



Involving patients in research priority setting

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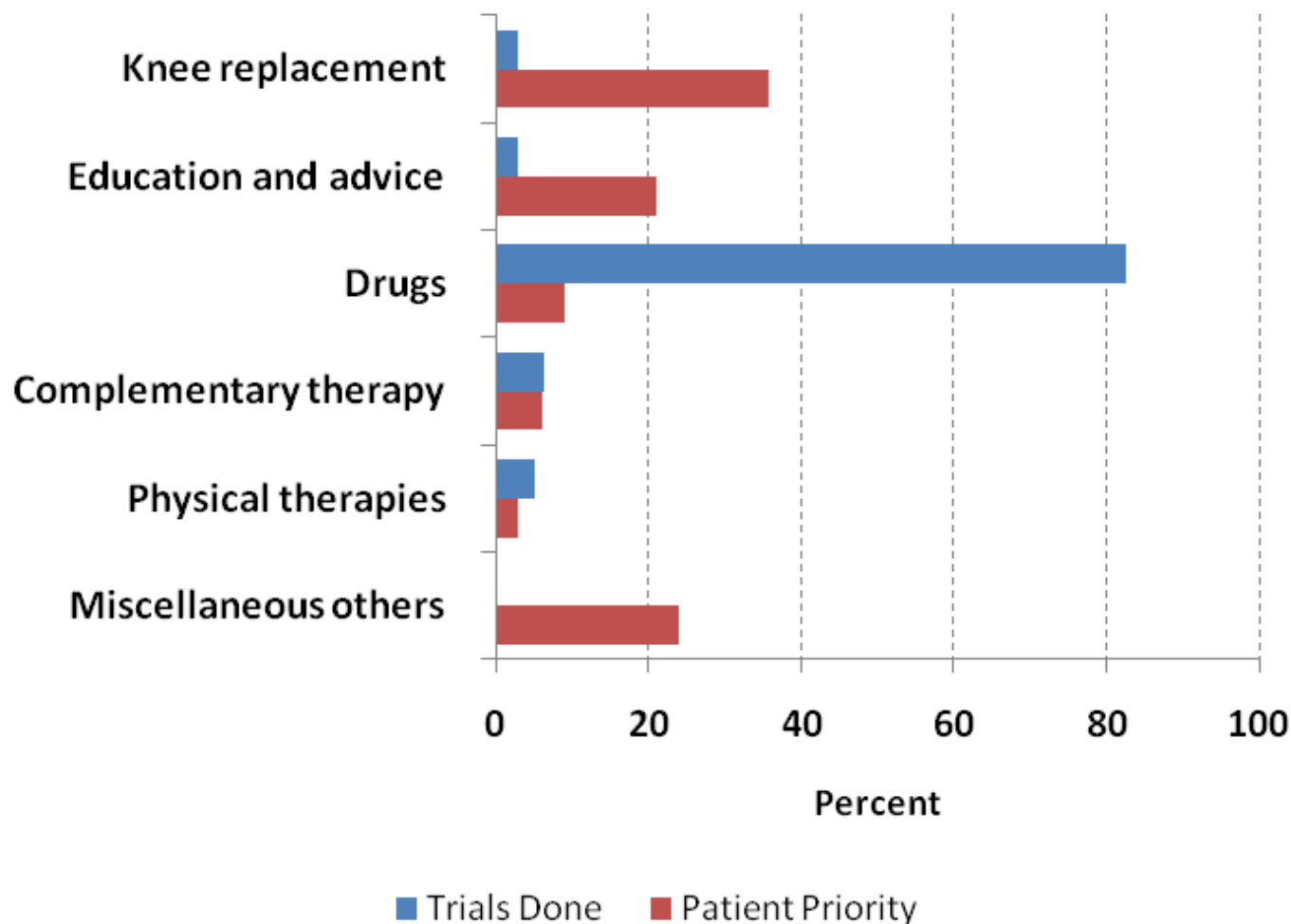
Editor, James Lind Alliance Guidebook

What will I cover?

- Why involve patients in research priority setting?
- The James Lind Alliance (JLA)
- How we involve patients in research priority setting



Why involve patients in research priority setting?



Tallon, D. *et al.* (2000) 'Relation between agendas of the research community and the research consumer', *The Lancet*, Vol. 355. pp. 2037-40



Why involve patients in research priority setting?

