

Workshop

Agenda setting: Evidence & Equity

20 Oct 2010, Joint Campbell-Cochrane Colloquium, Keystone, Co, USA

The workshop consisted of four presentations along with discussions and feedback.

Participants: Peter Tugwell, Finola Delamere, David Tovey, Rachel Marshall, Tamara Rader, Tracy Koehlmooos, Vivian Welch, Peter Bragge, Cynthia Boyd, Libby Bogdan-Lovis, Elizabeth Ghogomu, Sandy Oliver, Mona Nasser

Report from the discussion:

How should CRGs ensure that they are producing and maintaining high priority reviews?

We discussed several options how we could help Cochrane review groups to develop, conduct and implement a research agenda and prioritization project.

- 1) There was a long discussion on the benefits and challenges involving patients and clinicians in the process of prioritization.
- 2) Individual and tailored support of the proposed agenda setting methods group to the CRGs
- 3) Developing a list of feasible interventions that the CRG could do to improve their prioritization work
- 4) David mentioned that inequalities are the most difficult part to be addressed in agenda setting and priority setting. Mona, Peter, Erin and Vivian had developed an equity lens to guide priority setting projects. We would pilot it with some Cochrane review groups to explore whether it would work.
- 5) To encourage CRGs to more transparently report the acceptance/rejection of titles for Cochrane reviews
- 6) “Match making”: Sandy highlighted that there are a number of researchers who have the methodological expertise and would be interested to uptake important topics for Cochrane reviews, however, there need to be

strategies to be taken to improve the collaboration with these reviewers and CRGs

- 7) Vivian mentioned that the vacant list titles are a helpful approach to communicate potential priority topics that do not have yet an author team. The vacant title lists might need to be reported and communicated more consistently. One potential option is a central resource of all vacant titles in the Cochrane website or the Cochrane library website.
- 8) A potential problem is that an author team might overtake an important and priority topic but do not get it forward. It is recommended that CRGs put deadline afterwards the topic would be open for a new author team to take over.

How can CRGs ensure that they hear the priorities of all core stakeholders, not just the “usual suspects”?

- 1) Tamara reported about their experiences and challenges on involving consumer groups in different countries around the world. She also mentioned that regional branches and centers could be helpful in achieving it.
- 2) Mona stated that in some countries there are interested and enthusiastic individuals but due to organizational, political, economic or cultural issue, there is no formal branch established there. Informal network of authors in certain countries should be also recognized as potential stakeholders along with formal branches and centers.
- 3) Peter T highlighted that there are a lot of work done on how to develop and conduct priority setting and involving stakeholders. CRGs should be encouraged to involve external stakeholders and start gathering experiences
- 4) We also talked about evaluating the process and Peter B mentioned that the criteria of the prioritization could help in evaluating whether we have achieved our expected results or not. Content analysis of the Cochrane library can be also helpful. Media coverage can also provide potential helpful figures and it was suggested to communicate the figures identified by Wiley so that CRGs are aware on what topics are mostly covered in media.

How do we ensure that by prioritising, CRGs do not perceive themselves to be acting contrary to the Cochrane core principle of inclusion?

- 9) The CRGs should consider balancing conducting high priority topics and capacity building.
- 1) Mona highlighted that it is not always the case that important Cochrane reviews are difficult to conduct and she suggested that in some cases the CRGs might consider upgrading big topics. The author team would first

conduct a review on a more focus and narrower question, publish it and afterwards upgrade the review along with updating it to a wider question. This would keep them interested as there is an output and the bigger review can be eventually be finished

- 2) Sandy mentioned that new authors could also be encouraged to work on updating reviews as their first review and it is sometimes easier as starting one from scratch.
- 3) The Evidence mapping approach of GEM could help the CRG to identify and prioritise potential topics in certain health areas.
- 4) Vivian suggested CRG might want to consider lumping reviews in updating along with splitting. A potential barrier is that the different author teams might not agree to work together.

