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Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority Setting Partnership with the James Lind Alliance

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Complete List of Authors:	<p>Fernandez, Miguel; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma; University Hospitals Coventry and Warwickshire NHS Trust, Trauma & Orthopaedic Surgery</p> <p>Arnel, Laura; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma</p> <p>Gould, Jenny; Patient representative</p> <p>McGibbon, Alwin; Patient representative</p> <p>Grant, Richard; Patient representative</p> <p>Bell, Philip; Patient representative</p> <p>White, Stuart; Royal Sussex County Hospital</p> <p>Baxter, Mark; University Hospital Southampton NHS Foundation Trust</p> <p>Griffin, Xavier; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Kadoorie Centre</p> <p>Chesser, Tim; North Bristol NHS Trust, Trauma & Orthopaedics</p> <p>Keene, David; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma</p> <p>Kearney, R.S.; University of Warwick,</p> <p>White, Catherine; James Lind Alliance</p> <p>Costa, Matthew; University of Oxford, Nuffield Department of Orthopaedics, Rheumatology, and Musculoskeletal Sciences</p>
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3 **Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority**
4 **Setting Partnership with the James Lind Alliance.**
5

6 M. A. Fernandez^{1,2*}, L. Arnel¹, J. Gould³, A. McGibbon³, R. Grant³, P. Bell³, S. White⁴,
7 M. Baxter⁵, X. L. Griffin¹, T. J. S. Chesser⁶, D. J. Keene¹, R. Kearney⁷, C. White⁸, and M.
8 L. Costa¹
9

10
11
12 ¹Oxford Trauma, University of Oxford, Kadoorie Centre, John Radcliffe Hospital,
13 Headley Way, Oxford OX3 9DU, UK
14

15 ²University Hospitals Coventry & Warwickshire NHS Trust, Clifford Bridge Road,
16 Coventry, CV2 2DX, UK
17

18 ³ Patient representatives, UK
19

20 ⁴Royal Sussex County Hospital, Brighton, BN2 5BE, UK
21

22 ⁵University Hospital Southampton NHS Foundation Trust, Tremona Road,
23 Southampton, SO16 6YD, UK
24

25 ⁶North Bristol NHS Trust, Southmead Hospital, Bristol BS10 5NB, UK
26

27 ⁷University of Warwick, Clinical Trials Unit, Gibbet Hill Road, Coventry, CV4 7AL, UK
28

29 ⁸James Lind Alliance advisor (to Feb 2018), National Institute for Health Research,
30 University of Southampton, Enterprise Road, Southampton, SO16 7NS, UK
31

32 *corresponding author: Mr M. A. Fernandez, Oxford Trauma, University of Oxford,
33 Kadoorie Centre, John Radcliffe Hospital, Headley Way, Oxford OX3 9DU, UK.
34 miguel.fernandez@ndorms.ox.ac.uk Tel. 07939250006
35

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ABSTRACT

Objective: To determine research priorities in fragility fractures of the lower limb and pelvis, which represent the shared priorities of patients, their friends and families, carers, and healthcare professionals.

Design/Setting: A national (UK) research Priority Setting Partnership.

Participants: Patients: over 60 years of age who have experienced a fragility fracture of the lower limb or pelvis; carers involved in their care (both in and out of hospital); family and friends of patients; healthcare professionals involved in the treatment of these patients including but not limited to surgeons, anaesthetists, paramedics, nurses, general practitioners, physicians, physiotherapists, and occupational therapists.

Methods: Using established methodology in partnership with the James Lind Alliance over an 18-month period between August 2016 and January 2018, a national scoping survey asked respondents to submit their research uncertainties. These were then amalgamated into a smaller number of representative research questions. A search of the existing evidence was undertaken to ensure that the questions had not been answered. A second national survey was distributed asking respondents to prioritise the research questions. A final shortlist of 25 questions was taken to a multi-stakeholder workshop where a consensus was reached on the top 10 priorities.

Results: There were 963 original research uncertainties submitted by 365 respondents to the first survey. These original research uncertainties were refined into 88 representative research questions of which 76 were judged to be true uncertainties following a review of the current research evidence. Healthcare professionals and other stakeholders (patients, carers, friends and families) were represented equally in the respondents to both surveys. The top ten research questions represented uncertainties in rehabilitation, pain management, anaesthesia, and surgery.

Conclusions: We report the top 10 UK research priorities in patients with fragility fractures of the lower limb and pelvis derived by a Priority Setting Partnership with the James Lind Alliance.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Use of established and transparent JLA methodology.
- Survey responses from all over the UK with a 50:50 split between healthcare professionals and non-healthcare professionals (patients, carers, family & friends).
- While the research priorities are now reported, it is up to the research community and research funding organisations to refine and deliver the answers to these questions.

MORE INFORMATION

You can see the full list of original uncertainties and indicative research questions at the websites below, including out of scope questions:

JLA Website:

<http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/>

NDORMS Website:

<https://www.ndorms.ox.ac.uk/research-groups/oxford-trauma/broken-bones-in-older-people>

INTRODUCTION

Nine million new fragility fractures presented in the year 2000, with 50 million people worldwide suffering from the sequelae of these fractures.[1] Hip fractures alone are expected to rise from 1.31 million in 1990 to an estimated 6.26 million per year globally by 2050.[2] The associated treatment costs are around 2% of the total healthcare burden in the UK – approximately £3billion per year.[3]

Adults with fragility fractures of the lower limb or pelvis usually require treatment in hospital and often have other medical comorbidities, along with complex health and social care needs requiring intervention from a number of healthcare professionals and carers.

Research in the field of fragility fractures is usually driven by academics and pharmaceutical companies. There is evidence of a mismatch between the research priorities of patients and healthcare professionals and the research which is actually undertaken and delivered.[4-6] This situation is changing. Patient and public involvement (PPI) in research has flourished in the UK, driven by the National Institute of Health Research (NIHR) such that PPI involvement is now a key part of the design, conduct and delivery of research in health and social care.[7]

The James Lind Alliance (JLA) is a non-profit organisation hosted by the NIHR with the aim of raising awareness of research which is directly relevant and of potential benefit to patients and treating clinicians. The guiding principle is to bring together patients, carers, and clinicians to identify and agree on which research uncertainties are most important. To date, there have been over 50 priority setting partnerships across a range of disciplines with over 100 research topics addressed as a direct result of the JLA priority setting partnerships.[8,9]

The aim of this work is to establish the research priorities for adults with fragility fractures of the lower limb and pelvis, which represent the shared interests and priorities of patients, their families and friends, carers, and healthcare professionals.

METHODS

The 'Broken Bones in Older People' priority setting partnership (PSP) took place over an 18-month period between August 2016 and January 2018. An overview of the methodology is shown in Figure 1.

Steering group & Partner Organisations

The clinical lead (MC) initiated the priority setting partnership and guided the appointment of a steering group to oversee and contribute to the process. The

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2
3 steering group consisted of patient representatives, healthcare professionals, and
4 carers with established links to relevant partner organisations (see Appendix 1) to
5 ensure that a range of stakeholder groups were represented. A JLA Adviser (CW)
6 supported and guided the PSP as a neutral facilitator to ensure that it was
7 undertaken in a fair and transparent way with equal contribution from patients,
8 carers and healthcare professionals. An information specialist (MF) managed the
9 data and performed the analysis. This was overseen and advised on by the steering
10 group.
11

12 13 **Scope**

14 All research uncertainties related to fragility fractures of the lower limbs and pelvis
15 for patients over 60 years of age. All stages of the patient pathway were eligible
16 including the immediate care of fragility fractures by the emergency services, acute
17 in-hospital care, and out-of-hospital care. Primary prevention strategies for fragility
18 fractures were excluded.
19

20 21 **Scoping Survey & Identification of Themes**

22 A national scoping survey asked respondents to submit their research uncertainties
23 and provide some optional basic demographic information (gender, first three
24 letters of their postcode, and to identify themselves as either a carer, patient,
25 family/friend of someone over 60 years of age with a fragility fracture, or a
26 healthcare professional). The survey was available in both paper and online formats
27 (Bristol online survey tool)[10]. A pilot phase was undertaken to ensure acceptability
28 to all stakeholder groups prior to launch. In addition to submissions from survey
29 respondents, we included research uncertainties highlighted in relevant national
30 guidelines published by The National Institute for Health and Care Excellence
31 (NICE).[11,12]
32

33 All original submissions were analysed using techniques common to qualitative
34 thematic analysis to define themes and subthemes. The process included initial data
35 immersion (reading and re-reading the submissions), coding of common
36 ideas/themes, identification and naming of themes and subthemes, and a final
37 review to refine the overarching themes. The Steering Group oversaw and advised
38 on this work.
39
40

41 42 **Indicative Questions & Evidence Search**

43 The overarching themes and subthemes from the thematic analysis were used to
44 generate a smaller number of representative research questions, so called 'indicative
45 questions'. The indicative questions were reviewed by the steering group to ensure
46 that they were a true representation of the original submissions, and to ensure that
47 the language used was understandable to all stakeholder groups. For each indicative
48 question, a review of the current research evidence was undertaken to ensure that
49 the proposed indicative questions were 'true uncertainties' and had not already
50 been answered by research. MF searched PubMed, the grey literature
51 (www.opengrey.eu), The Cochrane Central Register of Controlled Trials (CENTRAL)
52 (www.cochranelibrary.com/about/central-landing-page.html), The WHO
53 international Clinical Trials Registry Platform Search Portal
54 (<http://www.who.int/ictrp/en>), Current Controlled trials
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3 (<http://www.controlledtrials.com/isrctn/>), the US National Institute of Health Trials
4 Registry (<https://clinicaltrials.gov>), and published UK national guidelines.[11,12]
5 Indicative questions were excluded if the steering group agreed that high quality
6 evidence was found (e.g. large clinical trials either published or in-progress,
7 published meta-analyses, or published national evidence based guidelines). The
8 remaining indicative questions went through to interim prioritisation.
9

