



JLA 2004-2015

Where have we come from?
And where are we now?

Katherine Cowan: Senior Adviser, JLA
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11 years of the JLA

- Current context
- Numbers and reach
- Methods evolution



National Institute for Health Research

Evaluation, Trials and Studies Coordinating Centre



National Institute for Health Research

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11 years of PSPs

- **31** PSPs completed
- **23** PSPs currently ongoing
- **86** logged enquiries



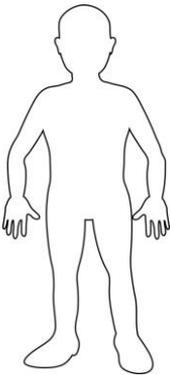
11 years of PSPs

- **26,000+** survey respondents
- **35** top 10s
 - 3 top 11s
 - 2 top 12s
 - 1 top 14
 - 1 top 15

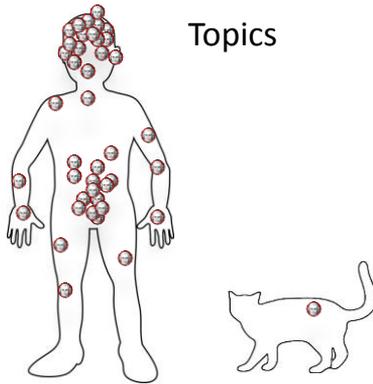
** Sight Loss & Vision PSP did 12!*



Topics



Topics



Geographical reach



Geographical reach



Geographical reach



Core values

- Transparency
- Inclusion / exclusion
- Equality
- Evidence base





Original review of methods





JLA Guidebook




The JLA process







The JLA process







The JLA process



Theme	Question
Balance problems	001 What is the link between balance and balance problems including Meniere's disease, benign paroxysmal positional vertigo?
Brain mechanisms	002 What are the mechanisms of vertigo? 003 What areas of the brain is responsible for vertigo? 004 Are there different types of vertigo?
Brain training	005 What are the mechanisms of brain training? 006 Are there different types of brain training?

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

Ranking: 1 is your first priority, 2 is your second and so on.

Number of your questions from the enclosed list in 2012

About yourself: Which of these categories best describes you? Please tick all that apply.

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




Priority Setting Partnerships

The JLA process





Priority Setting Partnerships

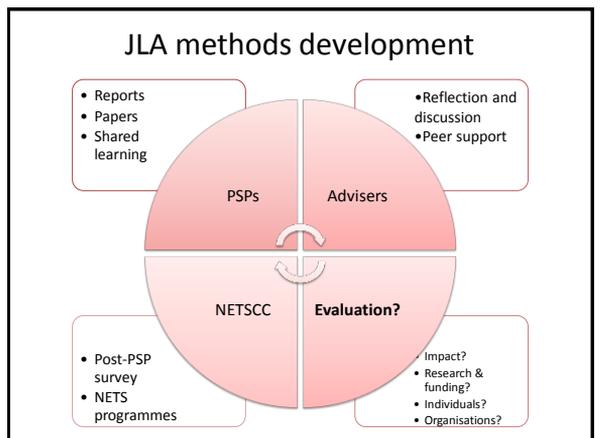
The JLA process








Priority Setting Partnerships





Thank you

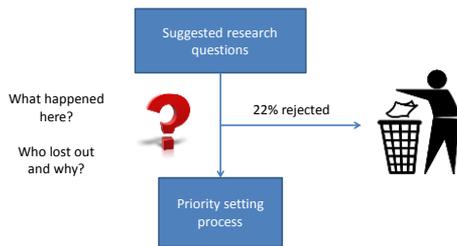
Katherine Cowan: Senior Adviser, JLA
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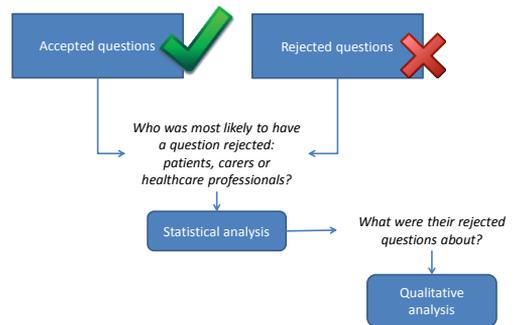
Is the JLA PSP process biased against patients and carers?

