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# BMJ Open

## Elbow Conditions: Research Priorities Setting in Partnership with the James Lind Alliance

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|-------------------------------|---|
| Journal:                      | <i>BMJ Open</i>   |
| Manuscript ID                 | bmjopen-2022-062177   |
| Article Type:                 | Original research   |
| Date Submitted by the Author: | 18-Feb-2022   |
| Complete List of Authors:     | Singh, Harvinder pal; Leicester General Hospital; University of Leicester<br>Chong, Han; Leicester General Hospital<br>Raval, Parag; Leicester General Hospital<br>Divall, Pip; University Hospitals of Leicester NHS Trust<br>Rangan, Amar; The James Cook University Hospital, Trauma and Orthopaedics; University of York, Department of Health Sciences<br>Bateman, Marcus; University Hospitals of Derby and Burton NHS Foundation Trust, Derby Shoulder Unit<br>Watts, Adam; Wrightington Wigan and Leigh Teaching Hospitals NHS Foundation Trust<br>Phadnis, Joideep; Brighton and Sussex University Hospitals NHS Trust Trauma and Orthopaedics<br>Gower, Jonathan; James Lind Alliance<br>Jones, Valerie; Sheffield Teaching Hospitals NHS Foundation Trust<br>Pandey, Radhakant; Leicester General Hospital<br>Gwilym, Steve; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences<br>Majed, Addie; Royal National Orthopaedic Hospital NHS Trust<br>Peach, Chris; Manchester University NHS Foundation Trust |
| Keywords:                     | Elbow & shoulder < ORTHOPAEDIC & TRAUMA SURGERY, QUALITATIVE RESEARCH, Trauma management < ORTHOPAEDIC & TRAUMA SURGERY   |
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# Elbow Conditions: Research Priorities Setting in Partnership with the James Lind Alliance

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**Key Terms:**

Elbow Joint, Clinical Research, Trauma management, Research Priorities, Partnership

Word count: 3287

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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 (HCP)

**Setting:** This was a national collaborative study organised through the British Elbow and Shoulder Society (BESS).

**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 multi-stakeholder 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.

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## BACKGROUND

Elbow Conditions encompass a wide range of pathologies including trauma and its 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, 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 method to identify priorities for future research through collaboration between patients, carers, and healthcare professionals 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 health care professionals (6, 7). This article describes the process and results of this UK based Priority Setting Partnership 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).

| 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.                            |
| Jan 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.   |

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://www.jla.nihr.ac.uk/priority-setting-partnerships/elbow-conditions/>.

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.

### ***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 healthcare professionals were asked for their input on the topics that mattered most to them about elbow conditions.

The survey was created in both a paper (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 (e.g. Royal College of General Practice, Royal College of Emergency Medicine, British Society for Rheumatology, BESS, The Faculty of Sport and Exercise Medicine), patient bodies (e.g. Arthritis UK, Patient UK), and sports organisations (e.g. Tennis UK, Golf Organisations UK)

### ***Collection of Questions and Classifying Research Suggestions***

The survey began on January 1, 2020 and ended on August 15, 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 upon 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 (e.g. tennis/golfer’s elbows) compared to nonsurgical 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 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

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3 separate groups: 1) responses from healthcare professionals and 2) responses from the patients /  
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5 carers. The information specialists combined the 13 most highly ranked questions from each group  
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7 which resulted in 18 final questions (because of overlap between the groups) that the Steering  
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9 Group agreed upon, for presentation in the final workshop.  
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### 16 17 ***Final Workshop: Deciding the 'Top Ten' Priorities***

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19 For a one-day virtual meeting, healthcare professionals, patients, and carers came together to  
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21 determine the final 'Top 10' research questions for elbow conditions. Participants were recruited  
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23 through the Steering Group invitation, social media, outpatient clinics, and respondents who  
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25 participated in the first and interim surveys. Places were assigned on a first-come, first-served basis,  
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27 with a cap on each group (the patients, healthcare professionals) to guarantee an equal number of  
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29 participants and also to get a range of demographics, conditions, HCP specialties.  
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33 The videoconference workshop took place on November 24, 2021. To reach consensus on the final  
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35 'Top Ten' priorities, the workshop used a modified nominal group methodology. Stakeholders were  
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37 split into four groups, with equivalent proportions of healthcare professionals and patient/carers.  
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39 With the help of the JLA facilitators, each group explored the 18 questions within their group and  
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41 ranked them in order of priority by consensus. The rankings from the four groups were then  
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43 combined and presented back to the workshop participants. Participants were then reassigned to  
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45 new groups, preserving a similar balance, and the combined rankings from the first session were  
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47 discussed and ranked again. The rankings from each of the four groups were then combined again to  
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49 produce a final ranked order (from 1 to 18) which was presented to the whole group. The 'Top Ten'  
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51 priorities were highlighted and participants were given the opportunity to comment on the order  
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53 which had been reached through this consensus-building process.  
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### 59 ***Dissemination of Results***

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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 National Institute for Health Research (NIHR), as well as partner organisations. The findings will be presented at speciality 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.

