



James
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Alliance

Priority Setting Partnerships

The James Lind Alliance

Finding out the questions that patients
and clinicians want research to answer

Beccy Maeso 28 September 2023

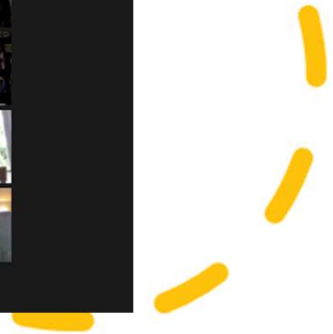
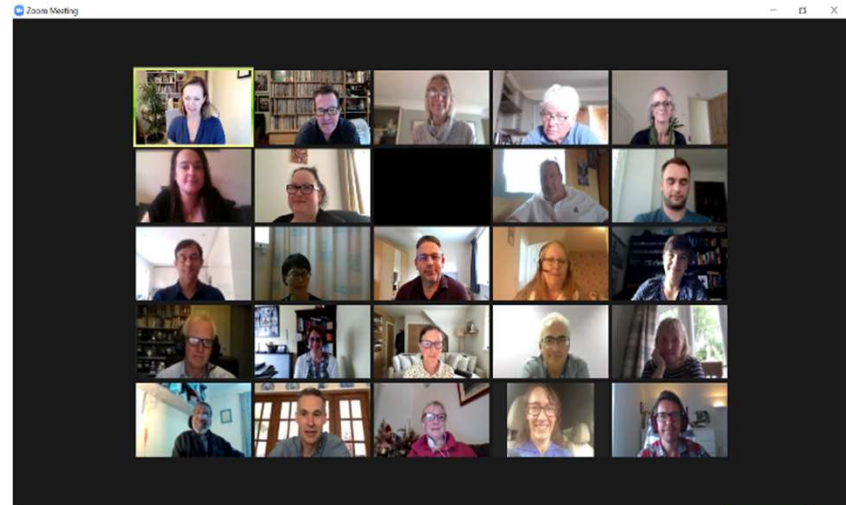


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What is the James Lind Alliance?

A method that brings patients, carers and health and social care professionals together in Priority Setting Partnerships (PSPs) to agree the Top 10 priorities for research in a particular condition or setting





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Why involve patients and clinicians?

Who normally decides what gets researched?