10 11 **Interim Prioritisation Survey**

12 A second national survey asked respondents to state the importance of each
13 indicative question on a five level Likert scale (1 not important, 2 low importance, 3
14 no opinion, 4 high importance, 5 extremely important). The survey was available in
15 paper and online formats and went through a pilot phase prior to launch. All
16 indicative questions were ranked (interim prioritisation) by calculating a mean score
17 per question based on the number of responses at each of the five response levels.
18 The results were reviewed by the steering group who decided to take the top 25 to
19 the final workshop.
20
21

22 **Final Workshop**

23 This was a one-day multi-stakeholder workshop involving patients, carers, and
24 healthcare professionals. Participants worked in small groups to independently rank
25 the top 25 indicative questions from the interim prioritisation process. The
26 combined results of small group discussions were presented to the whole group.
27 These were considered before a further round of small group discussions. Finally, the
28 whole group came back together again to establish a consensus on the top 10
29 research priorities for fragility fractures of the lower limb and pelvis.
30
31

32 **Patient & Public Involvement**

33 Patient and carer representatives were actively involved throughout the process;
34 from the initial stages of planning and overseeing the study as part of the steering
35 group, to participation in the final workshop to ensure that the patient and carer
36 'voice' was represented in the final prioritisation. The steering group made particular
37 efforts to approach a diverse range of patient and carer groups across a number of
38 settings to encourage responses to the surveys. The dissemination strategy of this
39 work includes a plain English summary alongside the scientific publication, which will
40 be circulated to the partner organisations and PPI groups.
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46 **RESULTS**

47 Nine hundred and sixty-three research uncertainties were submitted by 365
48 respondents to the first survey. After removal of 'out-of-scope' uncertainties, there
49 were 810 remaining. Respondents were located throughout the UK (see Figure 2).
50 Fifty-one percent (51%) of respondents identified themselves as healthcare
51 professionals and 49% non-healthcare professionals (23% family and friends, 16%
52 patients, 10% carers).
53

54 Eleven themes were identified: pain, nutrition, surgery, medications & devices,
55 anaesthesia, rehabilitation, falls, anxiety & depression, diagnosis, information, and
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3 service delivery. From these themes 88 indicative questions were formulated to
4 represent the original uncertainties. Twelve indicative questions were excluded
5 following a search of the research evidence leaving 76 indicative questions for
6 interim prioritisation.

7
8 The interim prioritisation survey received 209 responses from different regions of
9 the UK (Figure 3) of which 47% identified themselves as healthcare professionals and
10 53% non-healthcare professionals (15% family & friends, 28% patients, 10% carers).
11 Each question was scored based on the responses to interim prioritisation and
12 ranked from positions 1 to 76. The ranking was reviewed by the steering group and
13 the top 25 questions were taken to the final prioritisation workshop where a
14 consensus was reached on the top 10 research priorities (see Box 1 for priorities 1-
15 10 and Appendix 2 for priorities 11-25).

17 18 **DISCUSSION**

19 We have reported the results of a UK priority setting partnership with the James Lind
20 Alliance and identified the top 10 research priorities in patients with fragility
21 fractures of the lower limb and pelvis. These research priorities represent the shared
22 interests of the multiple stakeholders affected by fragility fractures: patients, family
23 & friends, carers, and healthcare professionals. The top 10 priorities emphasise the
24 lack of evidence to guide 'rehabilitation' following fragility fracture and highlight a
25 number of unanswered questions in postoperative physiotherapy, weight-bearing,
26 as well as rehabilitation pathways for patients with cognitive impairment.

27
28 This study has a number of strengths. Patient and carers were actively involved at all
29 stages of the process to ensure that the patient voice was heard and remained at the
30 centre of our efforts. We used the established and transparent JLA methodology to
31 conduct this priority setting partnership. All the original research submissions, as
32 well as the indicative questions (76 in total) are available on the JLA website.[8] The
33 number of survey responses were comparable to other JLA priority setting
34 partnerships,[13] and we achieved a 50:50 balance between responses from
35 healthcare professionals and non-healthcare professionals. Responses were
36 submitted from all over the UK and we are therefore confident that this work
37 represents a national viewpoint.

38
39 Fragility fractures affect frail older people disproportionately. Considerable efforts
40 were required to ensure that all patient groups were able to access and respond to
41 our national surveys. These strategies included accessing clinical environments (e.g.
42 GP surgeries, hospital outpatient clinics) with paper surveys as well as sending our
43 online survey link via the mailing lists of national organisations such as the National
44 Osteoporosis Society to ensure as widespread inclusion of patient groups as
45 possible. However, despite these efforts, it is possible that the research priorities
46 reported still underrepresent the frailest group which includes those with
47 permanent cognitive impairment for whom responding to a survey may not be
48 possible. However, we are encouraged to see a research uncertainty in the top 10
49 specifically directed towards identifying the key components of a rehabilitation
50 pathway for those with chronic cognitive impairment.

51
52 We found that research questions which were very specific - which identified the
53 intervention and comparator within the question - tended to attract a lower ranking
54 than more general questions asking a broader less well defined research question.
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3 For example, questions asking ‘what is the best physiotherapy?’ were found to
4 attract more votes than more specific questions comparing two specific
5 interventions (e.g. ‘Which is better, tai chi or standard physiotherapy?’). This may
6 reflect an opinion by survey respondents that broader questions may have wider
7 impact and cover multiple interventions.

8 This work has highlighted the top research questions in lower limb and pelvic
9 fragility fracture research. It is now up to the research community and research
10 funders to refine and deliver the answers to these questions. We hope this work will
11 shape the research landscape in this area and help to deliver meaningful advances in
12 the quality-of-life and care of patients.
13
14

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17 healthcare professionals who submitted responses to the national surveys. In
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23 Debs Smith, Josephine Rowling, Karen Keates, Stella Saunders, Sheila Holmes, Jean
24 Maston, Shirley MacWhirter, Thelma Sanders, Sue Bremner-Milne, Diane Hackford,
25 John Cocker, Sheela Upadhyaya, and Toto Anne Gronlund).
26
27
28

29 **AUTHOR CONTRIBUTIONS**

30 All authors have made substantial contributions to the design, implementation,
31 analysis, and delivery of this research. All authors have read and approved the final
32 version of this manuscript.
33
34

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40 expressed are those of the authors and not necessarily those of the NHS, the NIHR or
41 the Department of Health.
42
43

44 **COMPETING INTERESTS**

45 MC is a member of the NIHR HTA General Board.
46
47

48 **DATA SHARING STATEMENT**

49 Supplementary data including all submitted original research uncertainties and out
50 of scope submissions can be found on the JLA website at
51 [http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-
52 people/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/)
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BOX 1 The top ten UK research priorities in fragility fractures of the lower limb and pelvis.

- 1) What is the best physiotherapy and/or occupational therapy regime for adults during their in-hospital recovery from a fragility fracture of the lower limb?
- 2) What is the best physiotherapy and/or occupational therapy regime for adults during out-of-hospital recovery from a fragility fracture of the lower limb?
- 3) What is the best way to reduce harmful blood clots in adults treated with a plaster cast (or splint) for fragility fractures of the lower limb?
- 4) What information about recovery (e.g. rehabilitation, medication, exercises, nutrition, pain), and in what form, should be provided to patients and carers following a fragility fracture of the lower limb?
- 5) What is the best weight bearing regime following treatment (with or without surgery) for fragility fractures of the ankle?
- 6) What is most important to adults in their recovery from a fragility fracture of the lower limb?
- 7) What are the best treatments to prevent and treat confusion and delirium after surgery in adults with a fragility fracture of the lower limb?
- 8) What is the best pain relief, including non-drug therapies and alternatives to reduce morphine or opioid use, for adults with a lower limb fragility fracture during anaesthesia and immediate recovery after surgery?
- 9) What are the key components of a rehabilitation pathway for adults with dementia/cognitive impairment following a fragility fracture of the lower limb?
- 10) What is the best way to prevent surgical site infection in adults undergoing surgery for fragility fractures of the lower limb?

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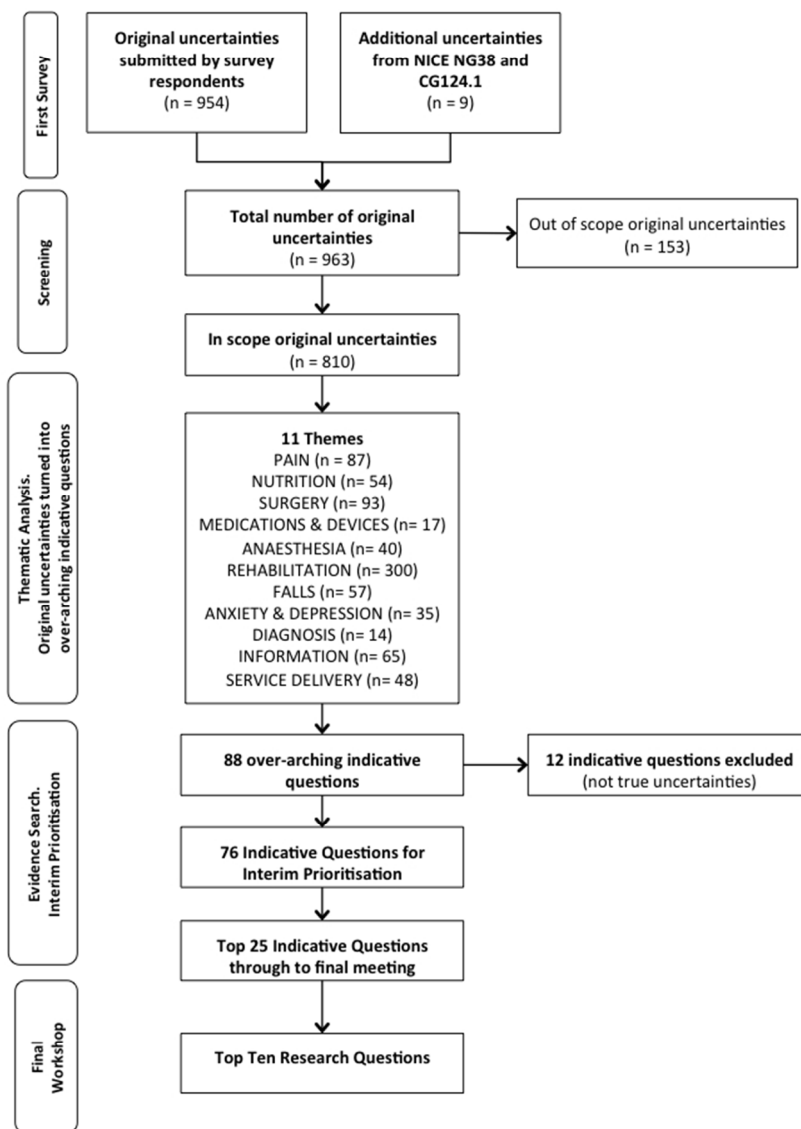