- It's **democratic**: many research bodies are funded by patients' donations.
- It's **consumerist**: helps to identify useful, relevant research questions.
- It's **advantageous**: UK funding agencies look for evidence of patient involvement in research proposals

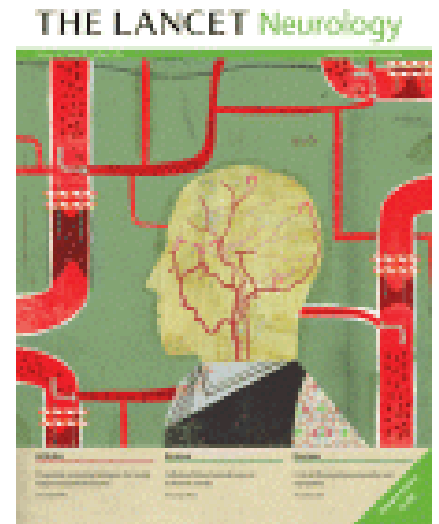


Why involve patients in research priority setting?

“Addressing research questions that matter to people affected by neurological disorders, in a way that satisfies the practical and ethical demands of patients and their families, is central to the success of clinical research.

Finding new ways of involving patients and the wider public in clinical studies is likely to become increasingly important in the future, as researchers recognise the enormous value of working in partnership with patient groups”.

*David Holmes, Lancet Neurology ,
Vol. 10, No. 10, October 2011*



What is the James Lind Alliance?

- *Tackling treatment uncertainties together*
- Finding out what research is important to:
 - Patients
 - Carers
 - Clinicians / healthcare professionals



What is the James Lind Alliance?

- A small initiative – four part-timers.



- Funded by the National Institute for Health Research



- Established in 2004

- Royal Society of Medicine – Dr John Scadding
- James Lind Library - Sir Iain Chalmers
- INVOLVE – Sir Nick Partridge



Priority Setting Partnerships

- Patients, carers and clinicians
 - Steering Group
 - Partners
- Focusing on single conditions
- **Identifying uncertainties** about treatments
- **Prioritising** the ones they think are most important for research to address
- A top 10



Priority Setting Partnerships

Completed Partnerships

- Asthma
- Urinary incontinence
- Vitiligo
- Prostate cancer
- Schizophrenia
- Type 1 diabetes
- Aspects of balance

Current Partnerships

- Cleft lip and palate
- Dementia
- Eczema
- Head and neck cancer
- Life after stroke in Scotland
- Lyme disease
- Pressure ulcers
- Pre-term birth



Identify treatment uncertainties

- no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exists
- up-to-date systematic reviews of research evidence show that uncertainty exists

It can include other health care interventions, including prevention, testing and rehabilitation.



Identify treatment uncertainties

- Survey
 - Patients and carers
 - Clinicians
- Research recommendations
- UK Database of Uncertainties about the Effects of Treatments (UK DUETs)
 - www.library.nhs.uk/duets



Identify treatment uncertainties

Case study: Type 1 Diabetes Priority Setting Partnership

Do you have an unanswered question or an uncertainty about the treatment of type 1 diabetes? Do you think that answering that question through research will help to improve the lives of people with type 1 diabetes? This is your chance to make your views known.

- 1. What question(s) about the treatments for type 1 diabetes would you like to see answered by research?** (You can submit as many or as few as you like.)
2. Consent
3. Some questions about you
4. Next steps



Check treatment uncertainties

- How safe is it for my baby if I am breastfeeding and taking antidepressant medication? (*patient*)
- In a critically ill patient is dopexamine effective at preventing renal failure? (*clinician*)
- Pharmacological interventions for epilepsy in people with intellectual disabilities (*Cochrane Epilepsy Group*)
- How effective are herbal remedies in treating vitiligo? (*patient*)
- What are the potential harms as well as benefits of different interventions for weight reduction? (*research recommendations*)



Check treatment uncertainties

Case study: Type 1 Diabetes Priority Setting Partnership

- Online survey promoted via partners and the JLA
- 583 people submitted 1141 uncertainties
- 890 were true uncertainties
- 118 uncertainties came from research recs/literature
- Combining duplicates, there were 350 verified uncertainties
- Steering Group shortlisted 47 based on number of submissions