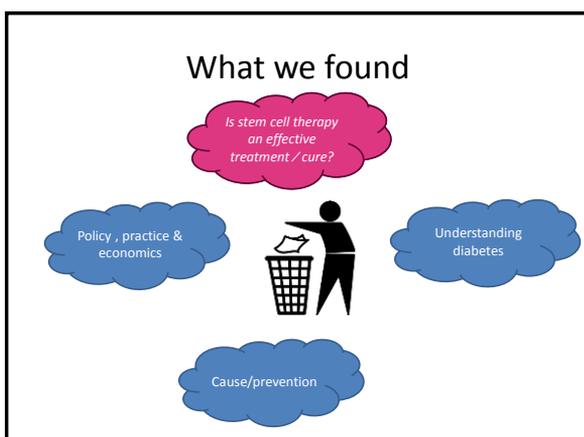
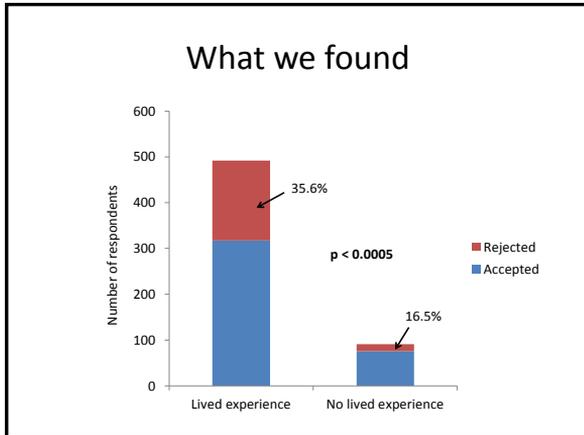
Rosamund Snow & Joanna Crocker
Health Experiences Institute, University of Oxford
JLA Symposium – 23rd June 2015

Case study: Type 1 diabetes PSP



What we did





- ### Implications for JLA
- Ask patients and carers to **co-define** scope of PSP and rules about rejection
 - **Plan** how to deal with suggestions and questions which fall outside the agreed scope of the PSP
 - Clearly **report** how and why suggested questions are rejected

Thank you

Rosamund Snow: rosamund.snow@phc.ox.ac.uk

Joanna Crocker: joanna.crocker@phc.ox.ac.uk

Acknowledgements:

- Sally Crowe
- Jenny Hirst
- Krys Matyka
- NIHR Oxford Biomedical Research Centre

Top 10 priorities

Overarching research aspiration—is stem cell therapy an effective treatment /cure?

1. Is it possible to constantly and accurately monitor blood sugar levels, in people with Type 1 diabetes, with a discrete device (non-invasive or invasive)?
2. Is insulin pump therapy effective (immediate vs. deferred pump, and comparing outcomes with multiple injections)?
3. Is an artificial pancreas for Type 1 diabetes (closed loop system) effective?
4. What are the characteristics of the best Type 1 diabetes patient education programmes (from diagnosis to longterm care) and do they improve outcomes?
5. What are the cognitive and psychological effects of living with Type 1 diabetes?
6. How can awareness of and prevention of hypoglycaemia in Type 1 diabetes be improved?
7. How tightly controlled do fluctuations in blood glucose levels need to be to reduce the risk of developing complications in people with Type 1 diabetes?
8. Does treatment of people with Type 1 diabetes by specialists (e.g. doctors, nurses, dieticians, podiatrists, ophthalmologists and psychologists) trained in personcentred skills provide better blood glucose control, patient satisfaction and self-confidence in the management of Type 1 diabetes, compared with treatment by non-specialists with standard skills?
9. What makes self management successful for some people with Type 1 diabetes, and not others?
10. Which insulins are safest and have the fewest longterm adverse effects?



Improving quality of care and outcomes at very preterm birth
 ARI-0 Programme Grant for Applied Research

Leading education and social research
 Institute of Education
 University of London

Preterm Birth Priority Setting Partnership

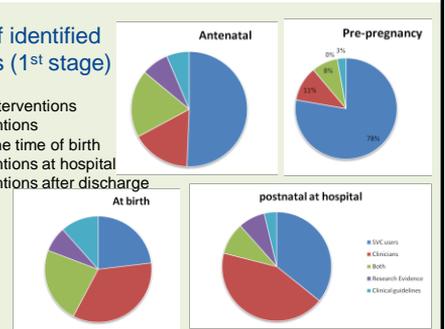
Last update: 16 June 2015
 Prof Sandy Oliver, Seilín Uhm

• 1st stage – Open Survey (N=356)
 • 2nd stage – Public Voting (N=587)

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 University of London

Numbers of identified uncertainties (1st stage)

