

James Lind Alliance

Priority Setting Partnerships

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26 November 2019

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- What are JLA Priority Setting Partnerships (PSPs)?
- JLA principles
- Completed, current and international PSPs
- How to do a PSP
- What happens after the Top 10 has been agreed
- Outcomes and funded research
- What people say about JLA

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What is the JLA?

The JLA provides a method that brings patients, care givers and health and social care professionals together in Priority Setting Partnerships, (PSPs) to identify and agree the Top 10 priorities for research in a particular area of health.







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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.

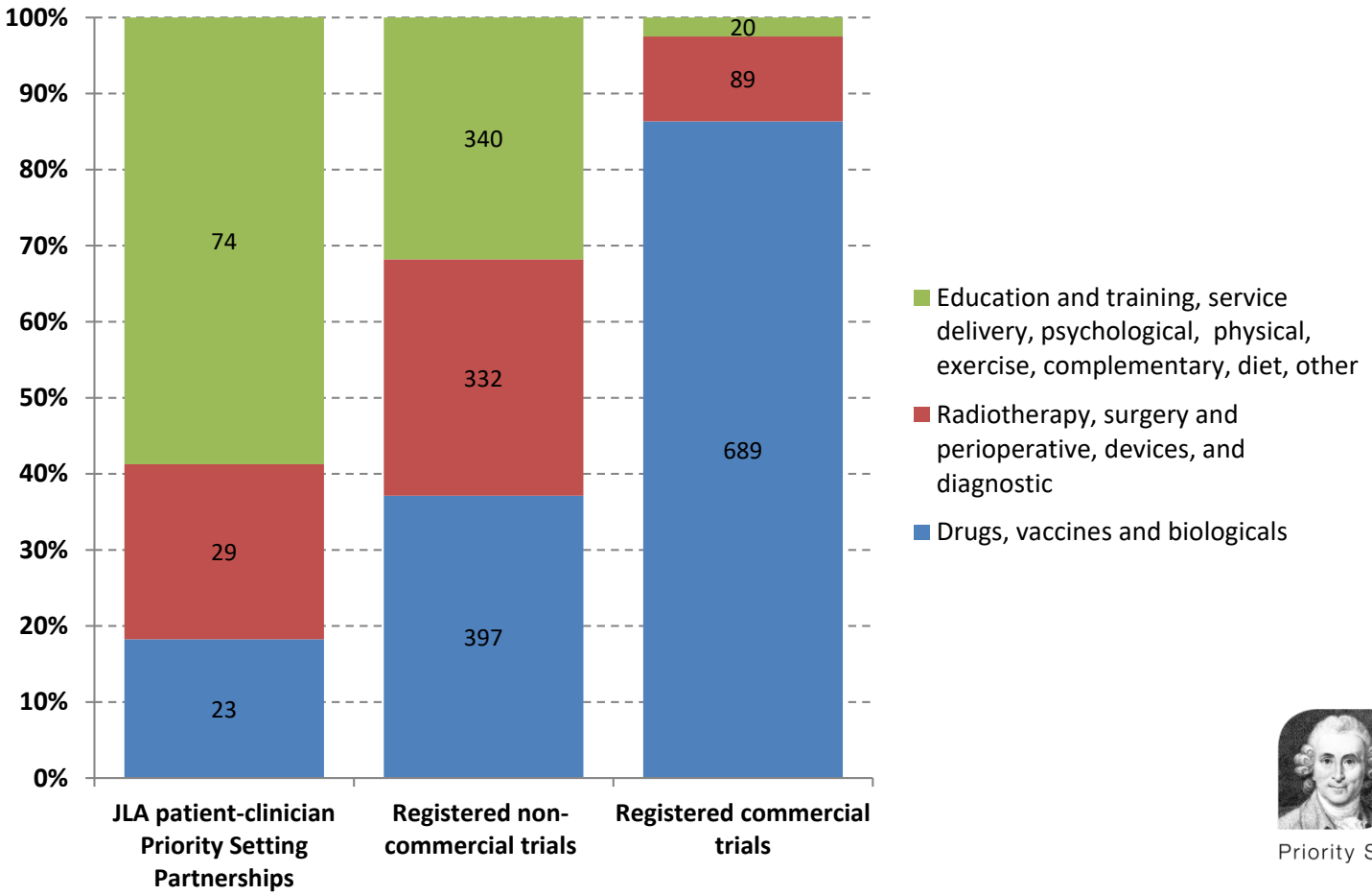


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A mismatch

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



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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