Researchers

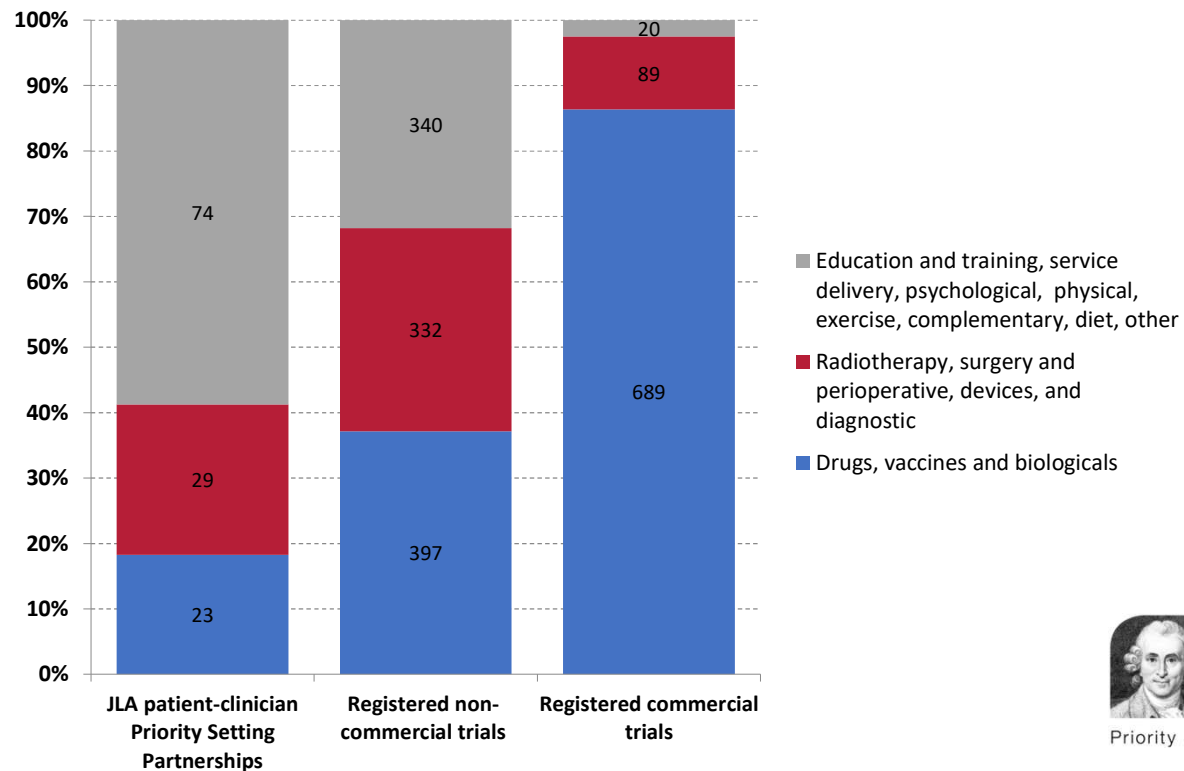
Pharmaceutical industry

The priorities of people with conditions and the people who treat and care for them can be very different from those of researchers.



A mismatch

Interventions mentioned in commercial trials, non-commercial trials and research priorities identified by JLA PSPs, 2003-2012.



Crowe *et al.* (2015) 'Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch', *Research Involvement and Engagement*, 1:2



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The JLA's founders



*Sir Iain
Chalmers*



Dr John Scadding



Sir Nick Partridge



James Lind?



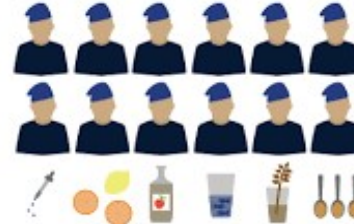
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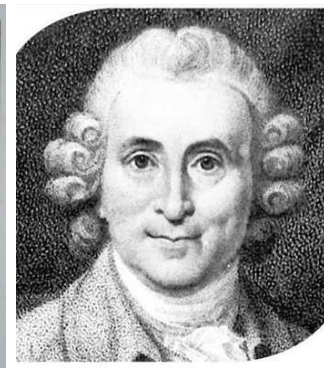
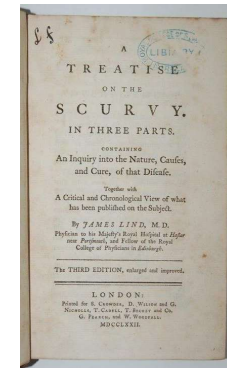
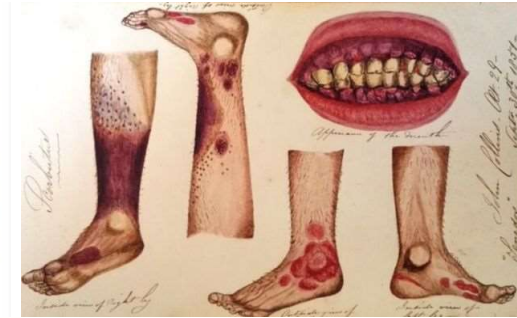
1747
Where it all began...



May 20, 1747 - Scottish physician James Lind conducted the first clinical study of the treatment of scurvy on 12 sailors.



Lind discovered that of six therapies, oranges and lemons had the greatest positive effect on the sailors' health.





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Priority Setting Partnerships

What is a Priority Setting Partnership (PSP)?

- Patients, carers and clinicians working as equals
- Focusing on a single condition or area of health and social care
- Identifying unanswered questions (evidence uncertainties)
- Prioritising the most important into a Top 10
- Promoting the Top 10 to researchers and funders