- Pre-pregnancy interventions
- Antenatal interventions
- Interventions at the time of birth
- Postnatal interventions at hospital
- Postnatal interventions after discharge
- Childhood
- Adulthood



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Overall top 40 priorities from service users, clinicians and both



Rank	Issue/Option	Count
1	General prevention	228
2	OT stress and physical workload	137
3	Examination of membranes	137
4	Prevention of maternal perineal pain	137
5	Use of forceps or ventouse	120
6	Use of epidural analgesia	96
7	OB infections/antibiotics	91
8	24-hour and night procedures	85
9	OT prevention of NICE?	82
10	OT prevention of NICE?	82
11	OT prevention of NICE?	82
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38	OT prevention of NICE?	82
39	OT prevention of NICE?	82
40	OT prevention of NICE?	82

Priorities from different groups

Overall	SVC users	Clinicians	Both
1. General prevention	1. General prevention	1. General prevention	1. General prevention
2. OT stress and physical workload			
3. Examination of membranes			
4. Prevention of maternal perineal pain			
5. Use of forceps or ventouse			
6. Use of epidural analgesia			
7. OB infections/antibiotics	7. OB infections/antibiotics	7. OB infections/antibiotics	7. OB infections/antibiotics
8. 24-hour and night procedures			
9. OT prevention of NICE?			
10. OT prevention of NICE?			
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40. OT prevention of NICE?			

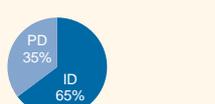
Communication patterns of steering group



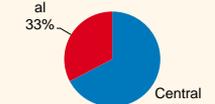
1st phase



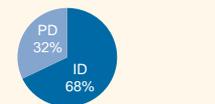
1st phase



2nd phase



2nd phase



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Evaluating the process



Tuckman's stages of group development

JLA's 5 stage of partnership working

Forming

Storming

Norming

Performing

Adjourning

Initiation

Identification

Summarisation

Prioritisation

Reporting

Tuckman (1965). "Developmental sequence in small groups". Psychological Bulletin 63 (6): 384-99.

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Oxford Biomedical Research Centre
Enabling translational research through partnership

National Institute for Health Research

Gathering treatment uncertainties from patients/carers using different methods: report of an evaluation

Sophie Petit-Zeman
Director of Patient Involvement, NIHR Oxford Biomedical Research Centre & Unit
Sandra Regan
JLA Hub Co-ordinator, NIHR Oxford Biomedical Research Centre

JLA Evaluation Symposium; June 23rd 2015

NIHR Oxford Musculoskeletal Biomedical Research Oxford University Hospitals NHS NHS Trust

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What we did

- 3 methods of data collection
- Contribution of patient/ carer voice for each method to:
 - HRCS categories
 - Top Ten priorities
- Costs – direct & hidden

Report available at http://oxfordbrc.nihr.ac.uk/working_groups/patients-active-in-research/patients-active-in-research-pair-projects/

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Data collection methods

- **Online survey** – 508 uncertainties in total
- 239 from patients/ carers
- **2 Discussion groups** – **Oxford**: dedicated group, 8 participants, 42 uncertainties + **Manchester**: mixed group, 11 uncertainties
- **Healthtalk.org** – 16 transcripts, 14 uncertainties

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Key findings – contribution of methods to Top 10

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Key findings – cost effectiveness

- **Survey:** direct costs £3325 (total) + hidden costs > £1600
- **Oxford patient/ carer discussion group:** direct costs £1442 + hidden costs ~ £2425
- **HTO:** direct costs £0 + hidden costs ~

NHS Oxford Musculoskeletal Biomedical Research
£3K

Oxford University Hospitals NHS Trust

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Implications for JLA

- Traditional (survey) method “most bang for buck”
- healthtalk.org a useful data source but high cost and time/not possible for all PSPs
- Discussion groups quick and cost-effective – a route for those wanting to do a pared-down process – “JLA Lite”?

NHS Oxford Musculoskeletal Biomedical Research

Oxford University Hospitals NHS Trust

Can you do JLA in a day?