NIHR Adding Value in Research

Raising the probability of benefits to society from health-related research for the tangible and intangible costs involved

Relevance and expressed need	High quality research that minimises bias		Open + transparent research+ research funding	
Set justifiable research priorities	**Design, conduct and analysis are robust and appropriate**	**Regulation and management are proportionate to risks**	**Complete information on methods and findings are accessible and usable**	**Findings are appropriately and effectively disseminated**
1. Priorities are set involving those who use and are affected by health research 2. New research should be set in the context of a systematic review or rigorously determined evidence gap	3. Designed using advances in research methods and taking steps to reduce bias 5. Studies registered at inception	4.Actively manage research in a risk proportionate way 6. Protocols, methods and materials should be made available early	7. Methods, interventions and findings reported in full 8. Support replication and reuse of data	9. Findings should be set in the context of previous evidence and systematic reviews. 10. Disseminate knowledge to end users. Usage of new knowledge should be supported and facilitated

The initial framework was developed based on the 2009 work of Sir Iain Chalmers and Professor Paul Glasziou on avoidable waste in research and the later Lancet series

Version 0.4

JLA established in UK in 2004

First PSP completed in 2007 in Asthma

Sir Iain Chalmers





Dr John Scadding

Sir Nick Partridge



NIHR | National Institute for Health Research



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The JLA now

JLA Advisers



JLA Guidebook



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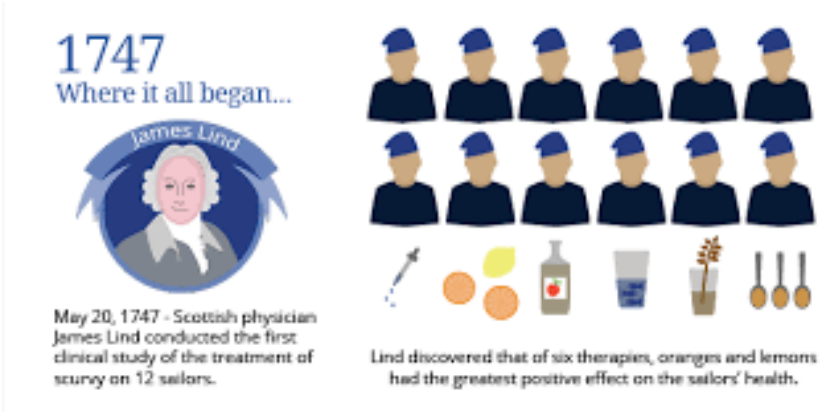
The JLA coordinating team at NIHR, Wessex Institute, University of Southampton