Agenda setting for research

Sandy Oliver reflected on three examples of agenda setting for research:

1. Setting the agenda for individual EPPI-Centre reviews starts with broad policy priorities of a government department. The relevant research literature is described in terms of its scope and methods. The Advisory Group for the EPPI-Centre, or for the individual review, engages in a round table discussion from the perspectives of policy, public and voluntary sector practice, and research, to decide which sub set of the literature deserves most attention in the review.
2. The agenda for NIHR Health Technology Assessment programme is described as 'needs-led and science-added'. Setting the agenda starts with gathering suggestions for unanswered research questions from policy groups, NHS organisations, a publicly accessible web site and systematic reviews' recommendations for research. These ideas are first sifted internally to produce a short list. A subsequent round table discussion involves people bringing clinical (and some research) and service user perspectives to decide which topics are recommended for research. Greater research input happens at the stage of commissioning the research, where proposals are peer reviewed and discussed by methodologists who recommend the teams for funding.
3. The research agenda for the James Lind Alliance starts with clinicians and patients. Agenda setting ends with a one day workshop for clinicians and patients to debate which suggestions for research are most important. The role for researchers is to ensure that suggestions where research already exists are excluded from deliberations early in the process, and to provide research information at the workshop if required.

These examples differ in terms of:

- (a) where the process begins
 - with policy makers for EPPI-Centre reviews
 - with researchers, policy organisations, clinicians and service users for the NIHR Health Technology Assessment programme
 - with patients and clinicians for the James Lind Alliance
- (b) who makes the decisions
 - Advisory Group for EPPI-Centre reviews (researchers, policy makers, practitioners)
 - Clinicians (often researchers too) and service users for the NIHR HTA programme
 - Clinicians (not researchers) and patients for the James Lind Alliance
- (c) What is the role of research?
 - Characterising the literature to inform the discussion – research activity and gaps – for EPPI-Centre reviews
 - Ensuring decisions are research informed for the NIHR HTA programme
 - Ensuring research priorities are not already answered for the James Lind Alliance

This raises questions about whether the appropriate starting place, appropriate decision-makers, and appropriate role of research differs depending on whether the research agenda is for a national research programme spanning different health areas, systematic review programmes within specified health areas, or individual studies.



Agenda setting: Evidence & Equity

Mona Nasser, DMD, MSc
Research associate
IQWiG

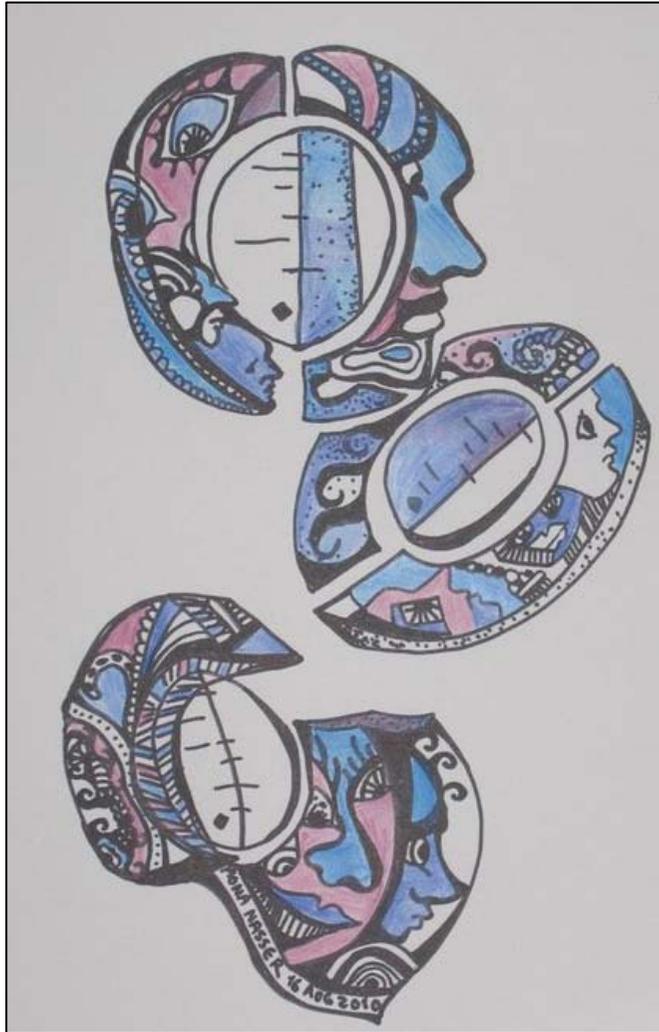




Workshop team



Peter Tugwell, Erin Ueffing,
Vivian Welch, Sandy Oliver,
Mona Nasser, Jordi Pardo,
Tamara Rader, Anne
Lyddiatt, Brian Buckley, Sally
Crowe, David Tovey/Rachel
Marshall



Agenda

Mona Nasser: *Agenda setting:
method, process and equity*

Sandy Oliver: *Involving different
stakeholders in setting research
agenda*

David Tovey/Rachel Marshall: *NHS
engagement project, Impact of JLA
project*



- How should CRGs ensure that they are producing and maintaining high priority reviews?
- How can CRGs ensure that they hear the priorities of all core stakeholders, not just the “usual suspects”?
- How do we ensure that by prioritising, CRGs do not perceive themselves to be acting contrary to the Cochrane core principle of inclusion?



