http://www.jla.nihr.ac.uk/about-the-james-lind-alliance

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Adding Value in Research –
maximising the potential impact of research

Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence.
Lancet 2009; 374 (9683): 86-89
Why patients and clinicians

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
Key principles

• Transparency
• Inclusion / exclusion
• Equality
• Evidence base
Current Partnerships: UK

- Ageing and multi-morbidity
- Alcohol related liver disease
- Blood transfusion and blood donation
- Bleeding disorders
- Cellulitis
- Common conditions affecting the hand and wrist
- Contraception
- Cystic fibrosis
- Digital technologies for mental health
- Emergency medicine
- Endometriosis
- Facial reconstruction
- Healthcare Associated Infections
- Idiopathic intracranial hypertension
- Living with and beyond cancer
- Learning difficulties in children and young people

- Mental health in children and young people
- Miscarriage
- Musculoskeletal trauma (fragility fractures)
- Non-alcohol related liver disease /gallbladder disorders
- Oral and dental health
- Patient safety in primary care
- Patient safety in specialist care
- Pessary use for prolapse
- Physiotherapy
- Rare anaemias
- Rare bone diseases
- Scoliosis
- Teenage and young adult cancer
- Type 2 diabetes
Netherlands: eating disorders

https://powertorecover.nl/

- Published July 2016

http://www.jla.nihr.ac.uk/priority-setting-partnerships/eating-disorders-netherlands/

- Funded by the Dutch Mental Health Foundation and the Rivierduinen Centrum Eetstoornissen Ursula

- The top three:
  - Which factors influence the duration of recovery and the possibility of complete recovery?
  - Which patient and disorder-related features can be used to provide more personalised treatment?
  - Is it more effective to address the eating disorder symptoms first or the underlying problems?

Canada: dementia, fibromyalgia, hypertension, kidney cancer, neurodevelopmental disorders, post mastectomy bread reconstruction, metastatic breast cancer, frailty
How does a Priority Setting Partnership work

Steering group and JLA adviser

- Collective responsibility for the PSP
- All are responsible for driving the PSP
- Transparency
  - Declarations of interest
  - Exclusions

- Gathering uncertainties – the survey
- Prioritise uncertainties – interim and final
- The final workshop – face to face; the top 10
- Promote priorities to researchers and funders
Q7. What are the benefits of breathing exercises as a form of physical therapy for **asthma**?
A lasting legacy: The patient

• “I found that being involved has given me back an element of control over my illness. This is so much more than I imagined I could ever have done when I first became ill. The workshop left me feeling that we patients have an important contribution to make.”

• Irenie Ekkeshis, *Sight Loss and Vision PSP*
A lasting legacy: The clinician

• “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