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## RESULTS

### *Initial Survey*

During the initial survey, 165 people contributed 467 original questions. Sixty-seven (41%) suffered from elbow conditions, the majority of whom were between the ages of 30-49 (52%). Most of the respondents (85%) were between the ages of 30 and 69, with a male predominance (88, 56%). One hundred and eighteen respondents (73%) were healthcare professionals, 40 (25%) were patients with elbow conditions, and four (2%) were family members, friends or carers. 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 (60%). In comparison to patients, family, friends, or carers (26%), the majority of responses (72%) were healthcare



professionals. Figure 2 illustrates a demographic summary. Using the described ranking method, top 8 ranked questions overlapped between healthcare professionals and the patients/carers and further top 5 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** healthcare professionals (including surgeons, rheumatologist, and allied health professionals) and **12** patients with elbow conditions or carers) (two patients were not able to attend). It was facilitated by four JLA representatives. The final ‘Top Ten’ Research priorities (See Table 2) was agreed and signed off by all stakeholder representatives. The full list of the top 18 priorities can be viewed in the Appendix 2.

| Table 2. Top 10 Research Priorities for Elbow Conditions (Nov 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? |

# 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 health care professionals. The top ten 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.

## 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 the supplementary material. 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. Firstly, 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 upon 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 amongst healthcare professional 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 ten questions for elbow conditions are due to be presented at the annual national conferences in 2022. The Top Ten 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

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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 health care professionals. This work should help guide the prioritisation, funding and future research for elbow conditions.

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## Acknowledgments

We would like to thank all those involved including patients, carers and health care professionals in the Steering Group for taking the time and effort with this study. Additionally, we would like to thank the British Orthopaedic Association, British Elbow Shoulder Society and the Leicester Shoulder Unit Charity for their support and funding to be able to complete this study. We thank Michelle Wallis, Peter Tippet, Brenden Gardiner, Paul Rodgers, Margaret Hughes and Ann Heaton for being part of our PSP as patient representative. We thank Elaine James for coordinating the Elbow PSP including communication and minutes recording. We thank all those who participated in the initial survey, interim prioritisation survey and final prioritisation workshop.

## Contributors

HS 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. HC and PR reviewed and coded all submissions from the initial survey. All the Steering Group members 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. HS, HC and PR drafted the manuscript. All authors reviewed and approved the final manuscript before submission.

## Funding

The Elbow Conditions Priority Setting Partnership was funded by the British Orthopaedic Association (BOA) (Pump priming grant, Grant number N/A), British Elbow and Shoulder Surgeon (BESS) (Pump priming grant, Grant number N/A), and Leicester Shoulder Unit Charity (Grant number N/A).

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Ethics Approval

Not Applicable

For peer review only

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## Conflict of Interest

AR, AW, SG, CP, HS 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 Ltd 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. All other authors declare no competing interests.



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## FIGURES CAPTION

**Figure 1:** Flowchart summarising the priority setting process for Elbow Conditions in line with James Lind Alliance methodology.