A/Prof Allison Tong | Sydney School of Public Health | The University of Sydney

James Lind Alliance Symposium 23rd June 2015
Central Hall Westminster, London, United Kingdom



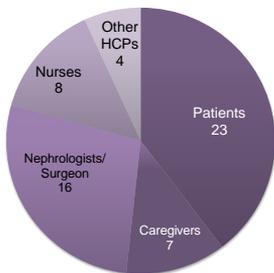
SYDNEY MEDICAL SCHOOL

THE UNIVERSITY OF SYDNEY



National priority setting workshop

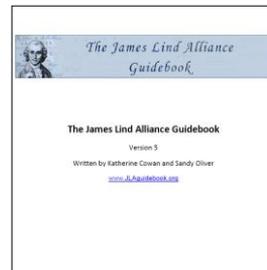
- Aim: to generate and prioritise research questions in chronic kidney disease
- 7th February 2014
- n=58
- Purposive sampling



Adapting JLA methods

Stages

1. Set up
2. Survey – collect uncertainties
3. Data assessment – refine uncertainties
4. Interim prioritisation – survey/ranking, shortlist
5. Final prioritisation - workshop



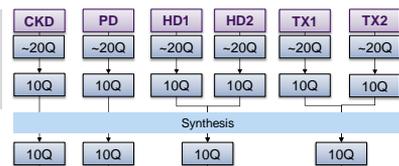
12-18 months → **4 months**

Collection, synthesis, prioritisation → **one-day workshop**

The process

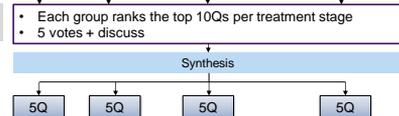
Phase 1

- Facilitated groups (n=8-10) - NGT
- PICO
- Stage-specific
- 5 votes



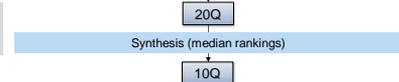
Phase 2

- Ranking by stage



Phase 3

- Plenary discussion
- Ranking top 20



83 research questions were generated

Question
1 How effective are lifestyle programs (diet, exercise and smoking cessation) for preventing deterioration in kidney function in patients with early chronic kidney disease?
2 What strategies will improve donor family consent to deceased donation taking different cultural groups into account?
3 What interventions can improve long term post-transplant outcomes (drugs, lifestyle)?
4 What are the effective interventions for post haemodialysis fatigue?
5 What can we do to improve and individualise drug therapy in terms of better management of side effects?
6 What strategies help patients maintain work while on haemodialysis?
7 What psychological interventions would improve the psychological health for transition between kidney stages?
8 How do we improve health outcomes in young transplant recipients?
9 What are the best interventions to improve the decision making process of people faced with haemodialysis?
10 Does provision of culturally appropriate information about early chronic kidney disease modify acknowledgement, medication adherence, and health service uptake in patients with early chronic kidney disease?

Qualitative findings

Patients/caregivers

- Minimising disease & treatment burden
 - Psychosocial
 - Lifestyle
- Long-term impact

Healthcare professionals

- Data driven & evidence gaps
- Equity
- Population benefit
- Healthcare delivery
- Feasibility

There are days where I need to be plugged into that machine. I need to be at work doing my job. You can't get an income. Dialysis takes up hours. It's not like pop 3 pills a day. You got to block hours to do it. - patient

Mine is probably more hierarchical, so the greatest benefit for the greatest number of people, then working it down to the individual. - nephrologist

Feedback on process

"I'm hoping that other groups and other disease areas will learn from the experience we've had here today. I think policy makers and funding agencies will find it extremely useful."

– Dr. Davina Ghersi

National Health and Medical Research Council

"The value of any such day, is to learn from each other. All the perspectives can be built up to create a more complete picture."

– Prof. Chris Baggoley CMO

Australian Government

"I would like to personally thank the patients and carers in our group for their contributions as I learnt a lot from them. They raised issues I hadn't considered despite 30+ years of specialty practice. Probably more of a reflection on me! So the day made a difference!"

– Dr. Carol Pollock, Nephrologist

"Great to feel involved and imagine you are helping to drive things in the right direction!"

– Patient

Reflections and Implications

- Methodological developments
 - Concurrent facilitated discussion groups
 - Three-phases with real-time data analysis to distil the number of priority questions to rank
 - Observe how priorities are identified together from the onset (why)
 - Compressed process → cost, resources, feasibility
- Limitations/what could be improved?
 - Not always PICO
 - Electronic voting
- Empiric comparative evidence
 - Different questions?
 - Perceived level and quality of engagement





UNIVERSITY OF SYDNEY

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 Professor Chris Baggoley, Chief Medical Officer, Australian Government, Dr. Davina Ghersi, National Health and Medical Research Council

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Co-facilitators
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Observers
 Anne Wilson, Chris Baggoley, Davina Ghersi, Luke Toy, Tim Mathew