Figure 1. Flow Chart of Priority Setting Partnership Process

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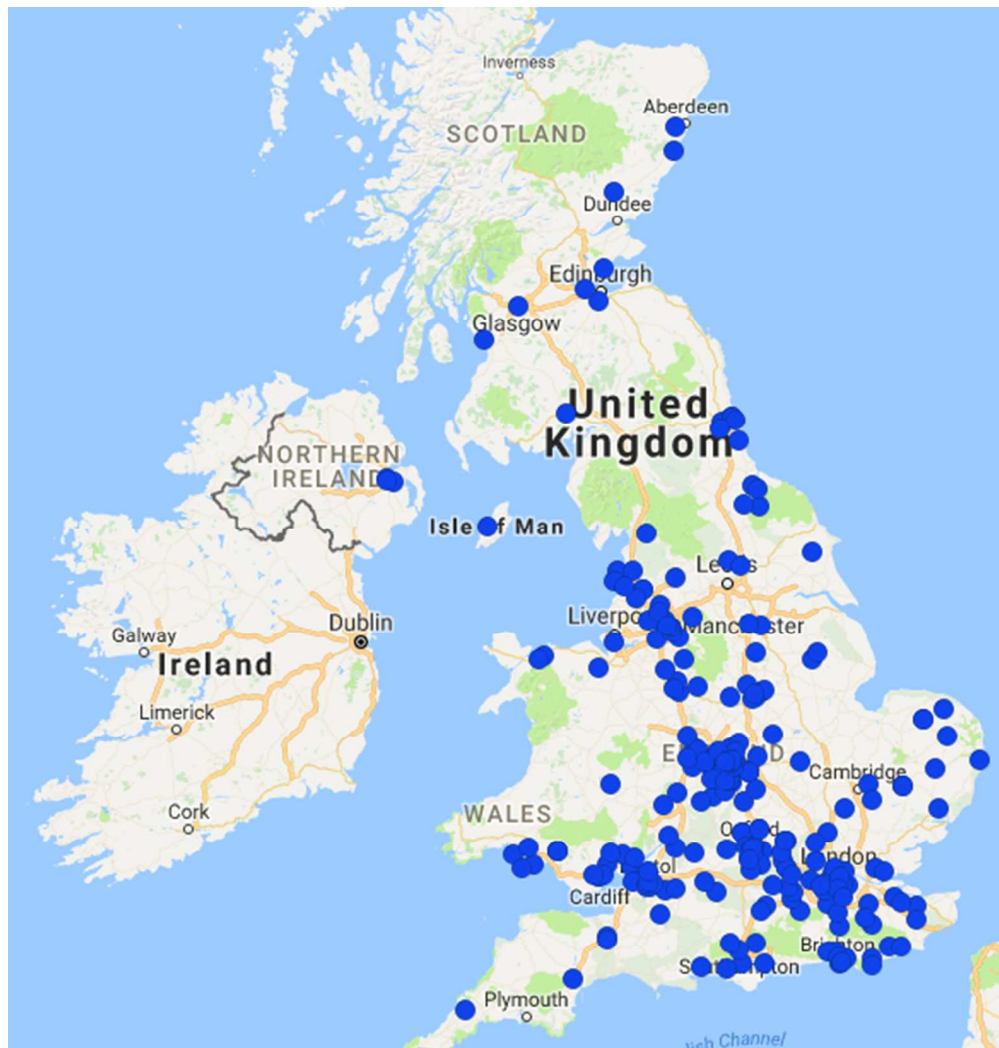


Figure 2. Maps showing geographical distribution of survey responses for first scoping survey (blue dots)
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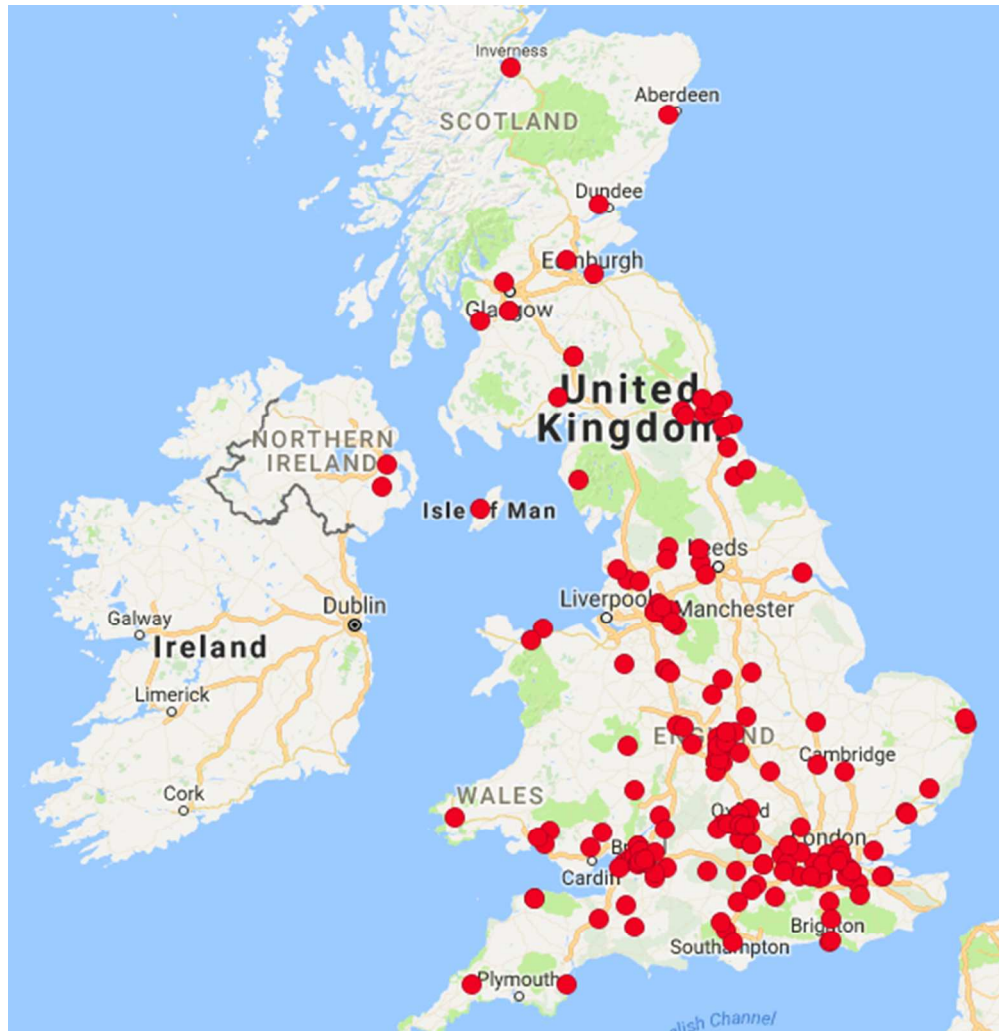


Figure 3. Maps showing geographical distribution of survey responses for interim prioritisation survey (red dots)

208x214mm (72 x 72 DPI)

APPENDIX 1: PARTNER ORGANISATIONS

Charity Organisations

Carers UK
National Care Association
University of the Third Age (U3A)
Association of Directors of Adult Social Services (ADASS)
National Osteoporosis Society (NOS)
Age Cymru
Age Scotland
Age UK
Association of Medical Charities
Involve People in research
St Johns Ambulance
Arthritis Research UK

Personal Contacts

AGILE (physios specializing in care of older adults)
Dr Anglea McCullagh
Coventry & Warwickshire Partnership Trust
National Institute for Health Research. Collaboration for Leadership in Applied Health Research and Care. West Midlands (NIHR CLAHRC WM)
Manor Court Surgery, Nuneaton

Professional Organisations

University/User Teaching and Research Action Partnership (UNTRAP)
Warwickshire Carers Association & Guideposts
Association of Trauma and Orthopaedic Chartered Physiotherapists (ATOCP)
The Chartered Society of Physiotherapy (CSP)
Age and Ageing
National Osteoporosis Guideline Group (NOGG)
National Hip Fracture Database (NHFD)
Orthopaedic Trauma Society (OTS)
Royal College of Emergency Medicine (RCEM)
The National Ambulance Research Steering Group (NARSG)
Cardiff and Vale Orthopaedic Centre (CAVOC)
Community Health Councils in Wales
Health and Care Research Wales
Health and Care Research Wales Support Centre
Health Services Research Unit – Scotland
Healthwatch England
Royal British Legion working with veterans
Research User Group (RUG) NIHR Manchester
The RNHA Registered Nursing Home Association
Welsh Arthritis Research Network
Age Anaesthesia Association (AAA)
British Geriatric Society

1
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3 Association of Anaesthetists of Great Britain and Ireland
4 Hip Fracture Perioperative Network (HipPeN)
5 National Institute of Academic Anaesthesia
6 Royal College Anaesthetists
7 British Orthopaedic Association (BOA)
8 Falls and Fragility Fracture Audit Project (FFFAP)
9 Society of Trauma Nurses (SOTN)
10 Trauma Audit & Research Network (TARN)
11 Cochrane
12 Contact, Help, Advice and Information (CHAIN) Network
13 PAIR
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19 **APPENDIX 2: RESEARCH PRIORITIES 11-25**