Publish treatment uncertainties



NHS Evidence - UK Database of Uncertainties about the Effects of Treatments (DUETs)

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- Cancer
- Cardiovascular diseases
- Ear nose and throat disorders
- Eyes and vision
- Gastroenterological and liver diseases
- Haematological disorders
- Infection
- Mental health
- Musculoskeletal diseases
- Neonatal diseases

You searched for: "a*"

Total records: 1520

From patients (387)	From carers (67)	From professionals (116)	Research recommendations (818)	Ongoing research (132)
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page: [1](#) | [2](#) | [3](#) | [4](#) | [5](#) | [6](#) | [7](#) | [8](#) | [9](#) | [10](#) » of [39](#)

[< Previous](#) | [Next >](#)

Acupuncture for depression

Publication Type: Known Uncertainty

Publication Date: 20 Aug 2007

[View detail](#)

Acupuncture for schizophrenia

Publication Type: Known Uncertainty

Publication Date: 11 Sep 2007

[View detail](#)

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Show summaries:

Per page:

Interim priority setting

- From a long list to a short list
- Top 10 uncertainties chosen by partners
 - As individuals
 - On behalf of members
 - On behalf of colleagues
 - Representing an organisation
- **Patients, carers and clinicians only**



Interim priority setting

Case study: Schizophrenia Priority Setting Partnership

Please do the following:

- Choose 10 unanswered research questions that you would like to go forward for consideration at the priority setting workshop, use the ID number in the document to show us your chosen ten in first column of the table below.
- Rank your ten using 1 = most important, working through to 10 = least important, and enter the rank order in the second column.
- This is optional but interesting to us: tell us, in the third column, why you made these choices.
- If you think that any of the uncertainties are not uncertainties, email us and cite the evidence that supports this view.

Chosen ten research questions Enter ID here	Priority 1 = most important 10 = least important	Comments about my choices We are interested in the reasons for your choices - please tell us here (optional)

ID	Uncertainties/Unanswered Questions
DRUGS	
137	Safety/tolerability and patient acceptability of low dose antipsychotic medication for people with schizophrenia
40	Sultopride for schizophrenia
139	Testosterone for schizophrenia
185	Utility, acceptability and safety of available drugs for urgent sedation (including atypical antipsychotics) for psychosis
245	Utility, acceptability and safety of available drugs for urgent sedation/control of acute behavioural disturbance (including benzodiazepines and antipsychotics), in settings that reflect current clinical practice, and systematically manipulating dosage and frequency of drug administration
83	Vitamin B for schizophrenia
41	What are the indications for discontinuing medication in patients with schizophrenia?
87	What is the best way of responding, in the short term, to severe challenging behaviour and agitation in relation to the use of antipsychotics in schizophrenia?
124	What is the experience for patients of drug treatments, both conventional and atypical antipsychotics, for schizophrenia?
115	What treatments are best for insomnia whilst taking antipsychotic drugs for schizophrenia?
EXERCISE	
25	Does activity scheduling and physical exercise increase well being of patients with schizophrenia?
6	Exercise therapy for schizophrenia
HEALTH	
272	Clinical and cost-effectiveness of cardiovascular screening of people

rethink
severe mental illness

Swansea University
Prifysgol Abertawe

Institute of
Psychiatry
at The Maudsley

KING'S
College
LONDON

The University of
Nottingham

Mental Health
Research Network

drawn with
a network
model of
mind

hafal

for recovery
from serious
mental illness



Final priority setting

- Priority setting workshop
- Patients, carers and clinicians
- A day of democratic discussion and ranking
 - Nominal Group Technique
- Prioritise the remaining uncertainties
- Agree the top 10



Final priority setting



Final priority setting



Final priority setting

Case study: ENT Aspects of Balance Priority Setting Partnership

- Took place in May 2011



“The dynamic was good. I felt that clinicians and patients realised they needed each other and I was very struck how much we all respected each other’s opinions. The JLA facilitators did all they could to encourage people to contribute. Everyone’s views were listened to very carefully and there was a surprising degree of mutual understanding.” **Andrew Higgins, patient representative**

“I have to take the outputs of the exercise, go back to colleagues and show them the list of priorities. I have some apprehension about how they will receive it, as the questions which have emerged are not your normal, ‘hard’ research questions. But I would argue to my colleagues that if that’s what the patients want, then that’s what we need to do.”