**Figure 2:** Demographic background (Role, Gender, Age distribution) of survey respondents.

**Figure 3:** Classification of research questions submitted during initial survey.

## APPENDICES

**Appendix 1:** Initial Survey Questionnaires – Paper Forms.

**Appendix 2:** The Top 18 ranked questions from the interim survey.

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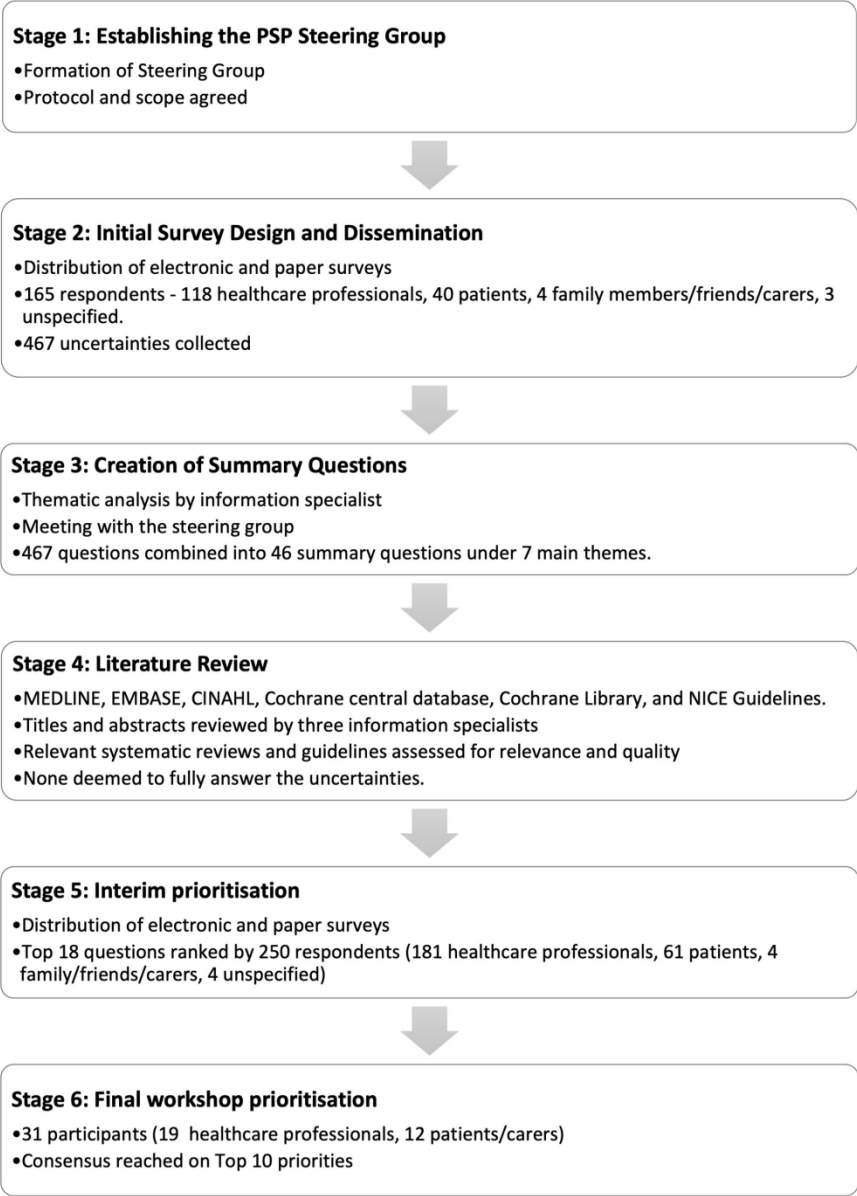
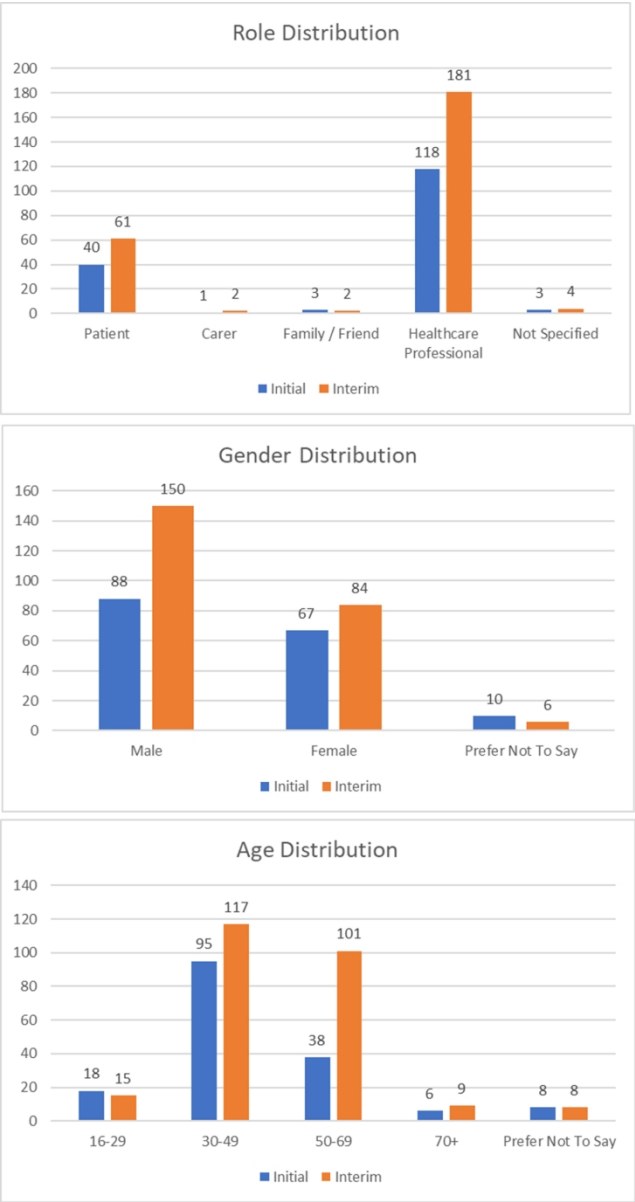


Figure 1: Flowchart summarising the priority setting process for elbow conditions in line with James Lind Alliance methodology.

155x214mm (300 x 300 DPI)



Demographic background (Role, Gender, Age distribution) of survey respondents.

127x239mm (300 x 300 DPI)

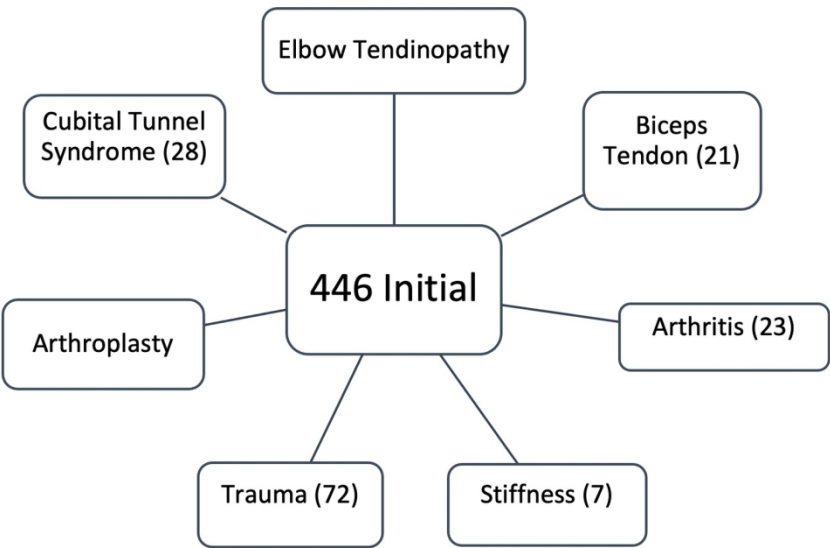


Figure 3: Classification of research questions submitted during initial survey.  
152x88mm (300 x 300 DPI)

**ABOUT YOU (optional)**

It is important that we know a little bit about you so that we can ensure we have collected the views from a wide range of people with different experiences.

