



# Using a partnership model for priority setting

Katherine Cowan

2<sup>nd</sup> June 2012

# What will I cover?

- What is the James Lind Alliance (JLA)?
- What do we do and why do we do it?
- How do we do it?
- What difference does it make?



# What is the JLA?

- A small initiative – four part-timers



- Funded by the National Institute for Health Research



- Supported by the Medical Research Council



# What is the JLA?

- Established in 2004 – *to see if it would work*
  - Royal Society of Medicine – Dr John Scadding
  - James Lind Library - Sir Iain Chalmers
  - INVOLVE – Sir Nick Partridge
- From 2013: the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)



# What is the JLA?

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

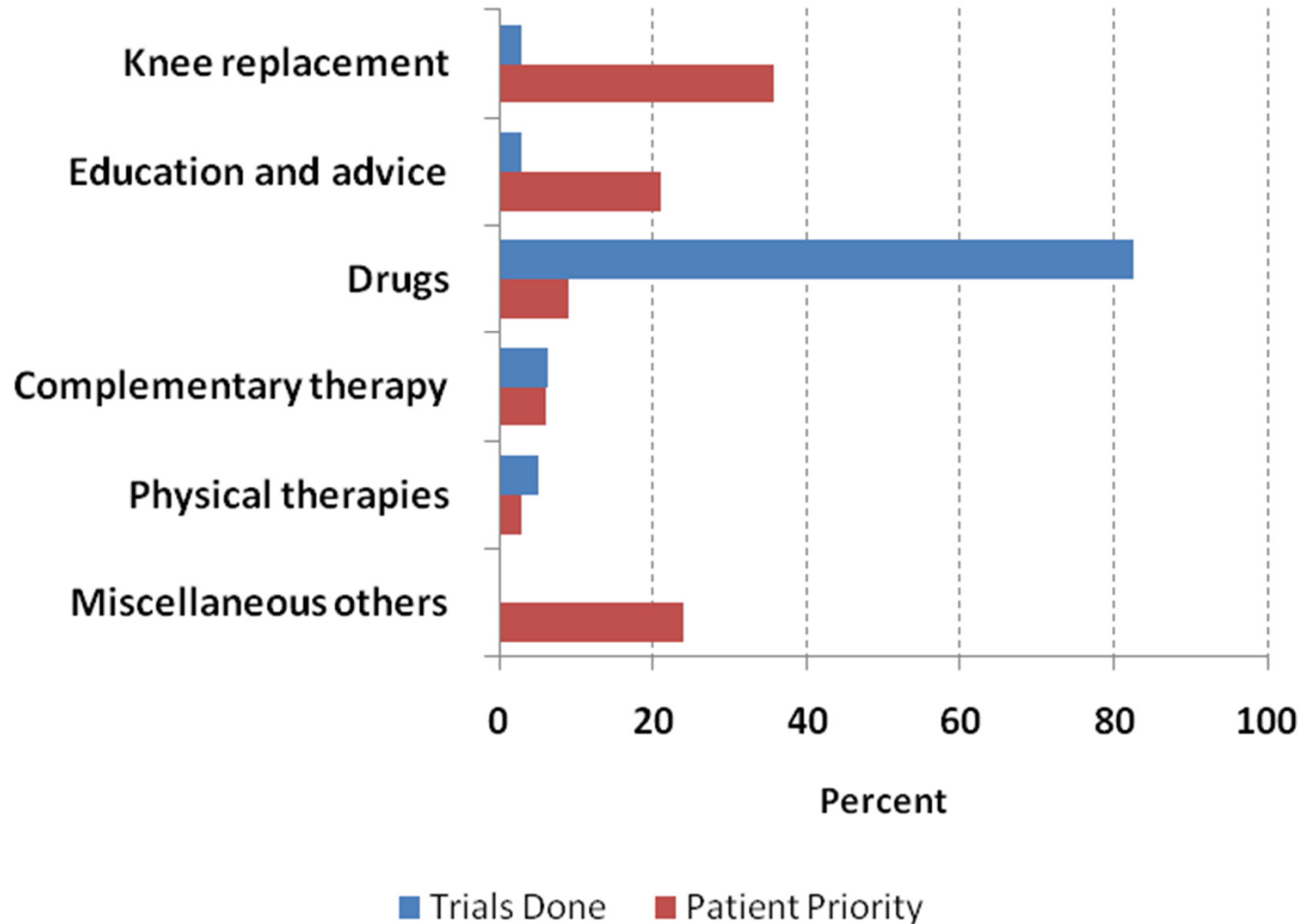


# Why involve stakeholders?

Why involve patients, carers and clinicians in research priority setting?