20
21
22 11) How can we improve the way we link services and the effectiveness of
23 rehabilitation when patients transition from one environment to another (e.g. from
24 hospital to home) following a lower limb fragility fracture?
25

26 12) What is the best pain relief, including non-drug therapies and alternatives to
27 reduce morphine or opioid use, for adults with a lower limb fragility fracture on
28 arrival in hospital (in the emergency department or ward)?
29

30
31 13) What is the best weight bearing regime following treatment (with or without
32 surgery) for fragility fractures of the pelvis and acetabulum (hip socket)?
33

34
35 14) What is the best method to assess pain in adults with and without confusion
36 (either short term or long term such as dementia) following a lower limb fragility
37 fracture?
38

39
40 15) What are the important parts of an enhanced recovery pathway (such as early
41 mobilisation) for adults with a fragility fracture of the lower limb?
42

43 16) What is the best pain relief, including non-drug therapies and alternatives to
44 reduce morphine or opioid use, for adults with a lower limb fragility fracture upon
45 discharge from hospital?
46

47
48 17) What is the best way to reduce harmful blood clots in adults with a fragility hip
49 fracture?
50

51
52 18) What is the best intervention/method to enable and support early discharge of
53 patients from hospital with a lower limb fragility fracture?
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56 19) What is the best weight bearing regime following treatment (with or without
57 surgery) for fragility fractures of the tibial plateau (the top of the shin bone which
58 forms part of the knee joint)?
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3 20) What are the best physical therapies to treat adults with a fear of falling after a
4 lower limb fragility fracture?
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6
7 21) What is the best pain relief, including non-drug therapies and alternatives to
8 reduce morphine or opioid use, for adults with a lower limb fragility fracture during
9 in-hospital rehabilitation?
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12 22) What are the best psychological therapies to treat adults with a fear of falling
13 after a lower limb fragility fracture?
14

15 23) What are the specific barriers to hospital discharge (factors which delay or
16 prevent discharge from hospital) for adults with a fragility fracture of the lower limb?
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18
19 24) What is the best way to promote healing in adults with a fragility fracture of the
20 lower limb?
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23 25) What is the best treatment for surgical infections in adults following surgery for
24 fragility fractures of the lower limb?
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Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority Setting Partnership with the James Lind Alliance

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Complete List of Authors:	<p>Fernandez, Miguel; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma; University Hospitals Coventry and Warwickshire NHS Trust, Trauma & Orthopaedic Surgery</p> <p>Arnel, Laura; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma</p> <p>Gould, Jenny; Patient representative</p> <p>McGibbon, Alwin; Patient representative</p> <p>Grant, Richard; Patient representative</p> <p>Bell, Philip; Patient representative</p> <p>White, Stuart; Royal Sussex County Hospital</p> <p>Baxter, Mark; University Hospital Southampton NHS Foundation Trust</p> <p>Griffin, Xavier; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Kadoorie Centre</p> <p>Chesser, Tim; North Bristol NHS Trust, Trauma & Orthopaedics</p> <p>Keene, David; University of Oxford Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences, Oxford Trauma</p> <p>Kearney, R.S.; University of Warwick,</p> <p>White, Catherine; James Lind Alliance</p> <p>Costa, Matthew; University of Oxford, Nuffield Department of Orthopaedics, Rheumatology, and Musculoskeletal Sciences</p>
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3 **Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority**
4 **Setting Partnership with the James Lind Alliance.**
5

6 M. A. Fernandez^{1,2*}, L. Arnel¹, J. Gould³, A. McGibbon³, R. Grant³, P. Bell³, S. White⁴,
7 M. Baxter⁵, X. L. Griffin¹, T. J. S. Chesser⁶, D. J. Keene¹, R. Kearney⁷, C. White⁸, and M.
8 L. Costa¹
9

10
11
12 ¹Oxford Trauma, University of Oxford, Kadoorie Centre, John Radcliffe Hospital,
13 Headley Way, Oxford OX3 9DU, UK
14

15 ²University Hospitals Coventry & Warwickshire NHS Trust, Clifford Bridge Road,
16 Coventry, CV2 2DX, UK
17

18 ³ Patient representatives, UK
19

20 ⁴Royal Sussex County Hospital, Brighton, BN2 5BE, UK
21

22 ⁵University Hospital Southampton NHS Foundation Trust, Tremona Road,
23 Southampton, SO16 6YD, UK
24

25 ⁶North Bristol NHS Trust, Southmead Hospital, Bristol BS10 5NB, UK
26

27 ⁷University of Warwick, Clinical Trials Unit, Gibbet Hill Road, Coventry, CV4 7AL, UK
28

29 ⁸James Lind Alliance advisor (to Feb 2018), National Institute for Health Research,
30 University of Southampton, Enterprise Road, Southampton, SO16 7NS, UK
31

32 *corresponding author: Mr M. A. Fernandez, Oxford Trauma, University of Oxford,
33 Kadoorie Centre, John Radcliffe Hospital, Headley Way, Oxford OX3 9DU, UK.
34 miguel.fernandez@ndorms.ox.ac.uk Tel. 07939250006
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ABSTRACT

Objective: To determine research priorities in fragility fractures of the lower limb and pelvis, which represent the shared priorities of patients, their friends and families, carers, and healthcare professionals.

Design/Setting: A national (UK) research Priority Setting Partnership.

Participants: Patients: over 60 years of age who have experienced a fragility fracture of the lower limb or pelvis; carers involved in their care (both in and out of hospital); family and friends of patients; healthcare professionals involved in the treatment of these patients including but not limited to surgeons, anaesthetists, paramedics, nurses, general practitioners, physicians, physiotherapists, and occupational therapists.

Methods: Using a multi-phase methodology in partnership with the James Lind Alliance over 18-months (August 2016 - January 2018), a national scoping survey asked respondents to submit their research uncertainties. These were amalgamated into a smaller number of research questions. The existing evidence was searched to ensure that the questions had not been answered. A second national survey asked respondents to prioritise the research questions. A final shortlist of 25 questions was taken to a multi-stakeholder workshop where a consensus was reached on the top 10 priorities.

Results: There were 963 original uncertainties submitted by 365 respondents to the first survey. These original uncertainties were refined into 88 research questions of which 76 were judged to be true uncertainties following a review of the research evidence. Healthcare professionals and other stakeholders (patients, carers, friends and families) were represented equally in the responses. The top ten represent uncertainties in rehabilitation, pain management, anaesthesia, and surgery.

Conclusions: We report the top 10 UK research priorities in patients with fragility fractures of the lower limb and pelvis. The priorities highlight uncertainties in rehabilitation, postoperative physiotherapy, pain, weight bearing, infection, and thromboprophylaxis. The challenge now is to refine and deliver answers to these research priorities.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Use of established and transparent James Lind Alliance methodology.
- Survey responses from all over the UK with a 50:50 split between healthcare professionals and non-healthcare professionals (patients, carers, family & friends).
- While the research priorities are now reported, it is up to the research community and research funding organisations to refine and deliver the answers to these questions.

INTRODUCTION

An estimated nine million fragility fractures occurred worldwide in the year 2000, with 50 million people suffering from the sequelae of these fractures.[1] Hip fractures alone are expected to rise from 1.31 million in 1990 to an estimated 6.26 million per year globally by 2050.[2] In the UK over 300,000 patients present to hospital with fragility fractures[3] and the associated treatment costs are around 2% of the total healthcare burden in the UK – approximately £3billion per year.[4]

Adults with fragility fractures of the lower limb or pelvis usually require treatment in hospital and often have other medical comorbidities, along with complex health and social care needs requiring intervention from a number of healthcare professionals and carers.

There is evidence of a mismatch between the research priorities of patients and healthcare professionals and the research which is actually undertaken and delivered.[5-7] This situation is changing. Patient and public involvement (PPI) in research has flourished in the UK, driven by the National Institute of Health Research (NIHR) such that PPI involvement is now a key part of the design, conduct and delivery of research in health and social care.[8]

The James Lind Alliance (JLA) is a non-profit organisation hosted by the NIHR with the aim of raising awareness of research which is directly relevant and of potential benefit to patients and treating clinicians. The guiding principle is to bring together patients, carers, and clinicians to identify and agree on which research uncertainties are most important. To date, there have been over 50 priority setting partnerships across a range of disciplines with over 100 research topics addressed as a direct result of the JLA priority setting partnerships.[9,10]

The aim of this work is to establish the research priorities for adults with fragility fractures of the lower limb and pelvis, which represent the shared interests and priorities of patients, their families and friends, carers, and healthcare professionals.

METHODS

The 'Broken Bones in Older People' priority setting partnership (PSP) took place over an 18-month period between August 2016 and January 2018. An overview of the methodology is shown in Figure 1.

Steering group & Partner Organisations

The clinical lead (MC) initiated the priority setting partnership and guided the appointment of a steering group to oversee and contribute to the process. The steering group consisted of patient representatives, healthcare professionals, and carers with established links to relevant partner organisations (see Appendix 1) to ensure that a range of stakeholder groups were represented. Steering group members did so on a voluntary basis and were expected to commit to the whole process where possible. A JLA Adviser (CW) supported and guided the PSP as a neutral facilitator to ensure that it was undertaken in a fair and transparent way with equal contribution from patients, carers and healthcare professionals. This is an important aspect of the JLA process and ensures that all voices are heard and respected throughout the process. An information specialist (MF) managed the data and performed the analysis. This was overseen and advised on by the steering group.

Scope

All research uncertainties related to fragility fractures of the lower limbs and pelvis for patients over 60 years of age were considered in scope. All stages of the patient pathway were eligible including the immediate care of fragility fractures by the emergency services, acute in-hospital care, and out-of-hospital care. Primary prevention strategies for fragility fractures were excluded. The decisions about whether submissions were in or out-of-scope were made by the information specialist and subsequently verified by the steering group.