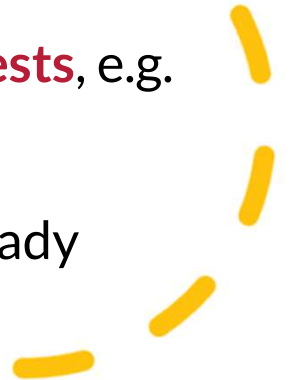


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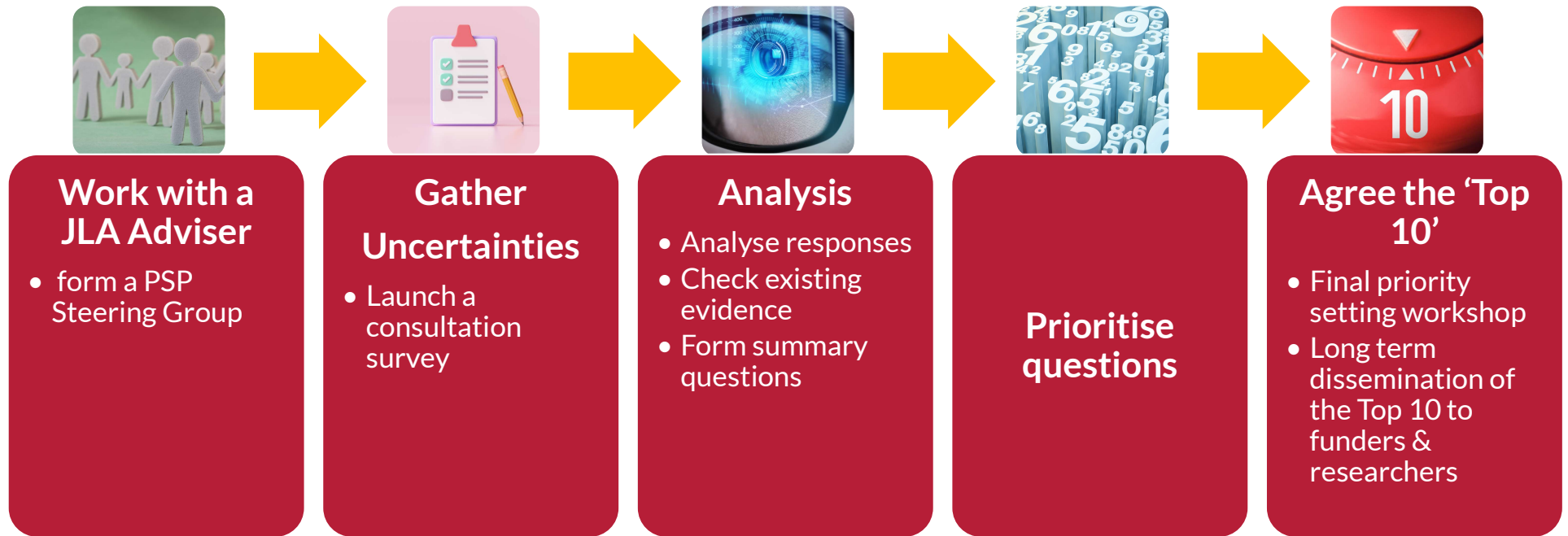
JLA principles

- **Transparency** of the process, so that what the PSP has done is clear
- **Balanced inclusion** of patient, carer and clinician interests and perspectives – equal voice
- Exclusion from voting of those professionals who don't treat patients
- **Exclusion** of groups or organisations that may have **competing interests**, e.g. pharmaceutical companies
- Using the **existing evidence** base to make sure questions are not already answered





The PSP process



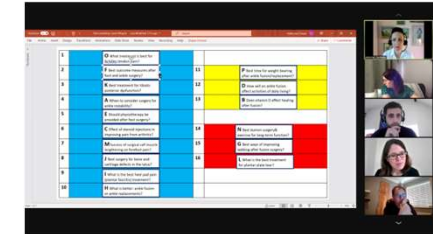
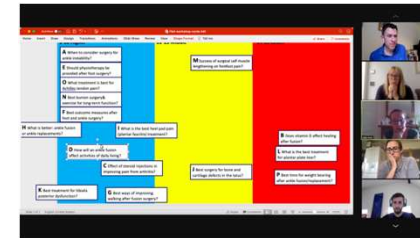
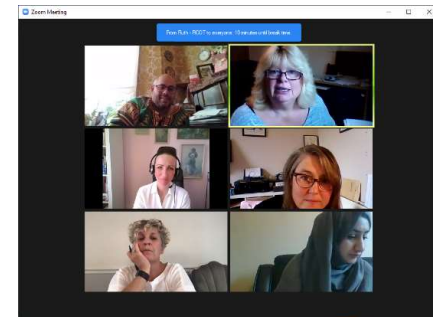
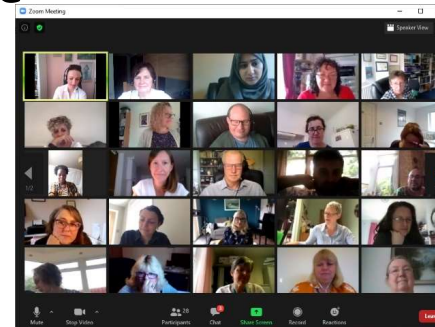
12 – 18 month process