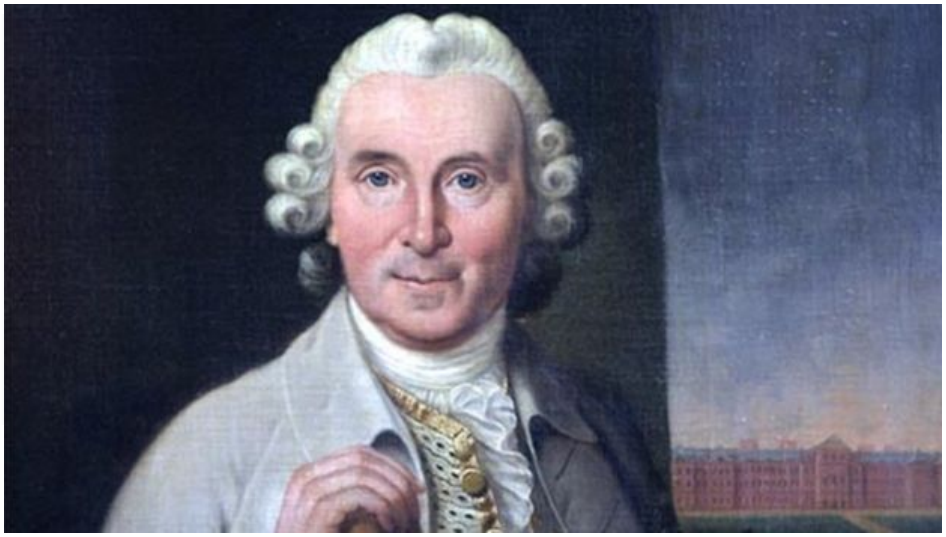


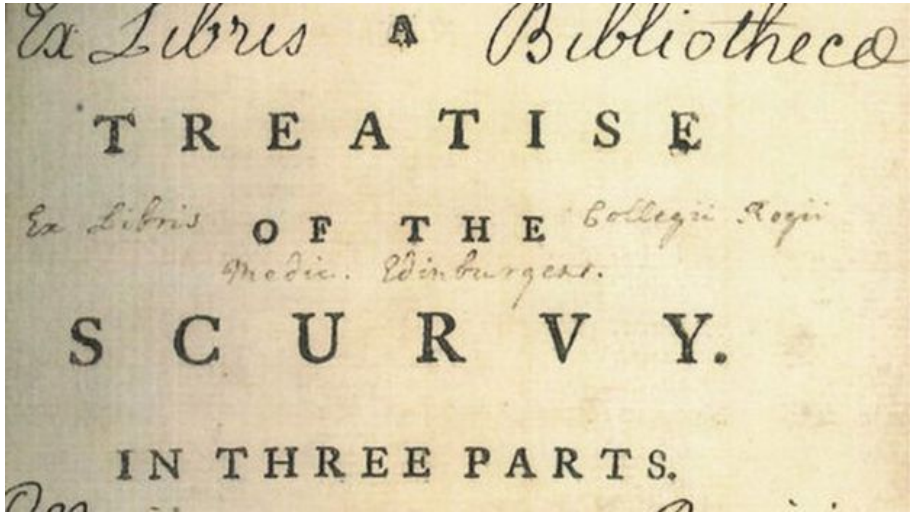


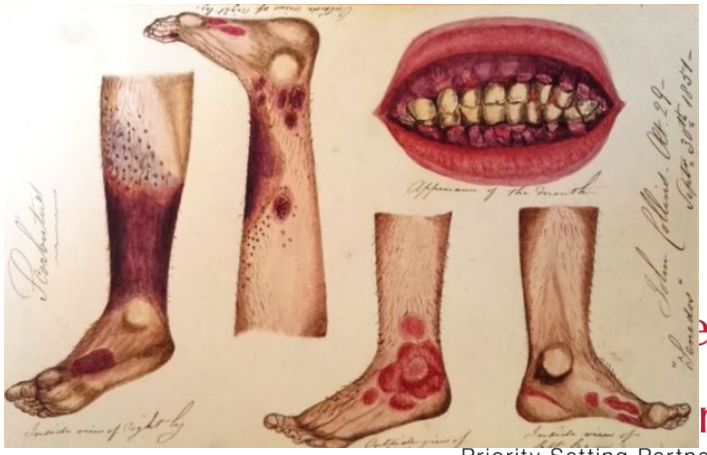


Why James Lind?









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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
- **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



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Completed PSPs in the UK



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Current PSPs in the UK



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International PSPs

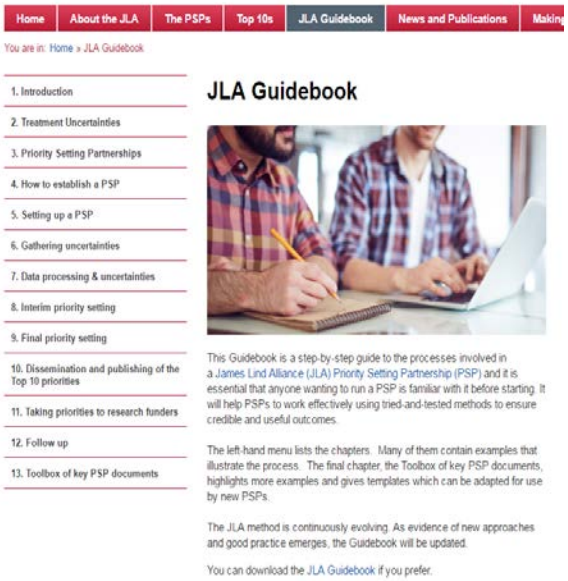
- **Netherlands**
  - Eating Disorders
  - Juvenile Idiopathic Arthritis
- **Germany**
  - Pancreatic Cancer
  - Colorectal Cancer
- **International (multi-country)**
  - Hyperemesis Gravidarum
  - Liver Glycogen Storage Disease
  - Degenerative Cervical Myelopathy
- **Uganda**
  - Maternal Health
- **Ethiopia**
  - Pelvic Floor Disorders
- **Canada**
  - Anaesthesia
  - Cardiac Arrest
  - Dementia
  - Epilepsy
  - Fibromyalgia
  - Frailty
  - Head and Neck Cancer
  - Hypertension
  - Kidney Cancer
  - Metastatic Breast Cancer
  - Myeloma
  - Neurodevelopmental Disorders
  - Post Mastectomy Breast Reconstruction
  - Seniors' Health (Alberta)
  - Sleep Apnoea (Saskatchewan)
  - Resuscitation
  - Venous Thromboembolic Disease



