Shaping research to make it useful
who's involved and how?

Sandy Oliver: 8th Symposium of the Swiss Clinical Trial Organisation
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Seilin Uhm

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Oliver S, Bangpan M, Dickson K (Accepted) Producing policy relevant systematic reviews: navigating the policy-research interface. Evidence and Policy.
Outline

1. Shaping a research agenda: consensus development
   – Achievements and challenges with the case of pre-term birth

2. Collective decision making: a rapid review
   – Current evidence from across academic disciplines & policy sectors

3. Shaping research questions: insider research & reflection
   – Implications for communicating between policy and research

4. Conclusions
Shaping a research agenda

Pre-term birth
James Lind Alliance

- A non-profit making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or unanswered questions, about the effects of treatments.

- The aim of this is to make sure that health research funders are aware of the issues that matter most to patients and clinicians.

http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/
What research Qs are important to clinicians and service users?

Are their Qs already answered?

Which Qs are more important than others?

Public consultation – Guided by a Steering Group of service users and clinicians.

- Paper-based survey at key venues
- Focus groups
- Web-based survey
- Comparing with current evidence
- Face to face meeting
- Teleconference
- On-line voting
**Methodology**

- Interpretivism
- Qualitative approach
- Ethnography
- Discourse analysis

**INVESTIGATING RESEARCH PRIORITIES**

- What research Qs are important to clinicians and service users?
- Are their Qs already answered?
- Which Qs are more important than others?

**Public consultation – Guided by a Steering Group of service users and clinicians.**

- Face to face meeting
- Teleconference
- On-line voting
- Web-based survey
- Focus groups
- Paper-based survey at key venues
- Systematic map
- Observation of meetings
- Individual interviews

**INVESTIGATING PERSPECTIVES & PARTNERSHIP WORKING**

- How do their Qs differ from each other or available research?
- How do they work together effectively?
- Who is more or less influential when reaching agreement and how does it happen?
- Conversation analysis
- Theme identification

- Are there gaps between individual priorities and collective priorities?
Priority setting: preterm birth research

26 organisations participated, 13 people representing 6 organisations formed steering group

386 respondents 540 systematic reviews 593 research uncertainties

Collated into 104 uncertainties 70 from survey, 28 systematic reviews, 24 from clinical guidelines

537 respondents voted Top 40 to workshop Top 15 chosen
Panel: Top 15 UK research priorities for preterm birth

• Which interventions are most effective to predict or prevent preterm birth?
• How can infection in preterm babies be better prevented?
• Which interventions are most effective to prevent necrotising enterocolitis in premature babies?
• What is the best treatment for lung damage in premature babies?
• What should be included in packages of care to support parents and families or carers when a premature baby is discharged from hospital?
• What is the optimum milk feeding strategy and guidance (including quantity and speed of feeding and use of donor and formula milk) for the best long-term outcomes of premature babies?
• What is the best way to judge whether a premature baby is feeling pain (for example, by their face, behaviours, or brain activities)?
• Which treatments are most effective to prevent early onset pre-eclampsia?
• What emotional and practical support improves attachment and bonding, and does the provision of such support improve outcomes for premature babies and their families?
• Which treatments are most effective for preterm premature rupture of membranes?
• When is the best time to clamp the umbilical cord in preterm birth?
• What type of support is most effective at improving breastfeeding for premature babies?
• Which interventions are most effective to treat necrotising enterocolitis in premature babies?
• Does specialist antenatal care for women at risk of preterm birth improve outcomes for mother and baby?
• What are the best ways to optimise the environment (such as light and noise) in order to improve outcomes for premature babies?
Mismatch?

Interventions mentioned in commercial trials, non-commercial trials and research priorities identified by James Lind Alliance Priority Setting Partnerships, 2003-2012³.

- **Education and training, service delivery, psychological, physical, exercise, complementary, diet, other**
  - JLA patient-clinician Priority Setting Partnerships: 23
  - Registered non-commercial trials: 397
  - Registered commercial trials: 689

- **Radiotherapy, surgery and perioperative, devices, and diagnostic**
  - JLA patient-clinician Priority Setting Partnerships: 29
  - Registered non-commercial trials: 340
  - Registered commercial trials: 89

- **Drugs, vaccines and biologicals**

³ JLA patient-clinician Priority Setting Partnerships.
Different priorities

- Research consistently shows that clinicians, service users and researchers have different priorities
- Inclusive research agendas are consistently different from existing research agendas
- *Who’s influencing these priorities? Clinicians, service users, researchers, or people with two or three hats?*
Lost priorities

- Stress & physical workload
- Preventing subsequent preterm birth
- Screening in the 1st trimester
- Multiple birth

Priorities:

- Low priority
- High priority

Timeline:

- Voting
- Workshop (am)
- Workshop (pm)
- Final rank
Collective decision making

Guidance and research
Tacit knowledge held by service users, researchers and facilitators

- eg, INVOLVE, Cartwright & Crowe, Telford et al

Formal and tacit knowledge

- eg, EULAR, James Lind Alliance

Knowledge formalized by organizations, research, or critical appraisal

- eg, WHO, AGREE II, Wright et al

Tacit knowledge offers guidance for interpersonal communication and support

Formalized knowledge offers guidance for structures, resources and procedures
Where is the evidence about group decision making?

- **Health services research** emphasises rigour and relevance of evidence presented to guideline development groups
- **Social psychology** emphasises experimental studies of small group decision-making
- **Business administration** emphasises observational studies of corporate boards and audit committees

What do we know about making decisions in groups? Group composition

Larger groups can be more diverse, possibly enhancing credibility and acceptance of decisions

More varied membership brings more perspectives, alternatives and better performance for non-routine tasks

> 6 people, reliability declines rapidly
> 10-12 people, reliability has diminishing returns

What do we know about making decisions in groups? Group facilitation

- Role of chair/ facilitator is crucial for establishing inclusive practices, an atmosphere of openness and trust

- Formal methods > informal methods, but don’t know why

- We have no up-to-date systematic review evidence about recent advances in IT to support decision making
What do we know about making decisions in groups? Group interactions

- In large groups, *participation* is related to *status*
- In small groups, *influence* is related to *status*
- Discussion allows sharing and evaluation of knowledge
- When time is short, less knowledge is shared and decisions are more the result of negotiating between prior preferences
- When tasks involve judgments (rather than problem solving) status within the group influences decisions
Shaping research questions
Study of policy-relevant reviews

• Insider research and reflective practice
• In-depth interviews with 11 review teams/programmes: researchers/policy makers
  • Driven by academics; professionals making or implementing policy; priority setting exercises.
• Themes clustered – supply and demand: motivations, engagement methods, structures and procedures
• Participant validation
Findings

• No research methodology uniquely appropriate for policy-relevant reviews

• Mutual engagement across the research-policy interface makes them policy relevant
  – thinking about the issues from multiple viewpoints, including lateral thinking, to identify and shape questions
  – prompting implicit or explicit value driven debates
  – engaging with unfamiliar issues, mutual challenge and tensions between technical and political issues.
Developing review questions

Parallels with

• qualitative analysis
• non-directive counselling

So there are *methods to shape review questions*; not just methods to provide answers
Conclusions

Making research useful depends on:

- Involving appropriate stakeholders
- Recognising their interests differ
- Recognising inherent hierarchies
- Giving time and encouragement for group members to share and evaluate knowledge
- Encouraging constructive conflict, not ‘going native’
Adding value in research...

...comes from developing methods to shape the questions as much as applying rigorous methods to find the answers.
Thank you

sandy.oliver@ucl.ac.uk