Priority setting workshop – final stage

In person



Online



A screenshot of a presentation slide showing a table with columns for questions and scores. The table lists various questions related to treatment and outcomes, with corresponding scores in columns Q1, Q2, Q3, and Q4. A 'Continued score - sort lowest to highest' column is also present.

Rank	ID	Question	Q1	Q2	Q3	Q4	Continued score - sort lowest to highest
1	O	What treatment is best for Achilles tendon pain?	10	10	10	10	10
2	K	Best treatment for tibialis posterior dysfunction?	10	10	10	10	10
3	F	Best outcome measures after foot and ankle surgery?	10	10	10	10	10
4	A	When to consider surgery for ankle instability?	10	10	10	10	10
5	B	Should physiotherapy be provided following foot surgery?	10	10	10	10	10
6	C	Effect of tibial resection in improving pain from arthritis?	10	10	10	10	10
7	M	Successes of surgical calf muscle lengthening on foot/ankle pain?	10	10	10	10	10
8	J	Best surgery for bone and cartilage defects in the talus?	10	10	10	10	10
9	I	What is the best foot and pain (plantar fasciitis) treatment?	10	10	10	10	10
10	H	What is better: ankle fusion or ankle replacements?	10	10	10	10	10
11	P	Best time for weight bearing after ankle fusion/replacement?	10	10	10	10	10
12	D	How well do ankle fuses affect activities of daily living?	10	10	10	10	10
13	B	Does vitamin C affect healing after fusion?	10	10	10	10	10
14	N	Best duration surgery & exercise for long-term function?	10	10	10	10	10
15	G	Best ways of improving walking after fusion surgery?	10	10	10	10	10
16	L	What is the best treatment for plantar plate tear?	10	10	10	10	10



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Over 150 Completed PSPs

Health conditions

- Physical health
- Epilepsy (2022)
 - Children's cancer (2022)
 - T1 Diabetes (2020)

- Mental health
- Digital technology for mental health (2018)
 - Bipolar (2016)

Health settings

- Emergency medicine
- 2017, 2022
- Intensive care
- 2014
- Primary care
- Patient safety in primary care (2017)