Scoping Survey & Identification of Themes

A national scoping survey asked respondents to submit their research uncertainties and provide some optional basic demographic information (gender, first three letters of their postcode, and to identify themselves as either a carer, patient, family/friend of someone over 60 years of age with a fragility fracture, or a healthcare professional). The survey was circulated via the steering group and their partner organisations as an open invitation. The survey was available in both paper and online formats (Bristol online survey tool)[11]. A pilot phase was undertaken to ensure that the survey was clearly written, understandable to all groups, and easy to complete. In addition to submissions from survey respondents, we included research uncertainties highlighted in relevant national guidelines published by The National Institute for Health and Care Excellence (NICE).[12,13] This work did not require formal ethical approval. Respondents to the surveys gave written consent to the inclusion of their anonymised data in this process.

All original submissions were analysed using techniques common to qualitative thematic analysis to define themes and subthemes. The process included initial data immersion (reading and re-reading the submissions), coding of common ideas/themes, identification and naming of themes and subthemes, and a final review to refine the overarching themes. The thematic analysis was undertaken by the information specialist and decisions verified by the steering group.

Indicative Questions & Evidence Search

The overarching themes and subthemes from the thematic analysis were used to generate a smaller number of representative research questions, so called 'indicative questions'. These were derived from the original submissions and were designed to summarise the submissions within each subtheme/theme. The information specialist undertook this process. The indicative questions were then reviewed by the steering group along with a selection of the original uncertainties to ensure that they were a true representation, and to ensure that the language used was understandable to all stakeholder groups. For each indicative question, a review of the current research evidence was undertaken to ensure that the proposed indicative questions were 'true uncertainties' and had not already been answered by research. MF searched PubMed, the grey literature (www.opengrey.eu), The Cochrane Central Register of Controlled Trials (CENTRAL) (www.cochranelibrary.com/about/central-landing-page.html), The WHO international Clinical Trials Registry Platform Search Portal (<http://www.who.int/ictrp/en>), Current Controlled trials (<http://www.controlledtrials.com/isrctn/>), the US National Institute of Health Trials

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3 Registry (<https://clinicaltrials.gov>), and published UK national guidelines.[12,13]
4 Indicative questions were excluded if the steering group agreed that high quality
5 evidence was found (e.g. large clinical trials either published or in-progress,
6 published meta-analyses, or published national evidence based guidelines). The
7 remaining indicative questions went through to interim prioritisation.
8

9 10 **Interim Prioritisation Survey**

11 A second national survey asked respondents to state the importance of each
12 indicative question on a five level Likert scale (1 not important, 2 low importance, 3
13 no opinion, 4 high importance, 5 extremely important). The survey was available in
14 paper and online formats and went through a pilot phase prior to launch. The
15 second survey was again circulated as an open invitation and not restricted to
16 respondents from the first survey. All indicative questions were ranked (interim
17 prioritisation) by calculating a mean score per question based on the number of
18 responses at each of the five response levels. The results were reviewed by the
19 steering group who decided to take the top 25 to the final workshop.
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22 **Final Workshop**

23 This was a one-day multi-stakeholder workshop involving patients, carers, and
24 healthcare professionals. Participants worked in small groups to independently rank
25 the top 25 indicative questions from the interim prioritisation process. The
26 combined results of small group discussions were presented to the whole group.
27 These were considered before a further round of small group discussions. Finally, the
28 whole group came back together again to establish a consensus on the top 10
29 research priorities for fragility fractures of the lower limb and pelvis. The role of the
30 steering group at this stage was to ensure that patients and carers were well
31 supported with information and with practical support on the day. As places in the
32 final workshop were limited, the majority of the steering group did not participate in
33 the final workshop.
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37 **Patient & Public Involvement**

38 Patient and carer representatives were actively involved throughout the process;
39 from the initial stages of planning and overseeing the study as part of the steering
40 group, to participation in the final workshop to ensure that the patient and carer
41 'voice' was represented in the final prioritisation. The steering group made particular
42 efforts to approach a diverse range of patient and carer groups across a number of
43 settings to encourage responses to the surveys. The dissemination strategy of this
44 work includes a plain English summary alongside the scientific publication, which will
45 be circulated to the partner organisations and PPI groups.
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51 **RESULTS**

52 Nine hundred and sixty-three research uncertainties were submitted by 365
53 respondents to the first survey. After removal of 'out-of-scope' uncertainties, there
54 were 810 remaining. Respondents were located throughout the UK. Fifty-one
55 percent (51%) of respondents identified themselves as healthcare professionals and
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3 49% non-healthcare professionals (23% family and friends, 16% patients, 10%
4 carers).

5 Eleven themes were identified: pain, nutrition, surgery, medications & devices,
6 anaesthesia, rehabilitation, falls, anxiety & depression, diagnosis, information, and
7 service delivery. From these themes 88 indicative questions were formulated to
8 represent the original uncertainties. Twelve indicative questions were excluded
9 following a search of the research evidence leaving 76 indicative questions for
10 interim prioritisation.

11
12 The interim prioritisation survey received 209 responses from different regions of
13 the UK of which 47% identified themselves as healthcare professionals and 53% non-
14 healthcare professionals (15% family & friends, 28% patients, 10% carers). Each
15 question was scored based on the responses to interim prioritisation and ranked
16 from positions 1 to 76. The ranking was reviewed by the steering group and the top
17 25 questions were taken to the final prioritisation workshop where a consensus was
18 reached on the top 10 research priorities (see Figure 2 for priorities 1-10 and
19 Appendix 2 for priorities 11-25). You can see the full list of original uncertainties and
20 indicative research questions at the following websites:

21
22 www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/
23 [www.ndorms.ox.ac.uk/research-groups/oxford-trauma/broken-bones-in-older-
24 people](http://www.ndorms.ox.ac.uk/research-groups/oxford-trauma/broken-bones-in-older-people)
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28 **DISCUSSION**

29 We have reported the results of a UK priority setting partnership with the James Lind
30 Alliance and identified the top 10 research priorities in patients with fragility
31 fractures of the lower limb and pelvis. These research priorities represent the shared
32 interests of the multiple stakeholders affected by fragility fractures: patients, family
33 & friends, carers, and healthcare professionals. The top 10 priorities emphasise the
34 lack of evidence to guide 'rehabilitation' following fragility fracture and highlight a
35 number of unanswered questions in postoperative physiotherapy, weight-bearing,
36 as well as rehabilitation pathways for patients with cognitive impairment.

37
38 This study has a number of strengths. This is the first study to report national
39 research priorities in fragility fractures of the lower limb and pelvis in partnership
40 with the James Lind Alliance. These priorities compliment research priorities
41 highlighted by national guidelines in this area which also highlight research
42 uncertainties in rehabilitation and physiotherapy.[12] Patient and carers were
43 actively involved at all stages of the process to ensure that the patient voice was
44 heard and remained at the centre of our efforts. We used the established and
45 transparent JLA methodology to conduct this priority setting partnership. All the
46 original research submissions, as well as the indicative questions (76 in total) are
47 available on the JLA website.[9] The number of survey responses were comparable
48 to other JLA priority setting partnerships,[14] and we achieved a 50:50 balance
49 between responses from healthcare professionals and non-healthcare professionals.
50 Responses were submitted from all over the UK and we are therefore confident that
51 this work represents a national viewpoint.

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our national surveys. These strategies included accessing clinical environments (e.g. GP surgeries, hospital outpatient clinics) with paper surveys as well as sending our online survey link via the mailing lists of national organisations such as the National Osteoporosis Society to ensure as widespread inclusion of patient groups as possible. However, despite these efforts, it is possible that the research priorities reported still underrepresent the frailest group which includes those with permanent cognitive impairment for whom responding to a survey may not be possible. However, we are encouraged to see a research uncertainty in the top 10 specifically directed towards identifying the key components of a rehabilitation pathway for those with chronic cognitive impairment.

We found that research questions which were very specific - which identified the intervention and comparator within the question - tended to attract a lower ranking than more general questions asking a broader less well defined research question. For example, questions asking 'what is the best physiotherapy?' were found to attract more votes than more specific questions comparing two specific interventions (e.g. 'Which is better, tai chi or standard physiotherapy?'). This may reflect an opinion by survey respondents that broader questions may have wider impact and cover multiple interventions. Nevertheless, we felt it was important to strike a balance between more general questions and questions about specific interventions such that the spectrum of the original submissions was accurately reflected. Future prioritisation partnerships will need to consider this aspect of the process and decide on the right balance between inclusion of specific versus general indicative questions.

This work has highlighted the top research questions in lower limb and pelvic fragility fracture research. It is now up to the research community and research funders to refine and deliver the answers to these questions. We hope this work will shape the research landscape in this area and help to deliver meaningful advances in the quality-of-life and care of patients.