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Method explained in detail in the JLA Guidebook





Steering Group

Establish a steering group

Gathering

Gathering potential uncertainties via paper and online surveys and literature search

Analysis

'Raw' questions counted, categorised and refined, duplications combined. Indicative questions created and checked against existing evidence

Prioritisation

Interim uncertainty prioritisation via paper and online surveys

Top 10 uncertainties

Final priority setting workshop

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Set up Steering Group

- Patient, caregiver and clinician representatives
- Collective responsibility
- Transparency – declare interests
- Resources and expertise
  - Regular meetings
  - Publicising the project
  - Overseeing the process
  - Responsible for dissemination
- Chaired by JLA Adviser – a neutral facilitator
- Agree protocol

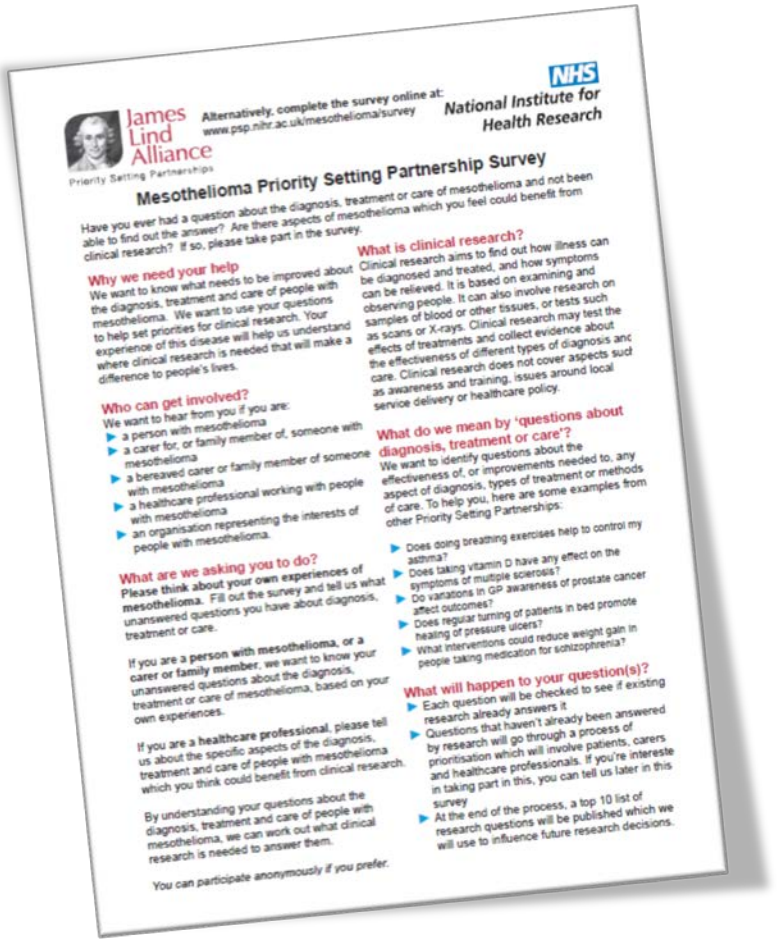


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Gather uncertainties

Mesothelioma PSP

- Do you have questions or comments about your experience of the **diagnosis** of mesothelioma?
- Do you have questions or comments about your experience of mesothelioma **treatments**?
- Do you have any other questions or comments about your experience of the **care** of someone with mesothelioma?



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Alternatively, complete the survey online at: www.psp.nihr.ac.uk/mesothelioma/survey

NHS National Institute for Health Research

Mesothelioma Priority Setting Partnership Survey

Have you ever had a question about the diagnosis, treatment or care of mesothelioma and not been able to find out the answer? Are there aspects of mesothelioma which you feel could benefit from clinical research? If so, please take part in the survey.

Why we need your help

We want to know what needs to be improved about the diagnosis, treatment and care of people with mesothelioma. We want to use your questions to help set priorities for clinical research. Your experience of this disease will help us understand where clinical research is needed that will make a difference to people's lives.

Who can get involved?

We want to hear from you if you are:

- a person with mesothelioma
- a carer for, or family member of, someone with mesothelioma
- a bereaved carer or family member of someone with mesothelioma
- a healthcare professional working with people with mesothelioma
- an organisation representing the interests of people with mesothelioma.