# Why involve stakeholders?



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



# What do we do?

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





# What do we do?

Completed Partnerships	Current Partnerships
<ul style="list-style-type: none"><li>•Asthma</li><li>•Urinary incontinence</li><li>•Vitiligo</li><li>•Prostate cancer</li><li>•Schizophrenia</li><li>•Type 1 diabetes</li><li>•ENT aspects of balance</li><li>•Stroke</li><li>•Eczema</li></ul>	<ul style="list-style-type: none"><li>•Cleft lip and palate</li><li>•Dementia</li><li>•Head and neck cancer</li><li>•Lyme disease</li><li>•Pressure ulcers</li><li>•Pre-term birth</li><li>•Sight loss and vision</li><li>•Tinnitus</li></ul>



# How do we do it?

The priority setting process:

- Set up steering group
- Invite partners
- Gather uncertainties
- Prioritise uncertainties
- Promote priorities to researchers and funders



# How do we do it?

Set up steering group

- Patient, carer and clinician representatives
- Resources and expertise
- Protocol



# How do we do it?

Invite partners

- Patients, carers, clinicians and their representatives
- Declaration of interests
- Affiliation
- Exclusions



# Invite partners

## Case study: Sight Loss & Vision Priority Setting Partnership

- 19 April 2012
- 78 attendees
- Organisations representing patients and healthcare professionals
- [www.sightlosspsp.org.uk](http://www.sightlosspsp.org.uk)

Patient perspective  
Dr Heather Giles



Patient perspective  
Carol Bronze



Orthoptics  
Dr Fiona Rowe



Optometry  
Jo Mullin



**Fight for Sight**  
Pioneering eye research



THE COLLEGE  
OF OPTOMETRISTS

**NHS**

National Institute for  
Health Research



THE ROYAL COLLEGE OF  
OPHTHALMOLOGISTS

**RNIB**  
supporting blind and  
partially sighted people



# How do we do it?

- Gather 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



# How do we do it?

## Gather uncertainties

- Survey

- Patients and carers
- Clinicians

- Research recommendations

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

- [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets)



# Gather 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

## 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 reccs/literature
- Combining duplicates, there were 350 verified uncertainties
- Steering Group shortlisted 47 based on number of submissions



# How do we do it?

Prioritise uncertainties – step 1 (interim stage)

- 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



# Interim prioritisation

## Case study: Tinnitus Priority Setting Partnership

Theme	Question
<b>Balance problems</b>	
001	What is the link between tinnitus and balance problems (including Meniere's disease, benign paroxysmal positional vertigo )
<b>Brain mechanisms</b>	
002	What are the mechanisms of tinnitus?
003	Which area of the brain is responsible for tinnitus?
004	Are there different types of tinnitus and can they be explained by c
005	What are the mechanisms of tinnitus? Does it involve the ear and/
<b>Brain training</b>	
006	Acoustic CR Neuromodulation is a commercial device for 'brain tra with tinnitus?
007	Can auditory 'brain training' improve tinnitus?
008	To what degree could a treatment harness the auditory brain's nat

**The deadline for completing and returning this form is 25 May 2012.**

Ranking - 1 is your first choice, 2 is your second and so on	Number of your question from the enclosed list e.g. 047
1	
2	
3	
4	
5	
6	
7	

**About yourself** Which of these categories best describes you? (please tick **all** that apply)

- I am a person with tinnitus
- I am a partner or relative or carer of someone with tinnitus
- I am the parent of a child aged under 16 who has tinnitus
- I am a healthcare professional
- I am part of an organisation representing people with tinnitus
- Other (please specify)