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AUTHOR CONTRIBUTIONS

MF analysed the data and wrote the manuscript. LA, JG, AM, RG, PB, SW, MB, XG, TC, DK, RK, CW, and MC provided significant edits to the manuscript and approved the data analysis. MF, LA, JG, AM, RG, PB, SW, MB, XG, TC, DK, RK, CW, and MC have all made significant contributions to the design, implementation, and delivery of this

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3 research. All authors (MF, LA, JG, AM, RG, PB, SW, MB, XG, TC, DK, RK, CW, and MC)
4 have read and approved the final version of this manuscript.
5

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12 the Department of Health.
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15 **COMPETING INTERESTS**

16 MC is a member of the NIHR HTA General Board.
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18

19 **DATA SHARING STATEMENT**

20 Supplementary data including all submitted original research uncertainties and out
21 of scope submissions can be found on the JLA website at
22 [http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-
23 people/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/)
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27 Figure Legends
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29 Figure 1. Flow Chart of Priority Setting Partnership Process
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31 Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and
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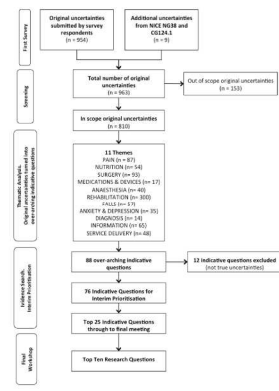


Figure 1. Flow Chart of Priority Setting Partnership Process

297x209mm (300 x 300 DPI)

new only

- Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and pelvis.**
- 1) What is the best physiotherapy and/or occupational therapy regime for adults during their in-hospital recovery from a fragility fracture of the lower limb?
 - 2) What is the best physiotherapy and/or occupational therapy regime for adults during out-of-hospital recovery from a fragility fracture of the lower limb?
 - 3) What is the best way to reduce harmful blood clots in adults treated with a plaster cast (or splint) for fragility fractures of the lower limb?
 - 4) What information about recovery (e.g. rehabilitation, medication, exercises, nutrition, pain), and in what form, should be provided to patients and carers following a fragility fracture of the lower limb?
 - 5) What is the best weight bearing regime following treatment (with or without surgery) for fragility fractures of the ankle?
 - 6) What is most important to adults in their recovery from a fragility fracture of the lower limb?
 - 7) What are the best treatments to prevent and treat confusion and delirium after surgery in adults with a fragility fracture of the lower limb?
 - 8) What is the best pain relief, including non-drug therapies and alternatives to reduce morphine or opioid use, for adults with a lower limb fragility fracture during anaesthesia and immediate recovery after surgery?
 - 9) What are the key components of a rehabilitation pathway for adults with dementia/cognitive impairment following a fragility fracture of the lower limb?
 - 10) What is the best way to prevent surgical site infection in adults undergoing surgery for fragility fractures of the lower limb?

Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and pelvis.

297x209mm (300 x 300 DPI)

APPENDIX 1: PARTNER ORGANISATIONS

Charity Organisations

Carers UK
National Care Association
University of the Third Age (U3A)
Association of Directors of Adult Social Services (ADASS)
National Osteoporosis Society (NOS)
Age Cymru
Age Scotland
Age UK
Association of Medical Charities
Involve People in research
St Johns Ambulance
Arthritis Research UK

Personal Contacts

AGILE (physios specializing in care of older adults)
Dr Anglea McCullagh
Coventry & Warwickshire Partnership Trust
National Institute for Health Research. Collaboration for Leadership in Applied Health Research and Care. West Midlands (NIHR CLAHRC WM)
Manor Court Surgery, Nuneaton

Professional Organisations

University/User Teaching and Research Action Partnership (UNTRAP)
Warwickshire Carers Association & Guideposts
Association of Trauma and Orthopaedic Chartered Physiotherapists (ATOCP)
The Chartered Society of Physiotherapy (CSP)
Age and Ageing
National Osteoporosis Guideline Group (NOGG)
National Hip Fracture Database (NHFD)
Orthopaedic Trauma Society (OTS)
Royal College of Emergency Medicine (RCEM)
The National Ambulance Research Steering Group (NARSG)
Cardiff and Vale Orthopaedic Centre (CAVOC)
Community Health Councils in Wales
Health and Care Research Wales
Health and Care Research Wales Support Centre
Health Services Research Unit – Scotland
Healthwatch England
Royal British Legion working with veterans
Research User Group (RUG) NIHR Manchester
The RNHA Registered Nursing Home Association
Welsh Arthritis Research Network
Age Anaesthesia Association (AAA)
British Geriatric Society

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3 Association of Anaesthetists of Great Britain and Ireland
4 Hip Fracture Perioperative Network (HipPeN)
5 National Institute of Academic Anaesthesia
6 Royal College Anaesthetists
7 British Orthopaedic Association (BOA)
8 Falls and Fragility Fracture Audit Project (FFFAP)
9 Society of Trauma Nurses (SOTN)
10 Trauma Audit & Research Network (TARN)
11 Cochrane
12 Contact, Help, Advice and Information (CHAIN) Network
13 PAIR
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19 **APPENDIX 2: RESEARCH PRIORITIES 11-25**

20
21
22 11) How can we improve the way we link services and the effectiveness of
23 rehabilitation when patients transition from one environment to another (e.g. from
24 hospital to home) following a lower limb fragility fracture?
25

26 12) What is the best pain relief, including non-drug therapies and alternatives to
27 reduce morphine or opioid use, for adults with a lower limb fragility fracture on
28 arrival in hospital (in the emergency department or ward)?
29

30
31 13) What is the best weight bearing regime following treatment (with or without
32 surgery) for fragility fractures of the pelvis and acetabulum (hip socket)?
33
34

35 14) What is the best method to assess pain in adults with and without confusion
36 (either short term or long term such as dementia) following a lower limb fragility
37 fracture?
38

39
40 15) What are the important parts of an enhanced recovery pathway (such as early
41 mobilisation) for adults with a fragility fracture of the lower limb?
42

43 16) What is the best pain relief, including non-drug therapies and alternatives to
44 reduce morphine or opioid use, for adults with a lower limb fragility fracture upon
45 discharge from hospital?
46
47

48 17) What is the best way to reduce harmful blood clots in adults with a fragility hip
49 fracture?
50

51
52 18) What is the best intervention/method to enable and support early discharge of
53 patients from hospital with a lower limb fragility fracture?
54

55 19) What is the best weight bearing regime following treatment (with or without
56 surgery) for fragility fractures of the tibial plateau (the top of the shin bone which
57 forms part of the knee joint)?
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3 20) What are the best physical therapies to treat adults with a fear of falling after a
4 lower limb fragility fracture?
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7 21) What is the best pain relief, including non-drug therapies and alternatives to
8 reduce morphine or opioid use, for adults with a lower limb fragility fracture during
9 in-hospital rehabilitation?
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12 22) What are the best psychological therapies to treat adults with a fear of falling
13 after a lower limb fragility fracture?
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15 23) What are the specific barriers to hospital discharge (factors which delay or
16 prevent discharge from hospital) for adults with a fragility fracture of the lower limb?
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18
19 24) What is the best way to promote healing in adults with a fragility fracture of the
20 lower limb?
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23 25) What is the best treatment for surgical infections in adults following surgery for
24 fragility fractures of the lower limb?
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Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority Setting Partnership with the James Lind Alliance

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Manuscripts

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3 **Research Priorities in Fragility Fractures of the Lower Limb and Pelvis: A UK Priority**
4 **Setting Partnership with the James Lind Alliance.**
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6 M. A. Fernandez^{1,2*}, L. Arnel¹, J. Gould³, A. McGibbon³, R. Grant³, P. Bell³, S. White⁴,
7 M. Baxter⁵, X. Griffin¹, T. Chesser⁶, D. Keene¹, R. S. Kearney⁷, C. White⁸, and M. L.
8 Costa¹
9

10
11
12 ¹Oxford Trauma, University of Oxford, Kadoorie Centre, John Radcliffe Hospital,
13 Headley Way, Oxford OX3 9DU, UK
14

15 ²University Hospitals Coventry & Warwickshire NHS Trust, Clifford Bridge Road,
16 Coventry, CV2 2DX, UK
17

18 ³ Patient representatives, UK
19

20 ⁴Royal Sussex County Hospital, Brighton, BN2 5BE, UK
21

22 ⁵University Hospital Southampton NHS Foundation Trust, Tremona Road,
23 Southampton, SO16 6YD, UK
24

25 ⁶North Bristol NHS Trust, Southmead Hospital, Bristol BS10 5NB, UK
26

27 ⁷University of Warwick, Clinical Trials Unit, Gibbet Hill Road, Coventry, CV4 7AL, UK
28

29 ⁸James Lind Alliance advisor (to Feb 2018), National Institute for Health Research,
30 University of Southampton, Enterprise Road, Southampton, SO16 7NS, UK
31

32 *corresponding author: Mr M. A. Fernandez, Oxford Trauma, University of Oxford,
33 Kadoorie Centre, John Radcliffe Hospital, Headley Way, Oxford OX3 9DU, UK.
34 miguel.fernandez@ndorms.ox.ac.uk Tel. 07939250006
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ABSTRACT

Objective: To determine research priorities in fragility fractures of the lower limb and pelvis, which represent the shared priorities of patients, their friends and families, carers, and healthcare professionals.

Design/Setting: A national (UK) research Priority Setting Partnership.

Participants: Patients: over 60 years of age who have experienced a fragility fracture of the lower limb or pelvis; carers involved in their care (both in and out of hospital); family and friends of patients; healthcare professionals involved in the treatment of these patients including but not limited to surgeons, anaesthetists, paramedics, nurses, general practitioners, physicians, physiotherapists, and occupational therapists.

Methods: Using a multi-phase methodology in partnership with the James Lind Alliance over 18-months (August 2016 - January 2018), a national scoping survey asked respondents to submit their research uncertainties. These were amalgamated into a smaller number of research questions. The existing evidence was searched to ensure that the questions had not been answered. A second national survey asked respondents to prioritise the research questions. A final shortlist of 25 questions was taken to a multi-stakeholder workshop where a consensus was reached on the top 10 priorities.

Results: There were 963 original uncertainties submitted by 365 respondents to the first survey. These original uncertainties were refined into 88 research questions of which 76 were judged to be true uncertainties following a review of the research evidence. Healthcare professionals and other stakeholders (patients, carers, friends and families) were represented equally in the responses. The top ten represent uncertainties in rehabilitation, pain management, anaesthesia, and surgery.

Conclusions: We report the top 10 UK research priorities in patients with fragility fractures of the lower limb and pelvis. The priorities highlight uncertainties in rehabilitation, postoperative physiotherapy, pain, weight bearing, infection, and thromboprophylaxis. The challenge now is to refine and deliver answers to these research priorities.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Use of established and transparent James Lind Alliance methodology.
- Survey responses from all over the UK with a 50:50 split between healthcare professionals and non-healthcare professionals (patients, carers, family & friends).
- While the research priorities are now reported, it is up to the research community and research funding organisations to refine and deliver the answers to these questions.