Do YOU have or have YOU had an Elbow problem? Yes ☐ No ☐

If YES, at what age did your elbow problem start?

☐ <16 ☐ 16-29 ☐ 30-49 ☐ 50-69 ☐ 70+

Which describes you?

☐ Patient

☐ Carer

☐ Family/ Friend

☐ Healthcare Professional, please specify \_\_\_\_\_

Are you: ☐ Male ☐ Female ☐ Prefer to self describe ☐ Prefer not to say?

Age: ☐ <16 ☐ 16-29 ☐ 30-49 ☐ 50-69 ☐ 70+ ☐ Prefer not to say

What is your post code, first 3 or 4 characters only     ?

What is your ethnicity?

☐ White ☐ Asian/Asian British ☐ Black/Caribbean/Black British

☐ Arab ☐ Mixed/multiple ethnic groups ☐ Prefer not to say

Other ethnic group ☐ please describe \_\_\_\_\_

**THANK YOU, please consider** completing this survey. Please hand it back to a staff member or return to **James Lind Alliance PSP Coordinator, Elaine James, elaine.james@uhl-tr.nhs.uk** using the envelope provided.

If you require assistance completing this survey, please do not hesitate to contact us:



<https://www.bess.org.uk/index.php/elbowJLA>



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[elbowjla@leicester.ac.uk](mailto:elbowjla@leicester.ac.uk)

# ELBOW CONDITIONS

Can you help us decide the questions that should be answered by research?

Have you had or cared for someone who had problems with their elbow that has required help from a healthcare professional?

OR

Are you a healthcare professional who is involved in the treating patients with elbow conditions?



Please complete the sections on the next page to suggest questions about treatment and recovery in elbow conditions that could be answered by research in the future.

To be completed by Patients, Carers, Family/Friends or Health Care Professionals

To find out more about this project visit  
<https://www.bess.org.uk/index.php/elbowJLA>



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**Who are we?**

We are a group of patients, clinicians and researchers who want to help improve the care and quality of life of patients who suffer from elbow joint conditions/ disorders/ diseases. This is a collaboration between the British Elbow and Shoulder Society, British Orthopaedic Association, Leicester Shoulder Elbow Unit Charity and the James Lind Alliance.

**What are the elbow conditions?**

- Examples of the elbow conditions include:
- Elbow Osteoarthritis
  - Inflammatory arthritis,
  - Tendonitis (like Tennis Elbow, Golfers Elbow),
  - Biceps or Triceps tendonitis
  - Elbow Stiffness,
  - Ulnar Nerve Problems,
  - Chronic Elbow Instability,
  - Biceps tendon rupture
  - Congenital elbow conditions or
  - Elbow Fractures or Dislocations,
  - Diagnosis referral pathways or
  - Long term outcomes

**YOU CAN COMPLETE THIS SURVEY ONLINE AT**  
<https://leicester.onlinesurveys.ac.uk/elbowpsp>

By participating in this survey you give us, and partner organisations, permission to publish your answers for the Priority Setting Partnership, but the information you give will be anonymised (so your name will not be published and you will not be identifiable from what you have told us).

**Why do we need your help?**

We are asking:

- patients,
- their carers/relatives and
- healthcare professionals

about the questions they feel need answering the most, in order to improve care and recovery.

We want your views to guide future research and for you to have a voice in shaping the advances in the management of such elbow conditions for future generations.

**What will we do with your survey results?**

We will collate your response with everyone else's. We then ask patients, their relatives/carers and healthcare professionals to rank which of these they think are the most important research priorities. This enables those funding research to know which questions are the most important to be answered.

**Want to contact us?**

If you would like to take part in this project or would want further information, **please email:**  
**elaine.james@uhl-tr.nhs.uk**

**THE SURVEY** – Please write in the boxes below any questions you have about elbow conditions and/or what is important to you.

Questions may be about treatment, recovery, the way care was delivered, diagnostic pathways and long-term recovery.

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

*Please feel free to add as many questions as you like.*

*Is there anything else you would like to tell us? (eg. any personal experiences about elbow conditions that you would like to share)*

BMJ Open 2022;12:e027179. doi:10.1136/bmjopen-2022-027179  
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|   |
|---|
| What is the best treatment (surgery or conservative management) for elbow arthritis in young /active patients?  |
| Which factors affect the outcome and longevity of elbow replacements?   |
| What is the best rehabilitation programme for prevention of stiffness following elbow trauma or surgery?  |
| What is the best treatment approach (surgery or without surgery) in management of early or persistent elbow tendinopathies (such as tennis/golfer's elbow)? |
| Comparing non-surgical treatments (such as medications, therapy interventions, injections etc), which is most effective in elbow arthritis?                 |
| What is the outcome of surgery (including open or key-hole surgery) in the management of elbow arthritis?   |
| What is the best treatment (including surgical and non-surgical) for non-arthritic elbow stiffness?   |
| How to manage pain (early/persistent) in common elbow conditions?   |
| What and when is the best treatment option for distal biceps tendon ruptures (surgical or non-surgical)?  |
| What are the best pre and post-op rehabilitation regimens for total elbow replacements, including advice on long term physical restrictions?                |