What are we asking you to do?

Please think about your own experiences of mesothelioma. Fill out the survey and tell us what unanswered questions you have about diagnosis, treatment or care.

If you are a **person with mesothelioma**, or a **carer or family member**, we want to know your unanswered questions about the diagnosis, treatment or care of mesothelioma, based on your own experiences.

If you are a **healthcare professional**, please tell us about the specific aspects of the diagnosis, treatment and care of people with mesothelioma which you think could benefit from clinical research.

By understanding your questions about the diagnosis, treatment and care of people with mesothelioma, we can work out what clinical research is needed to answer them.

You can participate anonymously if you prefer.

What is clinical research?

Clinical research aims to find out how illness can be diagnosed and treated, and how symptoms can be relieved. It is based on examining and observing people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical research may test the effects of treatments and collect evidence about the effectiveness of different types of diagnosis and care. Clinical research does not cover aspects such as awareness and training, issues around local service delivery or healthcare policy.

What do we mean by 'questions about diagnosis, treatment or care'?

We want to identify questions about the effectiveness of, or improvements needed to, any aspect of diagnosis, types of treatment or methods of care. To help you, here are some examples from other Priority Setting Partnerships:

- Does doing breathing exercises help to control my asthma?
- Does taking vitamin D have any effect on the symptoms of multiple sclerosis?
- Do variations in GP awareness of prostate cancer affect outcomes?
- Does regular turning of patients in bed promote healing of pressure ulcers?
- What interventions could reduce weight gain in people taking medication for schizophrenia?

What will happen to your question(s)?

- Each question will be checked to see if existing research already answers it
- Questions that haven't already been answered by research will go through a process of prioritisation which will involve patients, carers and healthcare professionals. If you're intereste in taking part in this, you can tell us later in this survey
- At the end of the process, a top 10 list of research questions will be published which we will use to influence future research decisions.



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How many uncertainties?

JLA PSP	Survey respondents	Submitted uncertainties
Bipolar	3,285	14,398
Depression	3,000	10,000+
Sight loss	2,220	4,461
Dementia	1,563	4,116
Dementia (Canada)	1,217	8,203
Tinnitus	835	2,483
Fibromyalgia (Canada)	550	4,557
Hypertension (Canada)	386	673



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Check the uncertainties

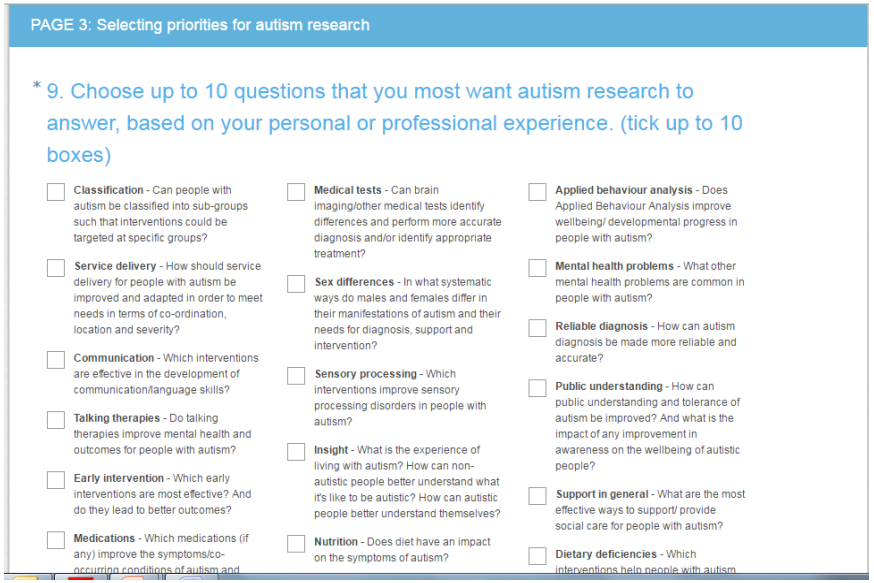
- Prepare the dataset
- Remove out-of-scope submissions, store and decide how to deal with them
- Categorise eligible submissions
- Format submissions
- Check the uncertainties against existing evidence
- Identify research recommendations
- Prepare the long list