INTRODUCTION

An estimated nine million fragility fractures occurred worldwide in the year 2000, with 50 million people suffering from the sequelae of these fractures.[1] Hip fractures alone are expected to rise from 1.31 million in 1990 to an estimated 6.26 million per year globally by 2050.[2] In the UK over 300,000 patients present to hospital with fragility fractures[3] and the associated treatment costs are around 2% of the total healthcare burden in the UK – approximately £3billion per year.[4]

Adults with fragility fractures of the lower limb or pelvis usually require treatment in hospital and often have other medical comorbidities, along with complex health and social care needs requiring intervention from a number of healthcare professionals and carers.

There is evidence of a mismatch between the research priorities of patients and healthcare professionals and the research which is actually undertaken and delivered.[5-7] This situation is changing. Patient and public involvement (PPI) in research has flourished in the UK, driven by the National Institute of Health Research (NIHR) such that PPI involvement is now a key part of the design, conduct and delivery of research in health and social care.[8]

The James Lind Alliance (JLA) is a non-profit organisation hosted by the NIHR with the aim of raising awareness of research which is directly relevant and of potential benefit to patients and treating clinicians. The guiding principle is to bring together patients, carers, and clinicians to identify and agree on which research uncertainties are most important. To date, there have been over 50 priority setting partnerships across a range of disciplines with over 100 research topics addressed as a direct result of the JLA priority setting partnerships.[9,10]

The aim of this work is to establish the research priorities for adults with fragility fractures of the lower limb and pelvis, which represent the shared interests and priorities of patients, their families and friends, carers, and healthcare professionals.

METHODS

The 'Broken Bones in Older People' priority setting partnership (PSP) took place over an 18-month period between August 2016 and January 2018. An overview of the methodology is shown in Figure 1.

Steering group & Partner Organisations

The clinical lead (MC) initiated the priority setting partnership and guided the appointment of a steering group to oversee and contribute to the process. The steering group consisted of patient representatives, healthcare professionals, and carers with established links to relevant partner organisations (see Appendix 1) to ensure that a range of stakeholder groups were represented. Steering group members did so on a voluntary basis and were expected to commit to the whole process where possible. A JLA Adviser (CW) supported and guided the PSP as a neutral facilitator to ensure that it was undertaken in a fair and transparent way encouraging equal contributions from patients, carers and healthcare professionals. This is an important aspect of the JLA process and ensures that all voices are heard and respected throughout the process. An information specialist (MF) managed the

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3 data and performed the analysis. This was overseen and advised on by the steering
4 group.
5

6 **Scope**

7 All research uncertainties related to fragility fractures of the lower limbs and pelvis
8 for patients over 60 years of age were considered in scope. All stages of the patient
9 pathway were eligible including the immediate care of fragility fractures by the
10 emergency services, acute in-hospital care, and out-of-hospital care. Primary
11 prevention strategies for fragility fractures were excluded. The decisions about
12 whether submissions were in or out-of-scope were made by the information
13 specialist and subsequently verified by the steering group.
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16 **Ethics Statement**

17 This work did not require ethics approval as per the JLA guidance[11] and guidance
18 published by the NHS National Patient Safety Agency National Research Ethics
19 Service.[12] Respondents to the surveys provided written consent to the inclusion of
20 their anonymised data in this process.
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24 **Scoping Survey & Identification of Themes**

25 A national scoping survey asked respondents to submit their research uncertainties
26 and provide some optional basic demographic information (gender, first three
27 letters of their postcode, and to identify themselves as either a carer, patient,
28 family/friend of someone over 60 years of age with a fragility fracture, or a
29 healthcare professional). The survey was circulated via the steering group and their
30 partner organisations as an open invitation. The survey was available in both paper
31 and online formats (Bristol online survey tool)[13]. A pilot phase was undertaken to
32 ensure that the survey was clearly written, understandable to all groups, and easy to
33 complete. In addition to submissions from survey respondents, we included research
34 uncertainties highlighted in relevant national guidelines published by The National
35 Institute for Health and Care Excellence (NICE).[14,15]
36

37 All original submissions were analysed using techniques common to qualitative
38 thematic analysis to define themes and subthemes. The process included initial data
39 immersion (reading and re-reading the submissions), coding of common
40 ideas/themes, identification and naming of themes and subthemes, and a final
41 review to refine the overarching themes. The thematic analysis was undertaken by
42 the information specialist and decisions verified by the steering group. In order to do
43 this the steering group were given to the opportunity to review all of the original
44 submissions under each theme/subtheme. These were then referred to during the
45 verification process.
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50 **Indicative Questions & Evidence Search**

51 The overarching themes and subthemes from the thematic analysis were used to
52 generate a smaller number of representative research questions, so called 'indicative
53 questions'. These were derived from the original submissions and were designed to
54 summarise the submissions within each subtheme/theme. The information specialist
55 undertook this process. The indicative questions were then reviewed by the steering
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3 group along with a selection of the original uncertainties to ensure that they were a
4 true representation, and to ensure that the language used was understandable to all
5 stakeholder groups. For each indicative question, a review of the current research
6 evidence was undertaken to ensure that the proposed indicative questions were
7 'true uncertainties' and had not already been answered by research. MF searched
8 PubMed, the grey literature (www.opengrey.eu), The Cochrane Central Register of
9 Controlled Trials (CENTRAL) ([www.cochranelibrary.com/about/central-landing-
10 page.html](http://www.cochranelibrary.com/about/central-landing-page.html)), The WHO international Clinical Trials Registry Platform Search Portal
11 (<http://www.who.int/ictrp/en>), Current Controlled trials
12 (<http://www.controlledtrials.com/isrctn/>), the US National Institute of Health Trials
13 Registry (<https://clinicaltrials.gov>), and published UK national guidelines.[14,15]
14 Indicative questions were excluded if the steering group agreed that high quality
15 evidence was found (e.g. large clinical trials either published or in-progress,
16 published meta-analyses, or published national evidence based guidelines). The
17 remaining indicative questions went through to interim prioritisation.
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21 **Interim Prioritisation Survey**

22 A second national survey asked respondents to state the importance of each
23 indicative question on a five level Likert scale (1 not important, 2 low importance, 3
24 no opinion, 4 high importance, 5 extremely important). The survey was available in
25 paper and online formats and went through a pilot phase prior to launch. The
26 second survey was again circulated as an open invitation and not restricted to
27 respondents from the first survey. All indicative questions were ranked (interim
28 prioritisation) by calculating a mean score per question based on the number of
29 responses at each of the five response levels. The results were reviewed by the
30 steering group who decided to take the top 25 to the final workshop.
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34 **Final Workshop**

35 This was a one-day multi-stakeholder workshop involving patients, carers, and
36 healthcare professionals. Participants worked in small groups to independently rank
37 the top 25 indicative questions from the interim prioritisation process. The
38 combined results of small group discussions were presented to the whole group.
39 These were considered before a further round of small group discussions. Finally, the
40 whole group came back together again to establish a consensus on the top 10
41 research priorities for fragility fractures of the lower limb and pelvis. The role of the
42 steering group at this stage was to ensure that patients and carers were well
43 supported with information and with practical support on the day. As places in the
44 final workshop were limited, the majority of the steering group did not participate in
45 the final workshop.
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48

49 **Patient & Public Involvement**

50 Patient and carer representatives were actively involved throughout the process;
51 from the initial stages of planning and overseeing the study as part of the steering
52 group, to participation in the final workshop to ensure that the patient and carer
53 'voice' was represented in the final prioritisation. The steering group made particular
54 efforts to approach a diverse range of patient and carer groups across a number of
55 settings to encourage responses to the surveys. The dissemination strategy of this
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work includes a plain English summary alongside the scientific publication, which will be circulated to the partner organisations and PPI groups.

RESULTS

Nine hundred and sixty-three research uncertainties were submitted by 365 respondents to the first survey. After removal of 'out-of-scope' uncertainties, there were 810 remaining. Respondents were located throughout the UK. Fifty-one percent (51%) of respondents identified themselves as healthcare professionals and 49% non-healthcare professionals (23% family and friends, 16% patients, 10% carers).

Eleven themes were identified: pain, nutrition, surgery, medications & devices, anaesthesia, rehabilitation, falls, anxiety & depression, diagnosis, information, and service delivery. From these themes 88 indicative questions were formulated to represent the original uncertainties. Twelve indicative questions were excluded following a search of the research evidence leaving 76 indicative questions for interim prioritisation.

The interim prioritisation survey received 209 responses from different regions of the UK of which 47% identified themselves as healthcare professionals and 53% non-healthcare professionals (15% family & friends, 28% patients, 10% carers). Each question was scored based on the responses to interim prioritisation and ranked from positions 1 to 76. The ranking was reviewed by the steering group and the top 25 questions were taken to the final prioritisation workshop where a consensus was reached on the top 10 research priorities (see Figure 2 for priorities 1-10 and Appendix 2 for priorities 11-25). You can see the full list of original uncertainties and indicative research questions at the following websites:

www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/
www.ndorms.ox.ac.uk/research-groups/oxford-trauma/broken-bones-in-older-people

DISCUSSION

We have reported the results of a UK priority setting partnership with the James Lind Alliance and identified the top 10 research priorities in patients with fragility fractures of the lower limb and pelvis. These research priorities represent the shared interests of the multiple stakeholders affected by fragility fractures: patients, family & friends, carers, and healthcare professionals. The top 10 priorities emphasise the lack of evidence to guide 'rehabilitation' following fragility fracture and highlight a number of unanswered questions in postoperative physiotherapy, weight-bearing, as well as rehabilitation pathways for patients with cognitive impairment.

This study has a number of strengths. This is the first study to report national research priorities in fragility fractures of the lower limb and pelvis in partnership with the James Lind Alliance. These priorities compliment research priorities highlighted by national guidelines in this area which also highlight research uncertainties in rehabilitation and physiotherapy.[14] Patient and carers were actively involved at all stages of the process to ensure that the patient voice was

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3 heard and remained at the centre of our efforts. We used the established and
4 transparent JLA methodology to conduct this priority setting partnership. All the
5 original research submissions, as well as the indicative questions (76 in total) are
6 available on the JLA website.[9] The number of survey responses were comparable
7 to other JLA priority setting partnerships,[16] and we achieved a 50:50 balance
8 between responses from healthcare professionals and non-healthcare professionals.
9 Responses were submitted from all over the UK and we are therefore confident that
10 this work represents a national viewpoint.