Martin Burton, ENT UK and Director, UK Cochrane Centre



Applying for funding for priority research

- Promote priorities to researchers and funders
- National Institute for Health Research Health Technology Assessment programme
- Liaison with relevant Cochrane Review Groups
- Dissemination of findings
 - Research audience
 - Scientific audience
 - Patient and carer audience



Involving patients in research priority setting

- **Inclusive**

- Balance of perspectives
- Accessible to all

- **Supportive**

- Recognising a range of capacities and skills

- **Transparent and democratic**

- Data sharing
- Agreed protocol
- Declaration of interests
- Neutral facilitation
- Communication and feedback



Positive outcomes

“Without this coming together of patients with the research community catalysed by the JLA, the subject of breathing exercises would never have been identified as one that received so much enthusiastic support.”

Professor Stephen Holgate, Chair of the UK Respiratory Research Collaborative



“We need to be answerable to our stakeholders – patients, families, and those who donate money – and fund the best research.”

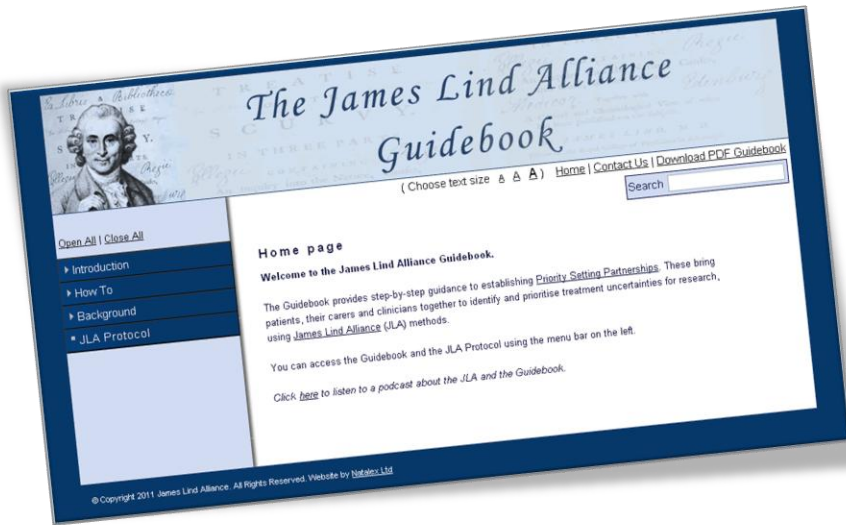
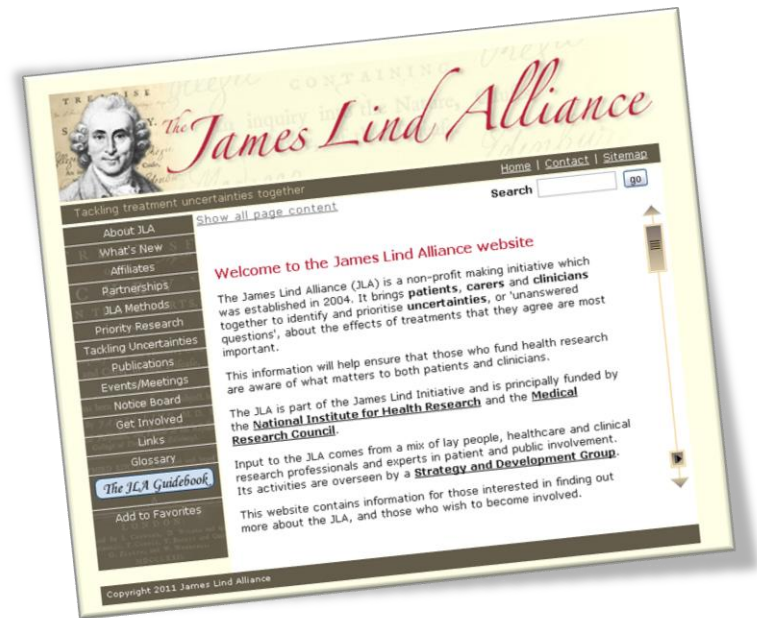
Emma Malcolm, Prostate Action



For more information...

www.lindalliance.org

www.JLAGuidebook.org



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Thank you!