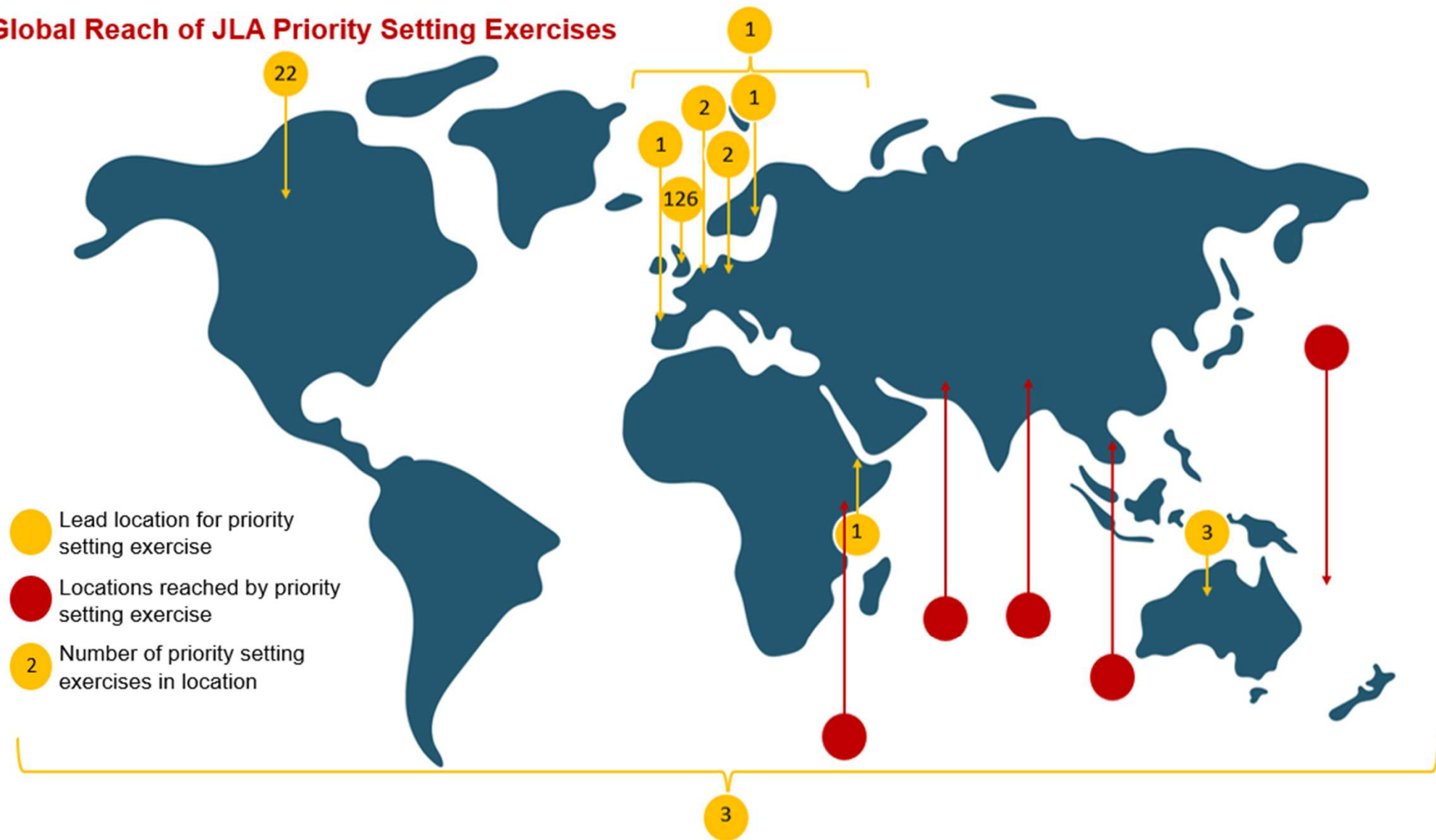
Locations

- UK
- Developmental childhood stammering (ongoing)
 - Breast cancer surgery (2022)
- International
- Myeloma (Canada) (2022),
 - Pancreatic cancer (Germany) (2020),
- LMICs
- Diabetic eye disease (ongoing),
 - Global burns (ongoing)

Funders

- Charities
- Royal Colleges
- Universities
- Grant applications

Global Reach of JLA Priority Setting Exercises



Top 10s

James Lind Alliance FOOT AND ANKLE SURGERY Priority Setting Partnership

'TOP 10' RESEARCH PRIORITIES IN FOOT AND ANKLE SURGERY

The James Lind Alliance and the British Orthopaedic Foot and Ankle Society have worked together to identify 'Top Ten' unanswered research themes in foot and ankle surgery by involving patients, carers, and clinicians.

ASK

Questions to patients, carers and clinicians

ANALYSE

What are your top most important questions?

PRIORITISE

What are your top most important questions?

1. What are the best outcome measures (ways of assessing the effect of the treatment) after foot and ankle surgery?
2. What treatment is best for Achilles tendon pain?
3. What is the best treatment (including surgery) for tibiotalar posterior (tendon on the inner side of the ankle) dysfunction leading to a successful long-term outcome?
4. Should physiotherapy be provided following foot and ankle surgery and is there an optimal amount needed to restore function after foot and ankle surgery?
5. At what stage should a patient with ankle instability (ie an ankle that keeps giving way) be considered for surgical treatment?
6. How effective are steroid injections in improving pain from arthritis in the foot and ankle?
7. What is the best surgery for bone and cartilage defects in the talus?
8. What is better, ankle fusion or ankle replacements?
9. What is the success of surgical lengthening of the calf muscle in improving forefoot pain?
10. When is the best time to start weight bearing after ankle fusion/replacement surgery?