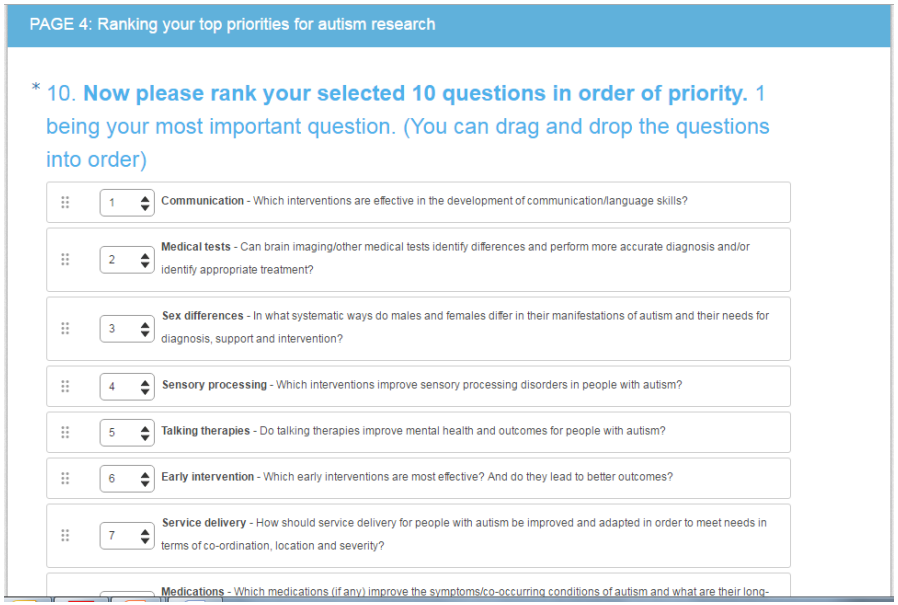


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Interim priority setting

- To move from a long to a short list of questions
- Ask patients, carers and professionals to vote on the most important questions in their experience





Priority Setting Workshop

- For patients, carers and professionals, facilitated by JLA Advisers
- A day of democratic discussion to prioritise the 25 – 30 most important questions and jointly agree the Top 10
- Recognition that all of the questions are important and are published on the JLA website www.jla.nihr.ac.uk







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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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The Top 10

UNIVERSITY OF LEICESTER

THE TOP 10 PRIORITIES FOR ADULT CARDIAC SURGERY RESEARCH

1

QUALITY OF LIFE

How does a patient's quality of life (QOL) change (e.g. disability-free survival) following heart surgery and what factors are associated with this?

2

FRAILTY

How can we address frailty and improve the management of frail patients in heart surgery?

3

CHRONIC CONDITIONS

How can we improve the outcomes of heart surgery patients with chronic conditions (obesity, diabetes, hypertension, renal failure, autoimmune diseases etc.)?

4

PREHABILITATION

Does prehabilitation (a programme of nutritional, exercise and psychological interventions before surgery) benefit heart surgery patients?

5

HEART VALVE INTERVENTION

When should heart valve intervention occur for patients without symptoms?

6

SURGICAL METHODS

How does minimally invasive heart surgery compare to traditional open surgery?

7

ORGAN DAMAGE

How do we minimise damage to organs from the heart-lung machine/ heart surgery (heart, kidney, lung, brain and gut)?

8

3D BIO-PRINTING

Can we use 3D bio-printing or stem cell technology to create living tissues (heart valves/heart) and repair failing hearts (myocardial regeneration)?

9

ATRIAL FIBRILLATION

What are the most effective ways of preventing and treating post-operative atrial fibrillation?

10

INFECTION

How do we reduce and manage infections after heart surgery including surgical site/sternal wound infection and pneumonia?



Outcomes

Q10. What interventions could reduce weight gain in **schizophrenia**?



Journals Library

NHS National Institute for Health Research 70 YEARS OF THE NHS 1948 - 2018

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Research Projects

- Efficacy and Mechanism Evaluation
- Health Services and Delivery Research
- Health Technology Assessment
- Public Health Research
- Systematic Reviews programme
- Programme Grants for Applied Research
- NIHR Clinical Trials Unit Support Funding

HTA - 12/28/05

STEPWISE: STructured lifestyle Education for People WIth Schizophrenia

Project title: STEPWISE: STructured lifestyle Education for People WIth Schizophrenia

Call to action: 12/28 12/28 Non-pharmacological interventions to reduce weight gain in people with schizophrenia prescribed antipsychotic medication