11
12 Fragility fractures affect frail older people disproportionately. Considerable efforts
13 were required to ensure that all patient groups were able to access and respond to
14 our national surveys. These strategies included accessing clinical environments (e.g.
15 GP surgeries, hospital outpatient clinics) with paper surveys as well as sending our
16 online survey link via the mailing lists of national organisations such as the National
17 Osteoporosis Society to ensure as widespread inclusion of patient groups as
18 possible. However, despite these efforts, it is possible that the research priorities
19 reported still underrepresent the frailest group which includes those with
20 permanent cognitive impairment for whom responding to a survey may not be
21 possible. However, we are encouraged to see a research uncertainty in the top 10
22 specifically directed towards identifying the key components of a rehabilitation
23 pathway for those with chronic cognitive impairment.

24
25 We found that research questions which were very specific - which identified the
26 intervention and comparator within the question - tended to attract a lower ranking
27 than more general questions asking a broader less well defined research question.
28 For example, questions asking 'what is the best physiotherapy?' were found to
29 attract more votes than more specific questions comparing two specific
30 interventions (e.g. 'Which is better, tai chi or standard physiotherapy?'). This may
31 reflect an opinion by survey respondents that broader questions may have wider
32 impact and cover multiple interventions. Nevertheless, we felt it was important to
33 strike a balance between more general questions and questions about specific
34 interventions such that the spectrum of the original submissions was accurately
35 reflected. Future prioritisation partnerships will need to consider this aspect of the
36 process and decide on the right balance between inclusion of specific versus general
37 indicative questions.

38
39 This work has highlighted the top research questions in lower limb and pelvic
40 fragility fracture research. It is now up to the research community and research
41 funders to refine and deliver the answers to these questions. We hope this work will
42 shape the research landscape in this area and help to deliver meaningful advances in
43 the quality-of-life and care of patients.
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55 Crouch, Andrew McAndrew, Nigel Rees, Helen Wilson, Pippa Ellery, Cliff Shelton,
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3 Debs Smith, Josephine Rowling, Karen Keates, Stella Saunders, Sheila Holmes, Jean
4 Maston, Shirley MacWhirter, Thelma Sanders, Sue Bremner-Milne, Diane Hackford,
5 John Cocker, Sheela Upadhyaya, and Toto Anne Gronlund).

7 **AUTHOR CONTRIBUTIONS**

8 MF analysed the data and wrote the manuscript. LA, JG, AM, RG, PB, SW, MB, XG,
9 TC, DK, RK, CW, and MC provided significant edits to the manuscript and approved
10 the data analysis. MF, LA, JG, AM, RG, PB, SW, MB, XG, TC, DK, RK, CW, and MC have
11 all made significant contributions to the design, implementation, and delivery of this
12 research. All authors (MF, LA, JG, AM, RG, PB, SW, MB, XG, TC, DK, RK, CW, and MC)
13 have read and approved the final version of this manuscript.
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22 the Department of Health.
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25 **COMPETING INTERESTS**

26 MC is a member of the NIHR HTA General Board.
27
28

29 **DATA SHARING STATEMENT**

30 Supplementary data including all submitted original research uncertainties and out
31 of scope submissions can be found on the JLA website at
32 [http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-
33 people/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/broken-bones-in-older-people/)
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36 **Figure Legends**

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40 Figure 1. Flow Chart of Priority Setting Partnership Process

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42 Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and
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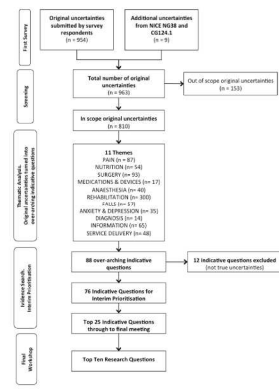


Figure 1. Flow Chart of Priority Setting Partnership Process

297x209mm (300 x 300 DPI)

new only

- Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and pelvis.**
- 1) What is the best physiotherapy and/or occupational therapy regime for adults during their in-hospital recovery from a fragility fracture of the lower limb?
 - 2) What is the best physiotherapy and/or occupational therapy regime for adults during out-of-hospital recovery from a fragility fracture of the lower limb?
 - 3) What is the best way to reduce harmful blood clots in adults treated with a plaster cast (or splint) for fragility fractures of the lower limb?
 - 4) What information about recovery (e.g. rehabilitation, medication, exercises, nutrition, pain), and in what form, should be provided to patients and carers following a fragility fracture of the lower limb?
 - 5) What is the best weight bearing regime following treatment (with or without surgery) for fragility fractures of the ankle?
 - 6) What is most important to adults in their recovery from a fragility fracture of the lower limb?
 - 7) What are the best treatments to prevent and treat confusion and delirium after surgery in adults with a fragility fracture of the lower limb?
 - 8) What is the best pain relief, including non-drug therapies and alternatives to reduce morphine or opioid use, for adults with a lower limb fragility fracture during anaesthesia and immediate recovery after surgery?
 - 9) What are the key components of a rehabilitation pathway for adults with dementia/cognitive impairment following a fragility fracture of the lower limb?
 - 10) What is the best way to prevent surgical site infection in adults undergoing surgery for fragility fractures of the lower limb?

Figure 2. The top ten UK research priorities in fragility fractures of the lower limb and pelvis.

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APPENDIX 1: PARTNER ORGANISATIONS

Charity Organisations

Carers UK
National Care Association
University of the Third Age (U3A)
Association of Directors of Adult Social Services (ADASS)
National Osteoporosis Society (NOS)
Age Cymru
Age Scotland
Age UK
Association of Medical Charities
Involve People in research
St Johns Ambulance
Arthritis Research UK

Personal Contacts

AGILE (physios specializing in care of older adults)
Dr Anglea McCullagh
Coventry & Warwickshire Partnership Trust
National Institute for Health Research. Collaboration for Leadership in Applied Health Research and Care. West Midlands (NIHR CLAHRC WM)
Manor Court Surgery, Nuneaton

Professional Organisations

University/User Teaching and Research Action Partnership (UNTRAP)
Warwickshire Carers Association & Guideposts
Association of Trauma and Orthopaedic Chartered Physiotherapists (ATOCP)
The Chartered Society of Physiotherapy (CSP)
Age and Ageing
National Osteoporosis Guideline Group (NOGG)
National Hip Fracture Database (NHFD)
Orthopaedic Trauma Society (OTS)
Royal College of Emergency Medicine (RCEM)
The National Ambulance Research Steering Group (NARSG)
Cardiff and Vale Orthopaedic Centre (CAVOC)
Community Health Councils in Wales
Health and Care Research Wales
Health and Care Research Wales Support Centre
Health Services Research Unit – Scotland
Healthwatch England
Royal British Legion working with veterans
Research User Group (RUG) NIHR Manchester
The RNHA Registered Nursing Home Association
Welsh Arthritis Research Network
Age Anaesthesia Association (AAA)
British Geriatric Society

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3 Association of Anaesthetists of Great Britain and Ireland
4 Hip Fracture Perioperative Network (HipPeN)
5 National Institute of Academic Anaesthesia
6 Royal College Anaesthetists
7 British Orthopaedic Association (BOA)
8 Falls and Fragility Fracture Audit Project (FFFAP)
9 Society of Trauma Nurses (SOTN)
10 Trauma Audit & Research Network (TARN)
11 Cochrane
12 Contact, Help, Advice and Information (CHAIN) Network
13 PAIR
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19 **APPENDIX 2: RESEARCH PRIORITIES 11-25**

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21
22 11) How can we improve the way we link services and the effectiveness of
23 rehabilitation when patients transition from one environment to another (e.g. from
24 hospital to home) following a lower limb fragility fracture?
25

26 12) What is the best pain relief, including non-drug therapies and alternatives to
27 reduce morphine or opioid use, for adults with a lower limb fragility fracture on
28 arrival in hospital (in the emergency department or ward)?
29

30
31 13) What is the best weight bearing regime following treatment (with or without
32 surgery) for fragility fractures of the pelvis and acetabulum (hip socket)?
33
34

35 14) What is the best method to assess pain in adults with and without confusion
36 (either short term or long term such as dementia) following a lower limb fragility
37 fracture?
38

39
40 15) What are the important parts of an enhanced recovery pathway (such as early
41 mobilisation) for adults with a fragility fracture of the lower limb?
42

43 16) What is the best pain relief, including non-drug therapies and alternatives to
44 reduce morphine or opioid use, for adults with a lower limb fragility fracture upon
45 discharge from hospital?
46
47

48 17) What is the best way to reduce harmful blood clots in adults with a fragility hip
49 fracture?
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52 18) What is the best intervention/method to enable and support early discharge of
53 patients from hospital with a lower limb fragility fracture?
54

55 19) What is the best weight bearing regime following treatment (with or without
56 surgery) for fragility fractures of the tibial plateau (the top of the shin bone which
57 forms part of the knee joint)?
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3 20) What are the best physical therapies to treat adults with a fear of falling after a
4 lower limb fragility fracture?
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7 21) What is the best pain relief, including non-drug therapies and alternatives to
8 reduce morphine or opioid use, for adults with a lower limb fragility fracture during
9 in-hospital rehabilitation?
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12 22) What are the best psychological therapies to treat adults with a fear of falling
13 after a lower limb fragility fracture?
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15 23) What are the specific barriers to hospital discharge (factors which delay or
16 prevent discharge from hospital) for adults with a fragility fracture of the lower limb?
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19 24) What is the best way to promote healing in adults with a fragility fracture of the
20 lower limb?
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23 25) What is the best treatment for surgical infections in adults following surgery for
24 fragility fractures of the lower limb?
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