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| 11 | In patients with partial thickness distal biceps ruptures, does surgical or non-surgical treatment lead to better outcomes?   |
| 12 | What is the best way to manage a radial nerve injury following humeral fracture or surgery?   |
| 13 | What are the non-surgical options for managing cubital tunnel syndrome and what is their effectiveness?   |
| 14 | What is the role of non-surgical treatments (including medications, injections) in elbow tendinopathies (e.g. tennis/golfer elbows)?  |
| 15 | What is the effectiveness of surgery for elbow tendinopathies (e.g. tennis/golfer's elbows) compared to nonsurgical management?   |
| 16 | Which rehabilitation programmes (such as splinting, exercise regimen, physical therapy) are most effective in the management of elbow tendinopathies (e.g. tennis / golfer elbows)? |
| 17 | Does elbow tendinopathy (e.g. golfer's and tennis elbow) get better by itself?  |
| 18 | Can elbow tendinopathies (e.g. tennis/golfer's elbows) be effectively self-managed?   |

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# BMJ Open

## Elbow Conditions: Research Priorities Setting in Partnership with the James Lind Alliance

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|---------------------------------|---|
| Journal:                        | BMJ Open  |
| Manuscript ID                   | bmjopen-2022-062177.R1  |
| Article Type:                   | Original research   |
| Date Submitted by the Author:   | 14-Oct-2022   |
| Complete List of Authors:       | Singh, Harvinder pal; Leicester General Hospital; University of Leicester<br>Chong, Han; Leicester General Hospital<br>Raval, Parag; Leicester General Hospital<br>Divall, Pip; University Hospitals of Leicester NHS Trust<br>Rangan, Amar; The James Cook University Hospital, Trauma and Orthopaedics; University of York, Department of Health Sciences<br>Bateman, Marcus; University Hospitals of Derby and Burton NHS Foundation Trust, Derby Shoulder Unit<br>Watts, Adam; Wrightington Wigan and Leigh Teaching Hospitals NHS Foundation Trust<br>Phadnis, Joideep; Brighton and Sussex University Hospitals NHS Trust Trauma and Orthopaedics<br>Majed, Addie; Royal National Orthopaedic Hospital NHS Trust<br>Jones, Valerie; Sheffield Teaching Hospitals NHS Foundation Trust<br>Pandey, Radhakant; Leicester General Hospital<br>Gower, Jonathan; James Lind Alliance<br>Gwilym, Steve; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences<br>Peach, Chris; Manchester University NHS Foundation Trust |
| <b>Primary Subject Heading</b>: | Surgery   |
| Secondary Subject Heading:      | Research methods  |
| Keywords:                       | Elbow & shoulder < ORTHOPAEDIC & TRAUMA SURGERY, QUALITATIVE RESEARCH, Trauma management < ORTHOPAEDIC & TRAUMA SURGERY   |
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# Elbow Conditions: Research Priorities Setting in Partnership with the James Lind Alliance

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**Key Terms:**

Elbow Joint, Clinical Research, Trauma management, Research Priorities, Partnership

Word count: 3287

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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 (HCP)

**Setting:** This was a national collaborative study organised through the British Elbow and Shoulder Society (BESS).

**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 multi-stakeholder 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.

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## 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 surgery for 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.

## BACKGROUND

Elbow Conditions encompass a wide range of pathologies including trauma and its 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, 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 method to identify priorities for future research through collaboration between patients, carers, and healthcare professionals 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 health care professionals (6, 7). This article describes the process and results of this UK based Priority Setting Partnership 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).

| 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.                                       |

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-psp/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.

**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 healthcare professionals were asked for their input on the topics that mattered most to them about elbow conditions. The survey was created in both a paper (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

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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 (e.g. Royal College of General Practice, Royal College of Emergency Medicine, British Society for Rheumatology, BESS, The Faculty of Sport and Exercise Medicine), patient bodies (e.g. Arthritis UK, Patient UK), and sports organisations (e.g. Tennis UK, Golf Organisations UK)

### ***Collection of Questions and Classifying Research Suggestions***

The survey began on January 1, 2020 and ended on August 15, 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 upon 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 (e.g. tennis/golfer's elbows) compared to nonsurgical 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,

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and 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 healthcare professionals 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 upon, for presentation in the final workshop.

### ***Final Workshop: Deciding the 'Top Ten' Priorities***

For a one-day virtual meeting, healthcare professionals, 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, healthcare professionals) and also to get a range of demographics, conditions, HCP specialties.

The videoconference workshop took place on November 24, 2021. To reach consensus on the final 'Top Ten' priorities, the workshop used a modified nominal group methodology. Stakeholders were split into four groups, with equivalent proportions of healthcare professionals 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 Ten' 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 National Institute for Health Research (NIHR), as well as partner organisations. The findings will be presented at speciality 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.

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# 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 healthcare professionals, 40 (24%) were patients with elbow conditions, and four (3%) were family members, friends or carers. 3 (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 healthcare professionals. 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%) were healthcare professionals, with 4 (2%) respondents did not specify. Figure 2 illustrates a demographic summary. Using the described ranking method, top 8 ranked questions overlapped between healthcare professionals and the patients/carers and further top 5 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** healthcare professionals (including surgeons, rheumatologist, and allied health professionals) and **12** patients with elbow conditions or carers) (two patients were not able to attend). It was facilitated by four JLA representatives. The final 'Top Ten' Research priorities (See Table 2) was agreed and signed off by all stakeholder representatives. The full list of the top 18 priorities can be viewed in the Appendix 2.