Research type: Primary Research

Chief investigator: Professor Richard Holt orcid.org/0000-0001-8911-6744

Lead Author: Professor Richard Holt

Contractor: Sheffield Health & Social Care NHS Foundation Trust

Cost: £2,010,679.64

Co-investigators: Dr Alex Mitchell, Dr Daniel Hind, Dr David Shiers, Dr Fiona Gaughran, Dr Helen Millar, Dr Jonathan Mitchell, Dr Marian Carey, Dr Richard Laugharne, Dr Shanaya Rathod, Dr Stephen Wright, Dr Thomas Yates, Mr John Pendlebury, Mr Mike Bradburn, Ms Angela Etherington, Professor Chris Dickens, Professor Kamlesh Khunti, Professor Katharine Barnard, Professor Melanie Davies, Professor Paul French, Professor Paul McCrone, Professor Tim Kendall.

Started: October 2013 | **Status:** Published November 2018

ISRCTN: 19447796

A structured lifestyle education programme for people with schizophrenia did not affect weight change after 12 months.

Toolkit

- Print
- Alerts & updates

PROJECT PUBLISHED ✔

VIEW REPORT

Latest project information

- Protocol (08 Mar 2017)
- Protocol (14 Jul 2016)
- Commissioning Brief (30 Apr 2012)

Share

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







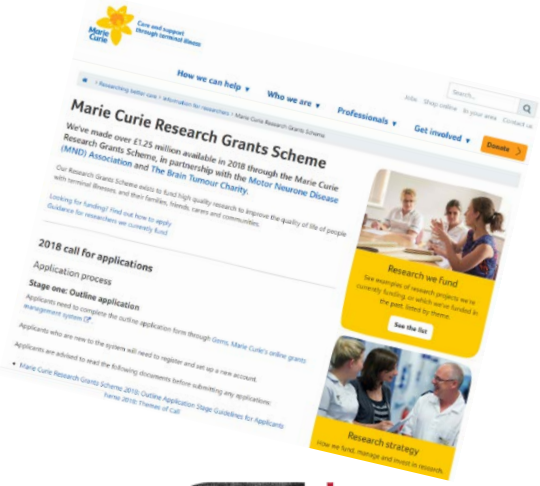


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Its not just the NIHR that funds PSP Priorities

- 2017 Canadian Frailty Network announced a Catalyst Grant Competition for proposals to address one or more of the Top 10 priorities from the Frailty PSP
- Parkinson's UK, 2015-16 funded 8 research projects worth more than £6 million
- Fight for Sight, over £6.5 million to projects addressing priorities from the Sight Loss and Vision PSP
- Marie Curie, Chief Scientist Office, MND Association, 9 projects worth £1,425,000
- British Tinnitus Association, Sands, MS Society, Diabetes UK, Intensive Care Foundation







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Impact

"It was an incredible process and we know from surveys that every participant felt it was a valuable use of their time. There is value in the process beyond developing the top 10. It helps build community, raise awareness, strengthen relationships with partners."

Neurodevelopmental Disorders (Canada) PSP



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What people say

"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 PSP



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Challenges?

- Engaging with patients
- Engaging with clinicians
- Unpredictability
- Difficult data
- Measuring impact

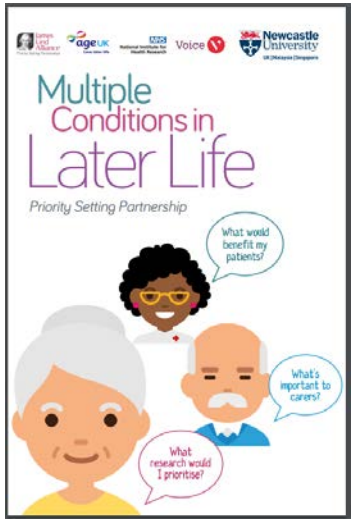




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What do PSPs need to get right

- A committed Steering Group
- Administrative support
- Resources
- A well-defined scope
- A vision beyond the top 10 and working with funders to define research questions







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How you can get involved?

www.jla.nihr.ac.uk

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Current surveys

If you are a patient, carer or family member, or health professional with experience of any of the following areas, please get involved with JLA Priority Setting Partnerships (PSPs) by completing their surveys.

