

19<sup>th</sup> Annual Cochrane Colloquium – Madrid

# Patient centred prioritisation of research

Saturday 22<sup>nd</sup> October  
Sally Crowe, Co Chair James Lind Alliance





# Tackling treatment uncertainties together

The team!



# The case for patient participation in prioritization of research....

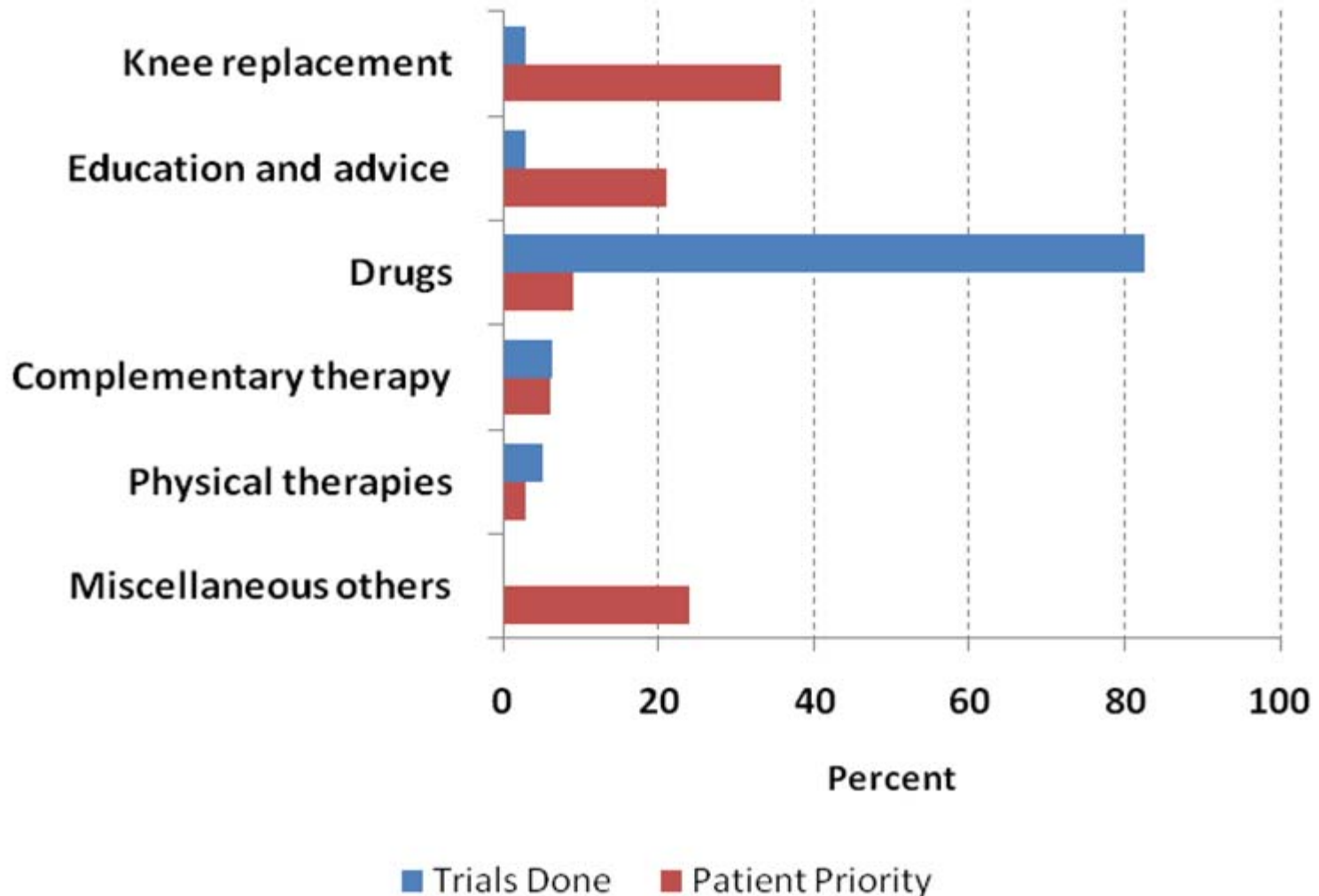
- ▶ It's democratic – who pays for research anyway?
- ▶ It's consumerist – more likely to fund relevant, useful research
- ▶ It's advantageous – in the UK funding agencies now looking for evidence of patient/public participation in research proposals
- ▶ There are mismatches....



Members of Pressure Ulcer  
Priority Setting Partnership  
March 2011

# Mismatches in research priorities – osteoarthritis of the knee

Tallon et al Lancet 2000





1. Gather treatment uncertainties
2. Refine them, and check for uncertainty
3. Publish them on [www.library.nhs.uk/DUETS/](http://www.library.nhs.uk/DUETS/)
4. Prioritise them
5. Publish results
6. Apply for funding for priority research areas





# 1. Gather treatment uncertainties

Uncertainties about the effects of treatment which cannot currently be answered by a relevant, reliable up-to-date systematic review of existing research evidence.

