.

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Contributors HPS and CP made the application to the James Lind Alliance for the Elbow Conditions priority setting partnership. JG was appointed the JLA adviser to the PSP. HHC, PD and PR reviewed and coded all submissions from the initial survey. All the Steering Group members (HPS, HHC, PR, PD, AR, MB, AW, JP, AM, VJ, RP, JG, SG and CP) contributed to the protocol design, production of both the initial survey and interim prioritisation survey, promotion and dissemination of surveys to partner organisations and formation of summary questions. HPS, HHC and PR drafted the manuscript. HPS is responsible for the overall content as the guarantor. All authors reviewed and approved the final manuscript before submission.

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Competing interests AR, AW, SG, CP and HPS report NIHR grant for research in shoulder and elbow surgery not related to the present project, these grants are provided to their institutions. AR reports DePuy J&J Educational grant to institution unrelated to present article. AW reports consulting fees and honoraria from Medartis and Wright Medical/Stryker unrelated to this work. AW, AR, VJ, MB, CP, AM and SG are/were members of BESS council. All additional interests are outside the direct remit of the submitted work.

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