THE TOP 10 PRIORITIES FOR EPILEPSY RESEARCH

The Dementia Brain Institute (DBI) is thinking differently about the way we do research. As a result, DBI, in partnership with Epilepsy Research UK and the James Lind Alliance have come together to organise a Priority Setting Partnership (PSP), an epilepsy research.

By bringing together patients, carers and health care providers the PSP helped identify and prioritise the top 10 unanswered questions around treatment and care. These priorities will be presented to researchers, funders and policy makers to shape the future of epilepsy research in Canada.

1. Can genetic markers be used to diagnose and treat epilepsy and seizure disorders?
2. What are the impacts of long-term use of anti-seizure drugs, the causes of the side effects of these treatments and how can we prevent the side effects?
3. What are the long-term impacts of seizures on a person's brain, and overall health and development?
4. How can the risk of SUDEP (Sudden Unexpected Death in Epilepsy) be reduced in people with epilepsy?
5. What is the most effective testing protocol for determining causes of seizures and/or a diagnosis of epilepsy or other seizure disorders, and to reduce time to diagnosis?
6. What are the brain changes, on a cellular level, that lead to seizure development?
7. How effective is surgical treatment for adults and children who experience seizure(s)?
8. What causes memory problems associated with seizures? Can these memory problems improve over time and what are the best treatment options for memory loss in people who experience seizures?
9. Aside from anti-seizure drugs and some brain lesions, what causes behavioural changes in people who experience seizures? What is the best way to treat behavioural issues?
10. What is the efficacy (i.e. the effectiveness of reducing seizures) of adding a second anti-seizure medication compared to changing the different anti-seizure medications? What are the outcomes which combinations of anti-seizure drugs are effective?

Visit <http://braininstitute.ca/epilepsy.asp> to learn more.

TOP 10 RESEARCH PRIORITIES FOR MITOCHONDRIAL DISEASE

1. Could an understanding of the cellular and molecular processes in mitochondrial disease lead to new treatments?
2. Can the damage to cells caused by mitochondrial disease be repaired (e.g. to restore hearing, vision, or repair the pancreas)?
3. What are the biological mechanisms that cause mitochondrial disease to get worse over time?
4. What biomarkers (biological markers that can be measured e.g. in blood samples) could be used to diagnose mitochondrial disease and to track its progress?
5. Could gene therapy help people with mitochondrial disease?
6. What are the psychological impacts of mitochondrial disease? What are the best ways to provide psychological support for people with mitochondrial disease and their families?
7. What are the best ways to reduce the risk of stroke-like episodes in people with mitochondrial disease?
8. What factors could trigger the start of mitochondrial disease in people who have a genetic mutation?
9. Why are people with the same genetic mutation affected so differently in mitochondrial disease?
10. What are the most effective ways to treat and manage fatigue?

CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP

Top 10 Priorities for Dementia Research

1. ADDRESSING STIGMA: What is the impact of stigma associated with dementia and mental health issues on persons with dementia and their families?
2. PREVENTION AND LIFESTYLE: What can be done to support nutritional well-being, including monitoring a variety of dietary, for persons with dementia?
3. IMPACT OF EARLY TREATMENT: Advise persons with dementia what is the impact of early treatment on quality of life, disease progression and cognitive symptoms?
4. HEALTH SYSTEM CAPACITY: How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their loved-ones for long-term care?
5. CAREGIVER SUPPORT: How can patients, supports and programs be created or adapted to support the needs of persons with dementia, including caregiver support, well-being and quality of life for persons with dementia and their families or loved-ones?
6. PERSONALISED MEDICATION AND CARE: What are the best ways to tailor care to the needs and preferences of persons with dementia and their families?
7. CARE PROVIDER EDUCATION: What dementia-related skills and knowledge should health and social care providers have? What are the best ways of providing them with these skills and this knowledge?
8. DEMENTIA-FRIENDLY COMMUNITIES: What makes the creation of dementia-friendly communities? What types of dementia-friendly activities, have an impact on dementia and their families, friends and caregivers?
9. IMPLEMENTATION OF BEST PRACTICES FOR CARE: What are the barriers to implementation and sustainability of best practices for dementia care within and across health care settings, including effective approaches to ensuring person-centred care?
10. NON-DRUG APPROACHES TO MANAGING BEHAVIOUR: How can non-pharmacological approaches be used to manage behaviour and psychological symptoms of dementia?