Initial surveys currently open - tell a PSP what comments or questions you have that you think more research might help to answer, in the following areas (please click on the link to go to the survey):

Anaesthesia (Canada)

Foot Health

Heart Surgery

Hyperemesis Gravidarum

Nutritional Screening and Malnutrition

Hypertension in Pregnancy

Revision Knee Replacement

Interim prioritisation surveys currently open - tell a PSP which of the questions they have collected are most important to you:

Broken Bones of the Upper Limb in People over 50

Healthcare Associated Infections

Oral and Dental Health

Safe Care for Adults with Complex Health Needs

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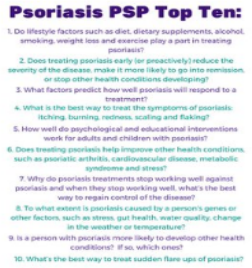
JLA on Twitter

Tweets by @LindAlliance

James Lind Alliance Retweeted

Psoriasis Association
@PsoriasisUK

The #PsoriasisTop10 research priorities have now been published! Take a look at the list and let us know what you think. We'll be looking at each of the priorities in more detail over the next couple of weeks so keep an eye out. ow.ly/3cMI30mqPo7 #psoriasis



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Looking for research topics?



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Top 10s of priorities for research

The final workshop of a Priority Setting Partnership (PSP) enables patients, carers and clinicians to agree the Top 10 priorities for future research. We have listed all of the Top 10s below. The dates in brackets are the year in which the Top 10 was published.

Whilst the JLA refers to each list as a Top 10, a few of the PSPs have not limited their list to exactly 10 priorities. To find out more about how each PSP arrived at their Top 10, please visit the The PSPs section of the website.

Regardless of their position, all of the unanswered questions for each PSP are important. Where provided by the PSP, further details of the 20-30 unanswered questions discussed at the final workshop are shown, including their ranking, an explanation of the uncertainty, and details of any existing research reviewed.

The agreement of a Top 10 marks the beginning of the next stage of work for a PSP. The research priorities need to be promoted to key groups such as research funders, researchers, patients and carers and the wider research community, and research questions need to be developed from the priorities. The Guidebook contains more advice on how PSPs can formulate research questions and work with researchers and research funders.

You can also find identified priorities for research alongside the key evidence around each health area at NICE Evidence search. Just enter your search term and filter by 'Evidence Uncertainties' to see the JLA priorities.

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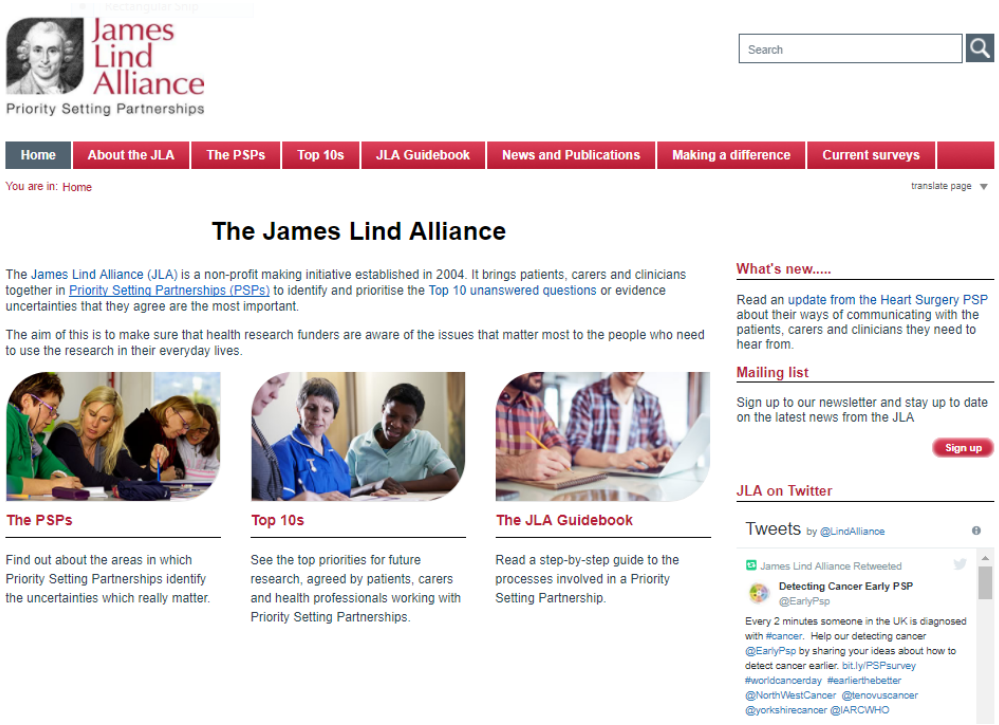
Bridon

@br13roch

Important for those of us living with #ChronicPain #psoriasis and #psa @PsoriasisUK @PsoriaticPstand https://twitt

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