- 170 uncertainties
- [www.tinnitus.org.uk/jla](http://www.tinnitus.org.uk/jla)



# How do we do it?

Prioritise uncertainties – step 2 (final)

- 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



# How do we do it?

Promote priorities to researchers and funders

- NIHR Health Technology Assessment programme
- Dissemination of findings



# What difference does it make?

- Asthma

- Funding has been awarded by NIHR HTA programme to fund research to provide better evidence on the effects of breathing exercises for asthma





# What difference does it make?

- Urinary Incontinence

- Five related studies have been funded and several more are in development, addressing six of the top 10 priorities, with two combined.



# What difference does it make?

- Vitiligo

- A pharmaceutical company is preparing to run a pilot multi-centre trial on number 6 of the top 10.

- The Centre of Evidence Based Dermatology is developing two research ideas from the top 10 into a trial protocol.

- [www.vitiligostudy.org.uk](http://www.vitiligostudy.org.uk) - light therapy



# What difference does it make?

- Prostate cancer
  - The prioritised list has informed the research funding strategies of Prostate Action and the Prostate Cancer Charity.
  - Over 15 projects addressing the priorities have been funded since the workshop in October 2010.



# Involving stakeholders in research priority setting – the JLA's principles

- **Inclusive**

- Balance of perspectives
- Accessible to all

- **Supportive**

- Recognising a range of capacities and skills

- **Transparent and democratic**

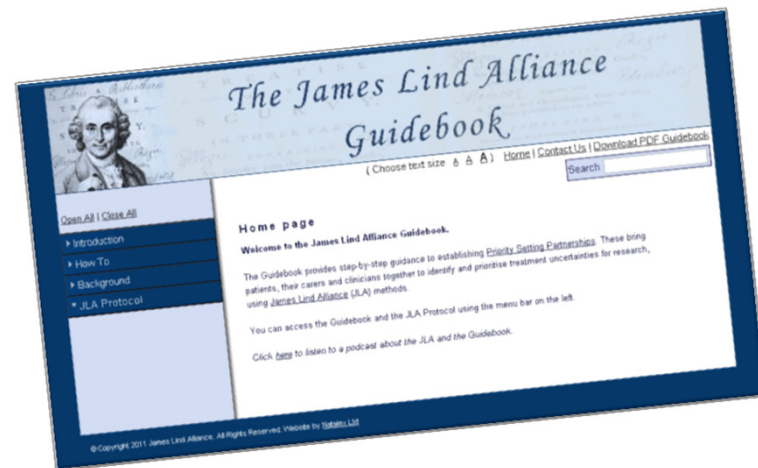
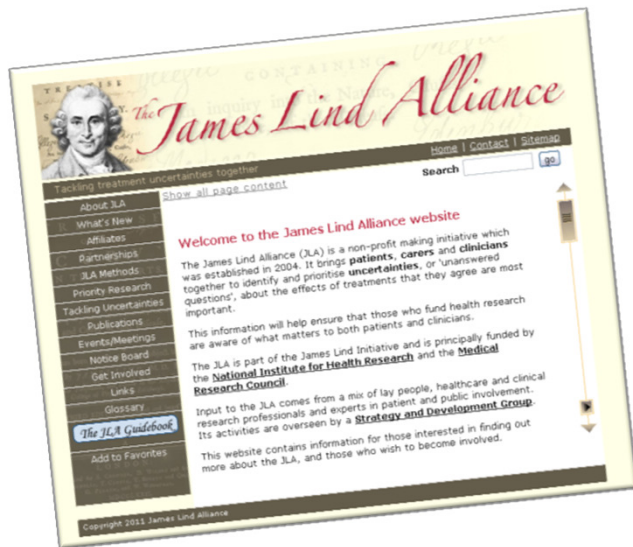
- Data sharing
- Agreed protocol
- Declaration of interests
- Neutral facilitation
- Communication and feedback



# For more information...

[www.lindalliance.org](http://www.lindalliance.org) – become an Affiliate

[www.JLAguidebook.org](http://www.JLAguidebook.org) – practical guidance



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Thank you!