James Lind Alliance Priority Setting Partnerships

Home About the JLA The PSPs Top 10s JLA Guidebook News and Publications Making a difference Current surveys JLA Lab

You are in: Home » The PSPs » Liver Glycogen Storage Disease (International) » Top 10 Priorities

Liver Glycogen Storage Disease Top 10

1. What are the best options (for example gene therapy or enzyme replacement therapy) for achieving sufficient amount of working enzyme in patients with liver GSD?
2. Can consensus guidelines (for management) be achieved for patients with liver GSD?
3. How should optimal metabolic control both clinically and biochemically (like lactate, ketones and/or lipids) be achieved in liver GSD?
4. How should sickness and emergency situations be managed for patients with liver GSD?
5. What is the best way to start dietary treatment, finding the optimal doses, and to administer the diet for patients with liver GSD?
6. How can existing cornstarch preparations be modified or alternative treatments be implemented that are easier to administer and/or keep blood sugar levels more stable for patients with liver GSD?
7. What is the role for new methods for monitoring metabolic control (like noninvasive continuous glucose and lactate measurements, new biomarkers) for patients with liver GSD?
8. How to manage diet regimen in relation to "before, during and after" physical exercise (sport, playing) for patients with liver GSD?
9. What are the long-term complications (liver, renal, gut) of a diet rich in uncooked cornstarch and/or high protein and should the diet be adjusted to prevent complications in liver GSD?
10. What are the risks and benefits of different options for overnight treatment for patients with liver GSD and how can we maximize safety?

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JLA on Twitter
Tweets by @JLAlliance

James Lind Alliance Revealed
Young at Heart @YAHBCH
Have YOUR say on the future of Congenital Heart Disease research! Tell us which questions are most important to you in UK #CHDsponties
ChildAnatomical surveymonkey.co.uk/3X0B4ZH
and Adult CHD surveymonkey.co.uk/3XQZTMD
participation.surveyMonkey.com/3XQZTMD

THE TOP 10 PRIORITIES FOR ADULT CARDIAC SURGERY RESEARCH

1. QUALITY OF LIFE: How do adult cardiac surgery patients experience their quality of life? What are the best ways to improve quality of life for these patients?
2. RECOVERY: How can recovery after adult cardiac surgery be improved? What are the best ways to manage recovery for these patients?
3. EMPLOYEE CORRELATION: How can the correlation between employee health and productivity be improved? What are the best ways to manage employee health and productivity for these patients?
4. PAIN MANAGEMENT: How can pain management for adult cardiac surgery patients be improved? What are the best ways to manage pain for these patients?
5. HEART TRANSPLANTATION: How can heart transplantation for adult cardiac surgery patients be improved? What are the best ways to manage heart transplantation for these patients?
6. MEDICAL INTERVENTIONS: How can medical interventions for adult cardiac surgery patients be improved? What are the best ways to manage medical interventions for these patients?
7. LIFELINE CARE: How can lifeline care for adult cardiac surgery patients be improved? What are the best ways to manage lifeline care for these patients?
8. BLOOD PRODUCTS: How can blood products for adult cardiac surgery patients be improved? What are the best ways to manage blood products for these patients?
9. ATRIAL FIBRILLATION: How can atrial fibrillation for adult cardiac surgery patients be improved? What are the best ways to manage atrial fibrillation for these patients?
10. INFECTIOUS: How can infectious diseases for adult cardiac surgery patients be improved? What are the best ways to manage infectious diseases for these patients?



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Next Steps

Promote priorities to researchers and funders

Ongoing dissemination of findings

- Launch event
- Publications – Journals, plain language report
- Detailed reports and explanation to funders
- Conferences
- Social media, blogs



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From Priorities to Research

Priority Setting Partnerships

Q7. What are the benefits of breathing exercises as a form of physical therapy for asthma?