**Table 2. Top 10 Research Priorities for Elbow Conditions (Nov 2021)**

| Rank     | Questions   |
|----------|---|
| <b>1</b> | What is the best treatment (surgery or conservative management) for elbow arthritis in young /active patients?  |
| <b>2</b> | Which factors affect the outcome and longevity of elbow replacements?   |
| <b>3</b> | What is the best rehabilitation programme for prevention of stiffness following elbow trauma or surgery?  |
| <b>4</b> | What is the best treatment approach (surgery or without surgery) in management of early or persistent elbow tendinopathies (such as tennis/golfer's elbow)? |

|    |  |
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| 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? |

## 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 health care professionals. The top ten 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 is a 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 ten" research priorities identified in this PSP were more "chronic" conditions (10).

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 the supplementary material. 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. Firstly, 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 upon 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 amongst healthcare professional 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

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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 ten questions for elbow conditions are due to be presented at the annual national conferences in 2022. The Top Ten 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 health care professionals. This work should help guide the prioritisation, funding and future research for elbow conditions.

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## Contributors

HS 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. HC, PD and PR reviewed and coded all submissions from the initial survey. All the Steering Group members (HS, HC, 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. HS, HC and PR drafted the manuscript. All authors reviewed and approved the final manuscript before submission.

## Funding

The Elbow Conditions Priority Setting Partnership was funded by the British Orthopaedic Association (BOA) (Pump priming grant, Grant number N/A), British Elbow and Shoulder Surgeon (BESS) (Pump priming grant, Grant number N/A), and Leicester Shoulder Unit Charity (Grant number N/A).



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## Conflict of Interest

AR, AW, SG, CP, HS 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 Ltd 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. All other authors declare no competing interests.

## Ethics Approval

Not Applicable

## Acknowledgments

We would like to thank all those involved including patients, carers and health care professionals in the Steering Group for taking the time and effort with this study. Additionally, we would like to thank the British Orthopaedic Association, British Elbow Shoulder Society and the Leicester Shoulder Unit Charity for their support and funding to be able to complete this study. We thank Michelle Wallis, Peter Tippet, Brenden Gardiner, Paul Rodgers, Margaret Hughes and Ann Heaton for being part of our PSP as patient representative. We thank Elaine James for coordinating the Elbow PSP including communication and minutes recording. We thank all those who participated in the initial survey, interim prioritisation survey and final prioritisation workshop.

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## Data Sharing

Data are available upon reasonable request

## FIGURES CAPTION

**Figure 1:** Flowchart summarising the priority setting process for Elbow Conditions in line with James Lind Alliance methodology.

