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

Katherine Cowan: Senior Adviser, JLA
@katherine_JLA

11 years of the JLA
• Current context
• Numbers and reach
• Methods evolution
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!
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

<table>
<thead>
<tr>
<th>JLA methods development</th>
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<tbody>
<tr>
<td>Reflection and discussion</td>
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<tr>
<td>Peer support</td>
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</table>

| PSPs |
| Advisers |
| NETSCC |
| Evaluation |

- Reports
- Papers
- Shared learning
- Reflection and discussion
- Peer support
- Post-PSP survey
- NETS programmes
- Impact?
- Research & funding?
- Individuals?
- Organisations?
Thank you

Katherine Cowan: Senior Adviser, JLA
@katherine_JLA

Case study: Type 1 diabetes PSP

What happened here?
Who lost out and why?

Suggested research questions
22% rejected

Priority setting process

What we did

Accepted questions

Rejected questions

Who was most likely to have a question rejected: patients, carers or healthcare professionals?

Statistical analysis

What were their rejected questions about?

Qualitative analysis
What we found

- **Policy, practice & economics**
  - Is stem cell therapy an effective treatment/cure?

- **Understanding diabetes**

- **Cause/prevention**

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**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 aspiration—is stem cell therapy an effective treatment /cure?
- 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)?
- Is insulin pump therapy effective (immediate vs. deferred pump, and comparing outcomes with multiple injections)?
- Is an artificial pancreas for Type 1 diabetes (closed loop system) effective?
- What are the characteristics of the best Type 1 diabetes patient education programmes (from diagnosis to longterm care) and do they improve outcomes?
- What are the cognitive and psychological effects of living with Type 1 diabetes?
- How can awareness of and prevention of hypoglycaemia in Type 1 diabetes be improved?
- 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?
- Does treatment of people with Type 1 diabetes by specialists (e.g. doctors, nurses, dieticians, paediatricians, 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?
- What makes self management successful for some people with Type 1 diabetes, and not others?
- Which insulins are safest and have the fewest longterm adverse effects?

Preterm Birth
Priority Setting Partnership

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

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

Pre-pregnancy

Antenatal

Natal

Postnatal at hospital

At birth
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

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/

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

Key findings – contribution of methods to Top 10
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 ~ £3k

Implications for JLA

- Traditional (survey) method “most bang for buck”
- [healthtalk.org](http://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”?

Can you do JLA in a day?

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

Collection, synthesis, prioritisation → one-day workshop

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Phased groups (n=8-10) - NGT</th>
<th>PICO</th>
<th>Stage specific</th>
<th>5 votes</th>
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<tbody>
<tr>
<td>CKD</td>
<td>10Q</td>
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<td>Synthesis</td>
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<thead>
<tr>
<th>Phase 2</th>
<th>Ranking by stage</th>
<th>Each group ranks the top 10Qs per treatment stage</th>
<th>5 votes + discuss</th>
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<tr>
<th>Phase 3</th>
<th>Plenary discussion</th>
<th>Ranking top 20</th>
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<td>TX2</td>
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<tr>
<td>Synthesis (median rankings)</td>
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<td>10Q</td>
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83 research questions were generated

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<tr>
<th>Question</th>
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<tbody>
<tr>
<td>How effective are lifestyle programs (diet, exercise and smoking cessation) for preventing deterioration in kidney function in patients with early chronic kidney disease?</td>
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<td>What strategies will improve donor family consent to deceased donation taking different cultural groups into account?</td>
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<td>What are the effective interventions for post haemodialysis fatigue?</td>
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<td>What can we do to improve and individualise drug therapy in terms of better management of side effects?</td>
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<tr>
<td>What strategies help patients maintain work while on haemodialysis?</td>
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<td>What psychological interventions would improve the psychological health for transition between kidney stages?</td>
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<td>How do we improve health outcomes in young transplant recipients?</td>
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<tr>
<td>What are the best interventions to improve the decision making process of people faced with haemodialysis?</td>
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<tr>
<td>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?</td>
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## Qualitative findings

<table>
<thead>
<tr>
<th>Patients/caregivers</th>
<th>Healthcare professionals</th>
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<tbody>
<tr>
<td>Minimising disease &amp; treatment burden</td>
<td>Data driven &amp; evidence gaps</td>
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<tr>
<td>• Psychosocial</td>
<td>• Equity</td>
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<tr>
<td>• Lifestyle</td>
<td>• Population benefit</td>
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<tr>
<td>• Long-term impact</td>
<td>• Healthcare delivery</td>
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<td></td>
<td>• Feasibility</td>
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</table>

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 2 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—not nephrologist

## 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

## Feedback on process

"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 Baggaley CMO
Australian Government

"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

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

— Patient

"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

## Acknowledgements

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

Participants

Co-facilitators
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Observers
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