**Published in UK Database of Uncertainties about the Effects of Treatments**

**[www.library.nhs.uk/DUETs/](http://www.library.nhs.uk/DUETs/)**

## 2. Refine treatment uncertainties and check them for uncertainty

- ▶ 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*)

# 3. Publish treatment uncertainties



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

[NHS Evidence Home](#) > [Specialist Collections](#) >

[UK Database of Uncertainties about the Effects of Treatments \(DUETs\) Home](#) > Search Results

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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

<b>From patients (387)</b>	From carers (67)	From professionals (116)	Research recommendations (818)	Ongoing research (132)
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### 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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# 4. Prioritise treatment uncertainties: Priority Setting Partnerships (PSPs)



# 4. Priority Setting Partnerships

## Inclusive

- ▶ Balance of perspectives
- ▶ Accessible to all

## Transparent and democratic

- ▶ Data sharing
- ▶ Agreed protocol
- ▶ Declaration of interests

## Evidence based

- ▶ Working with 'known unknowns'
- ▶ Patient/carer experience, and clinical behaviour



Schizophrenia Priority Setting Partnership  
Jan 2011

# Important to talk.....

- ▶ **Professional, (doctor):**

“why is there non compliance of antipsychotic drugs in young men with schizophrenia”

- ▶ **Patient (young man with schizophrenia)**

“I take a break from my drugs because they make me impotent and sometimes I want a sex life!”

**5. Publish the results**  
**“Democratizing Clinical Research”**  
Nature , Lloyd K, White J 2011

## Survey

- Online/paper survey = 583 respondents
- 1,141 uncertainties expressed

## Collation analysis

- 118 uncertainties were added from UK DUETs = 1,259
- 251 not related to treatment, removed = 1,008

## Combining

- 222 of these were unique - removed = 786
- The rest were similar enough to combine, into 88 indicative questions



# Type 1 diabetes



## Voting

- Steering Group agreed a 'long list' of 47 from the 88
- Long list sent out for voting – people chose their top ten

## Discussion and voting

- Shortlist of 24 established
- Workshop to discuss the 24, and agree a top ten

## Discussion

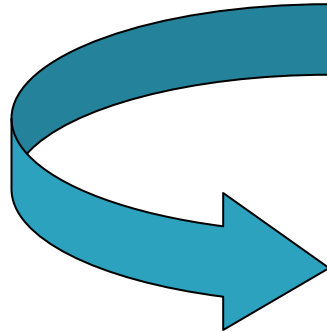
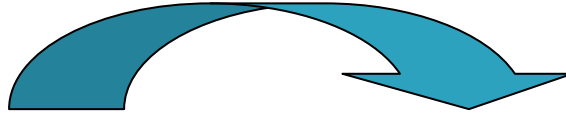
- Steering group seek feedback on top ten, and reformulate



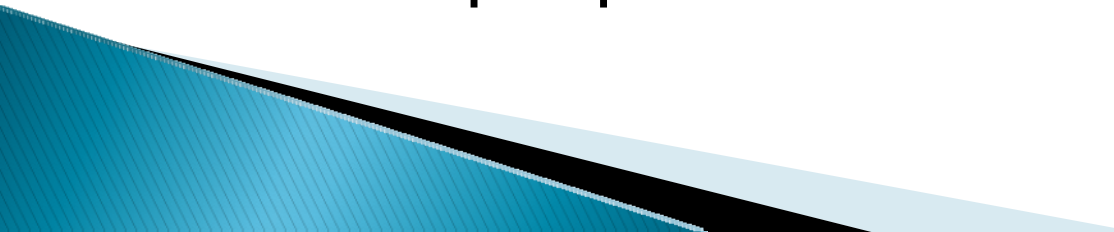
# Type 1 diabetes







# Some observations.....

1. Importance of treatment uncertainty v research 'friendly' questions
  2. Research priorities for the 'greater good' v research issues that affect smaller populations
  3. Single issue participants
  4. Managing hierarchies in clinical and patient communities
  5. The importance of 'neutral' facilitators and chair 'people'
- 

# Priority Setting Partnerships

## ▶ Completed

- Asthma
- Urinary Incontinence
- Schizophrenia
- Prostate Cancer
- Vitiligo
- Type 1 diabetes
- Ear Nose and Throat – aspects of balance



## ▶ Ongoing

- Life after Stroke
- Pressure Ulcers
- Eczema
- Head and Neck Cancer
- Pre Term Birth
- Lyme disease
- Intensive Care
- Tinnitus
- Cleft Lip and Palette

# Are there themes across priorities?

- ▶ Long term effects of treatments
- ▶ Safety and adverse effects of treatments
- ▶ Using non prescribed treatments
- ▶ Professional training and education (for early diagnosis and treatment and to harmonise clinical behaviour)
- ▶ Self care – effectiveness and safety

Is this the difference that patient participation makes?