**Figure 2:** Demographic background (Role, Gender, Age distribution) of survey respondents.

**Figure 3:** Classification of research questions submitted during initial survey.

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## APPENDICES

**Appendix 1:** Initial Survey Questionnaires – Paper Forms.

**Appendix 2:** The Top 18 ranked questions from the interim survey.

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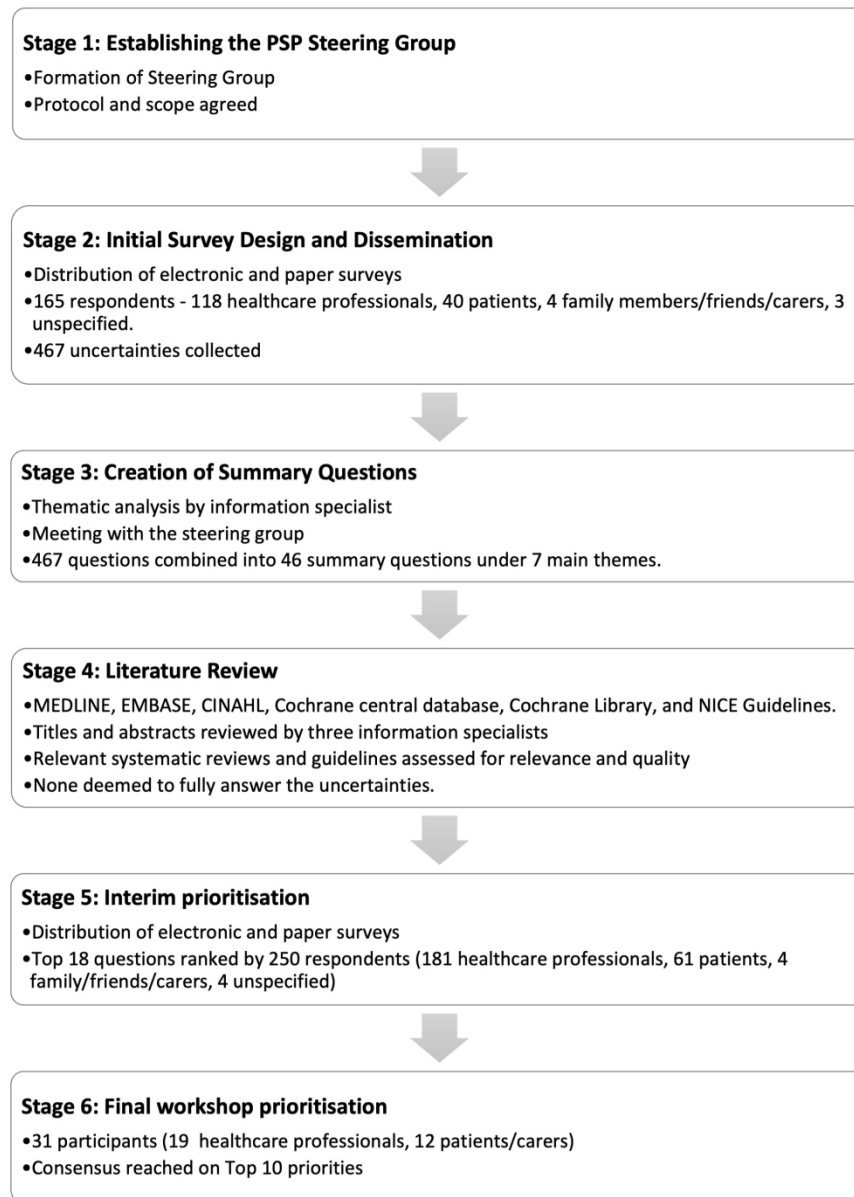
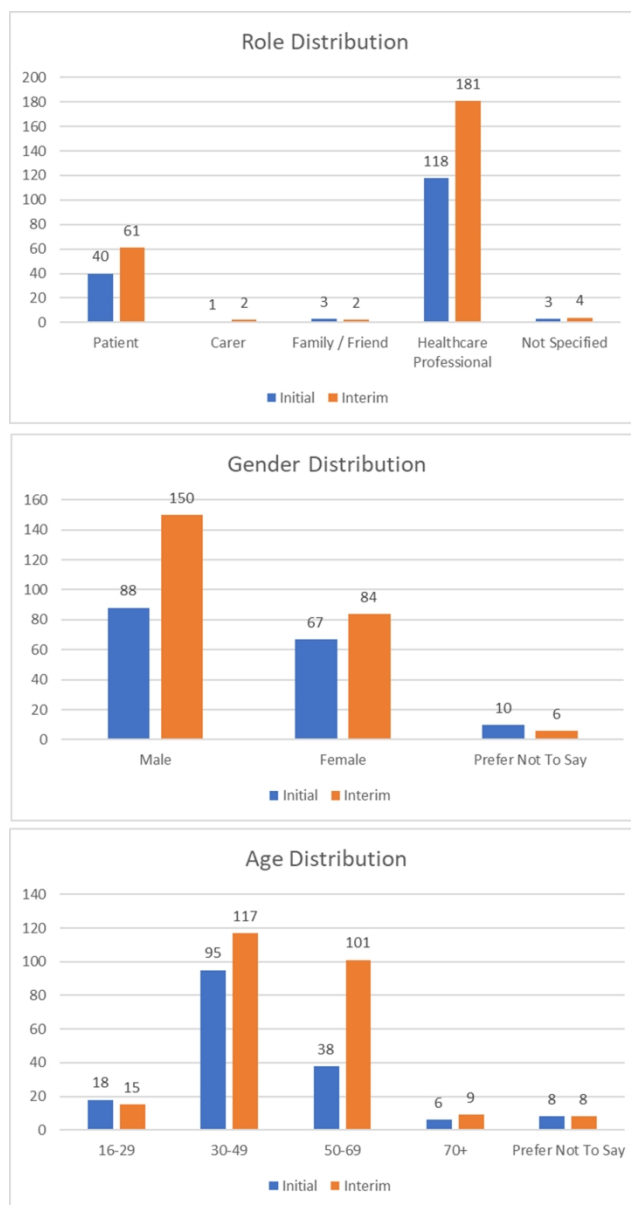


Figure 1: Flowchart summarising the priority setting process for elbow conditions in line with James Lind Alliance methodology.

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Demographic background (Role, Gender, Age distribution) of survey respondents.

127x239mm (330 x 330 DPI)

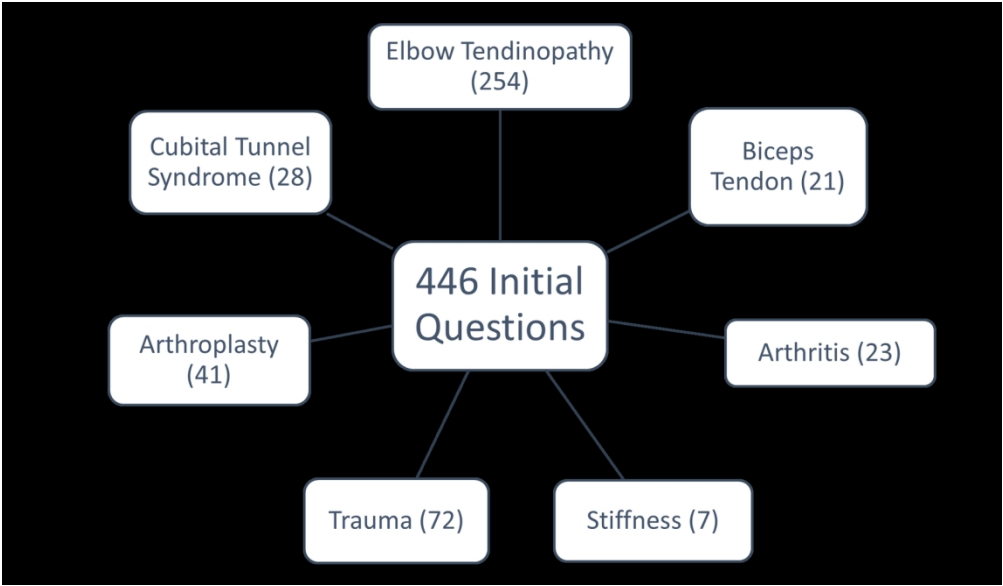


Figure 3: Classification of research questions submitted during initial survey  
152x88mm (300 x 300 DPI)

**ABOUT YOU (optional)**

It is important that we know a little bit about you so that we can ensure we have collected the views from a wide range of people with different experiences.