NHS National Institute for Health Research

Evaluation, Trials and Studies

You are here: Home > Project portfolio > 09/104/19

Research programmes HTA - 09/104/19: A controlled study of the effectiveness of breathing training exercises taught by a physiotherapist by either instructional videos/DVD/internet download or by face-to-face sessions in the management of asthma in adults

Funding opportunities

Project portfolio

Browse projects

Resources for researchers **Notify me** when this item is published

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Public and patient involvement

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Project title A controlled study of the effectiveness of breathing training exercises taught by a physiotherapist by either instructional videos/DVD/internet download or by face-to-face sessions in the management of asthma in adults

Research type Primary Research

Status Research in progress

Start date November 2011

Publication date November 2016

Cost £ 1,204,276.00

Breathing exercises help asthma patients with quality of life

Published: 14 December 2017



A study led by the University of Southampton has found that people who continue to get problems from their asthma, despite receiving standard treatment, experience an improved quality of life when they are taught breathing exercises. The majority of asthma patients have some degree of impaired quality of life.

Researchers, funded by the National Institute for Health Research (NIHR), also found that the benefits of the breathing exercises were similar, whether they were taught in person by a physiotherapist in three face-to-face sessions, or delivered digitally for use in their own home (in this study via DVD). Their findings are published in a paper in the journal *The Lancet Respiratory Medicine*.

The controlled trial recruited 655 UK adults who reported impaired asthma-related quality of life. Participants were randomised to receive a breathing exercise intervention delivered via DVD (261 people), or face to face with a physiotherapist (132 people). A third 'control' group received 'usual care' (262 people) continuing to take normal asthma medication, with no further intervention.



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Breathing Freely
Your guide to breathing retraining for asthma

Welcome to the online version of Breathing Freely. Developed by an experienced team of GPs, physiotherapists, psychologists and patients at the University of Southampton, Breathing Freely was shown to improve the lives of people with asthma, in the Breathe Study. The Breathe Study is now finished but you can try Breathing Freely yourself using the links below - it's completely free.

Get started! Click this button if you want to sign up to the Breathing Freely Programme - it's completely free and you can do it at a time that's convenient for you.

See a demo To get the most benefit of Breathing Freely, we recommend signing up for the full version, which has email support. But if you want, you can see some of the advice and videos available in Breathing Freely without logging in.

The study 655 people with asthma recently took part in a study of the Breathing Freely programme. Click this button to see the full details of the study.

THE LANCET Respiratory Medicine

Volume 6, No. 1, p19-28, January 2018

Physiotherapy breathing retraining for asthma: a randomised controlled trial

Prof Anne Britton, PhD, Prof Amanda Lee, PhD, Prof Lucy Yardley, PhD, Prof James Raby, PhD, Emily Arden-Close, PhD, Sarah Kirby, PhD, Shihua Zhu, PhD, Manimekalai Thiruvalluvar, MSc, Frances Wooley, Lyn Taylor, Denise Gibson, MSc, Gunguo Yao, PhD, Mark Stafford-Watson, Jenny Verrall, PhD, Prof Michael Moore, FRCP, Steve George, FRCP, Prof Paul Little, FRMEd, Prof Kozo Tsubokawa, PhD, Prof David Price, FRCP, Prof Ian D Pavord, FRMEd, Prof Stephen Holgate, FRMEd, Prof Mike Thomas, PhD

Published: 14 December 2017

Open access funded by Department of Health UK

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Linked Articles: Remote or in-person breathing retraining for uncontrolled asthma symptoms



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Making a difference

*“I then learned of the opportunity to participate in the UK Epilepsy PSP Workshop and felt that I could add huge value by not only representing other parents like myself, but by **giving my little girl a voice.**”*

Parent involved in the Epilepsy UK PSP



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Making a difference

“This has changed how I practice medicine. It has changed my understanding of what it means to listen to patients. It has changed the language I use when I speak with them. Most importantly it has changed my vision of how to deliver the care we give them. It has made it our vision.”

Noémi Roy, Rare Inherited Anaemias Priority Setting Partnership

For more
information

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