



James Lind Alliance

Priority Setting Partnerships



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

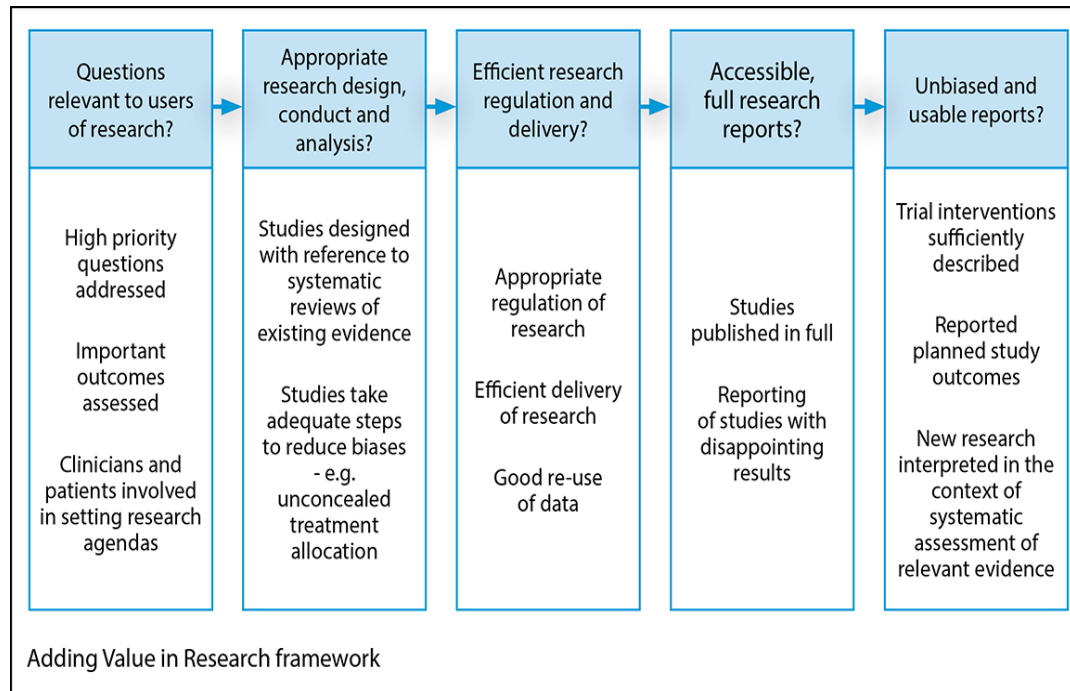


jla@southampton.ac.uk



Steph Garfield-Birkbeck
Wessex Institute, University of Southampton

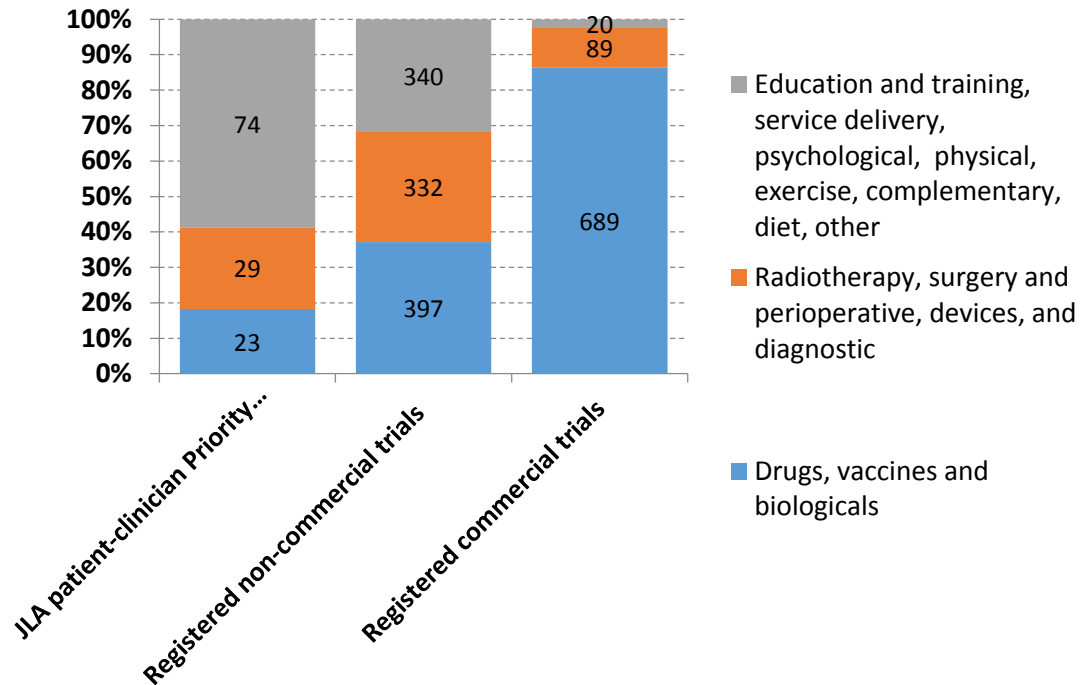
Adding Value in Research – maximising the potential impact of research



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

JLA International

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 breast 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

Getting the most from Partnerships

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

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

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Project title	A controlled study of the effectiveness of breathing training exercises taught by a physiotherapist by either instructional videos/DVDs/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
Completion date	November 2016
Estimated cost	£ 1,204,276.00

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Dame Sally Davies on the importance of global action



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*](#)



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