Do YOU have or have YOU had an Elbow problem? Yes ☐ No ☐

If YES, at what age did your elbow problem start?

☐ <16 ☐ 16-29 ☐ 30-49 ☐ 50-69 ☐ 70+

Which describes you?

☐ Patient

☐ Carer

☐ Family/ Friend

☐ Healthcare Professional, please specify \_\_\_\_\_

Are you: ☐ Male ☐ Female ☐ Prefer to self describe ☐ Prefer not to say?

Age: ☐ <16 ☐ 16-29 ☐ 30-49 ☐ 50-69 ☐ 70+ ☐ Prefer not to say

What is your post code, first 3 or 4 characters only     ?

What is your ethnicity?

☐ White ☐ Asian/Asian British ☐ Black/Caribbean/Black British

☐ Arab ☐ Mixed/multiple ethnic groups ☐ Prefer not to say

Other ethnic group ☐ please describe \_\_\_\_\_

**THANK YOU, please consider** completing this survey. Please hand it back to a staff member or return to **James Lind Alliance PSP Coordinator, Elaine James, elaine.james@uhl-tr.nhs.uk** using the envelope provided.

If you require assistance completing this survey, please do not hesitate to contact us:



<https://www.bess.org.uk/index.php/elbowJLA>



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[elbowjla@leicester.ac.uk](mailto:elbowjla@leicester.ac.uk)

# ELBOW CONDITIONS

Can you help us decide the questions that should be answered by research?

Have you had or cared for someone who had problems with their elbow that has required help from a healthcare professional?

OR

Are you a healthcare professional who is involved in the treating patients with elbow conditions?



Please complete the sections on the next page to suggest questions about treatment and recovery in elbow conditions that could be answered by research in the future.

To be completed by Patients, Carers, Family/Friends or Health Care Professionals

To find out more about this project visit  
<https://www.bess.org.uk/index.php/elbowJLA>





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**Who are we?**

We are a group of patients, clinicians and researchers who want to help improve the care and quality of life of patients who suffer from elbow joint conditions/ disorders/ diseases. This is a collaboration between the British Elbow and Shoulder Society, British Orthopaedic Association, Leicester Shoulder Elbow Unit Charity and the James Lind Alliance.

**What are the elbow conditions?**

- Examples of the elbow conditions include:
- Elbow Osteoarthritis
  - Inflammatory arthritis,
  - Tendonitis (like Tennis Elbow, Golfers Elbow),
  - Biceps or Triceps tendonitis
  - Elbow Stiffness,
  - Ulnar Nerve Problems,
  - Chronic Elbow Instability,
  - Biceps tendon rupture
  - Congenital elbow conditions or
  - Elbow Fractures or Dislocations,
  - Diagnosis referral pathways or
  - Long term outcomes

**YOU CAN COMPLETE THIS SURVEY ONLINE AT**  
<https://leicester.onlinesurveys.ac.uk/elbowpsp>

By participating in this survey you give us, and partner organisations, permission to publish your answers for the Priority Setting Partnership, but the information you give will be anonymised (so your name will not be published and you will not be identifiable from what you have told us).

**Why do we need your help?**

We are asking:

- patients,
- their carers/relatives and
- healthcare professionals

about the questions they feel need answering the most, in order to improve care and recovery.

We want your views to guide future research and for you to have a voice in shaping the advances in the management of such elbow conditions for future generations.

**What will we do with your survey results?**

We will collate your response with everyone else's. We then ask patients, their relatives/carers and healthcare professionals to rank which of these they think are the most important research priorities. This enables those funding research to know which questions are the most important to be answered.

**Want to contact us?**

If you would like to take part in this project or would want further information, **please email:**  
**elaine.james@uhl-tr.nhs.uk**

**THE SURVEY** – Please write in the boxes below any questions you have about elbow conditions and/or what is important to you.

Questions may be about treatment, recovery, the way care was delivered, diagnostic pathways and long-term recovery.

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

*Please feel free to add as many questions as you like.*

*Is there anything else you would like to tell us? (eg. any personal experiences about elbow conditions that you would like to share)*

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>

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| 11 | In patients with partial thickness distal biceps ruptures, does surgical or non-surgical treatment lead to better outcomes?   |
| 12 | What is the best way to manage a radial nerve injury following humeral fracture or surgery?   |
| 13 | What are the non-surgical options for managing cubital tunnel syndrome and what is their effectiveness?   |
| 14 | What is the role of non-surgical treatments (including medications, injections) in elbow tendinopathies (e.g. tennis/golfer elbows)?  |
| 15 | What is the effectiveness of surgery for elbow tendinopathies (e.g. tennis/golfer's elbows) compared to nonsurgical management?   |
| 16 | Which rehabilitation programmes (such as splinting, exercise regimen, physical therapy) are most effective in the management of elbow tendinopathies (e.g. tennis / golfer elbows)? |
| 17 | Does elbow tendinopathy (e.g. golfer's and tennis elbow) get better by itself?  |
| 18 | Can elbow tendinopathies (e.g. tennis/golfer's elbows) be effectively self-managed?   |

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