## 6. Apply for funding for priority research

*“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





# Models for participation

- ▶ Patient Panel (Centre for Evidence Based Dermatology) and Cochrane Skin Group

*“Having patients and carers involved helps us:*

- Answer research questions that are relevant to patients.
- Share research news with patients and the public.
- Ensure that the needs of patients are considered throughout the research process.”

PSPs in Vitiligo (2010) and Eczema (2011)

# Models for participation

- ▶ Working with Asthma UK and Cochrane Airways Group

“To create indicative domains by grouping the ~250 questions generated by the JLA initiative in 2007.” How do these relate to the current CAG review portfolio?

CAG and JLA now working with Asthma UK on prioritisation for their research strategy

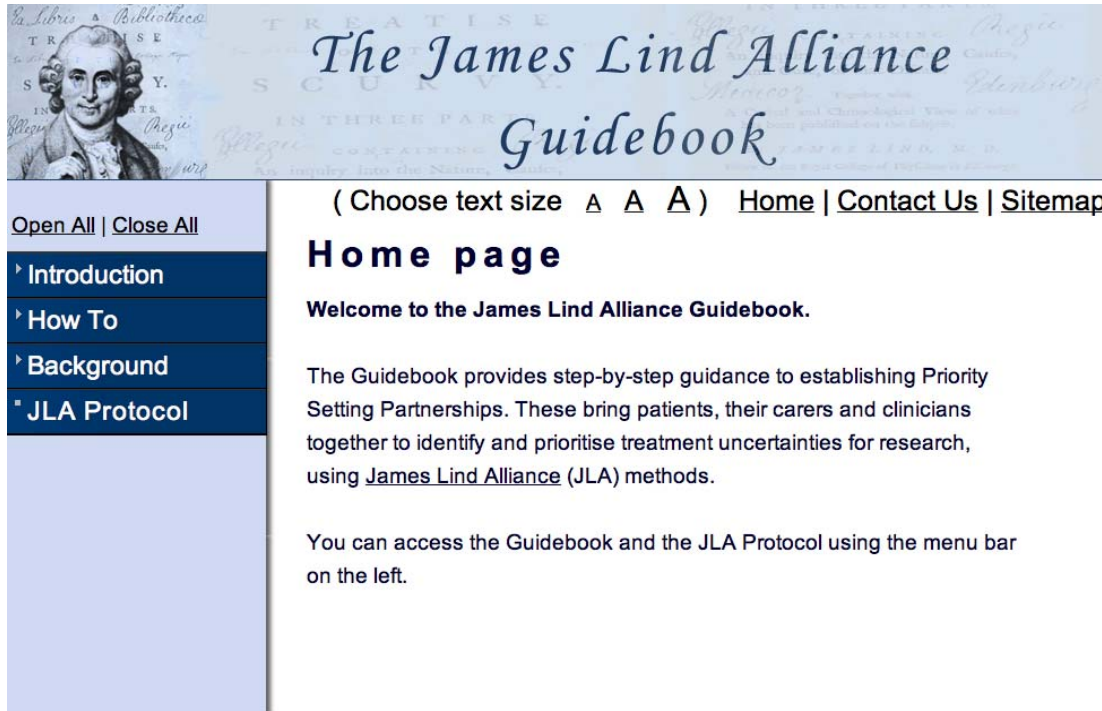


# Possible new Cochrane agenda setting and priority setting methods group

- ▶ Co-convenors: Mona Nasser, Vivian Welch, Sally Crowe, Sandy Oliver, Alessandro Liberati, Prathap Tharyan
- ▶ **Aim** inform the Cochrane entities on the empirical evidence available for methods to set research agendas or priorities, in particular (but not limited) for methods to set a research agenda for systematic reviews
- ▶ Serve as a discussion forum, connecting interested people from outside the Cochrane Collaboration
- ▶ **Join us on our journey!**



<http://www.jlaguidebook.org/>



The screenshot shows the website for the James Lind Alliance Guidebook. At the top left is a portrait of James Lind. The main title is "The James Lind Alliance Guidebook". Below the title are navigation links: "(Choose text size A A A) Home | Contact Us | Sitemap". The page is titled "Home page" and includes a welcome message: "Welcome to the James Lind Alliance Guidebook." The main text states: "The Guidebook provides step-by-step guidance to establishing Priority Setting Partnerships. These bring patients, their carers and clinicians together to identify and prioritise treatment uncertainties for research, using James Lind Alliance (JLA) methods." Below this, it says: "You can access the Guidebook and the JLA Protocol using the menu bar on the left." On the left side, there is a menu bar with the following items: "Open All | Close All", "Introduction", "How To", "Background", and "JLA Protocol".



<http://lindalliance.org>

**Guide to involving patients  
and the public, available at the  
BMJ Books Blackwell Wiley Stand**