The voyage of discovery is not
in seeking new landscapes
but in having new eyes.

Marcel Proust



All (health)
research
should start
and end with
a systematic
review

Principles of the Cochrane Collaboration

Collaboration,
Building on the enthusiasm of individuals,
Avoiding duplication,
Minimizing bias,
Keeping up to date,
Striving for relevant,
Promoting access,
ensuring quality,
continuity,
enabling wide participation.





Example: Cochrane Consumer Network

- Workshop to define criteria for ranking published Cochrane reviews to plan dissemination strategy
examples: Harms weighed against benefits, Prioritised in healthcare system, Newsworthy
- An online survey (spanish and english) along with a dissemination strategy to reach consumers
- Second survey and workshop
- Data were collected on the characteristic of the participants
- Dissemination and communication strategy planned



Example: Cochrane Eyes and vision group

- Identify important clinical questions in clinical guidelines and translate them into answerable clinical research questions
- Identify the evidence that appears to exist for each question,
- Present this information to international clinical experts in the field and ask them to prioritize the questions
- Evaluating the process



Example: Cochrane Infectious diseases group

- Strategic planning to increase the number of high impact Cochrane reviews
- Author teams submit topics to the Editorial unit
- The Editorial unit categorize based on the criteria: strategically important or reviews requested by policyamkers with deadline, potentially important for MDGs or health in developing countries, results of the review of minimal relevance to achieving the MDGs along with the experience of the authors and the availability of trials
- They have a diagram that they follow, a lower priority topics with a few trials might be accepted with the intention to do capacity building



Methods & Processes

- Why agenda setting?
- Systematic reviews and primary studies
- How priority setting is currently done in the Cochrane Collaboration?
- How can other priority setting approaches inform the process and methods in Cochrane
- How can we achieve a more transparent, inclusive, fair and equity oriented approach in setting our research agenda?
- What is the evidence for the benefits or adverse consequences of one approach over another?



Cochrane Review on priority setting

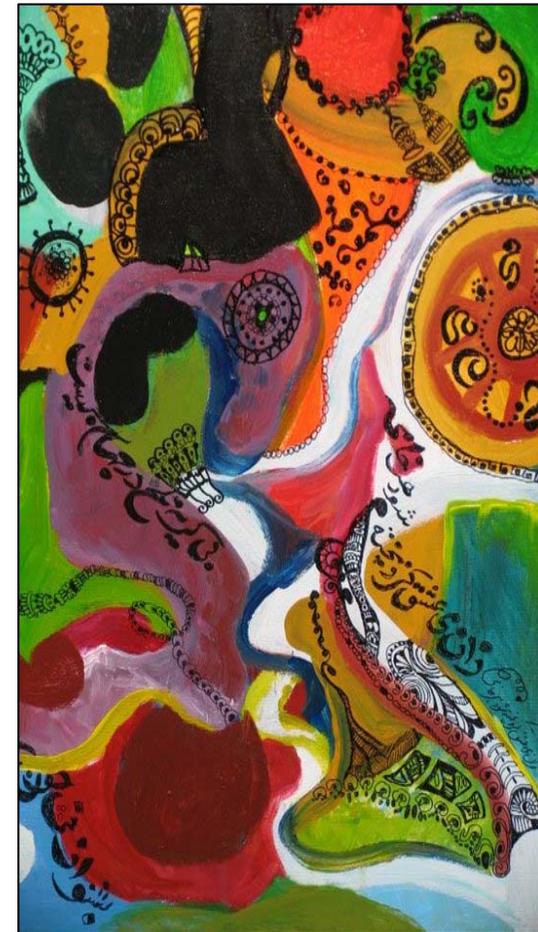
A series of articles in Journal of Clinical Epidemiology

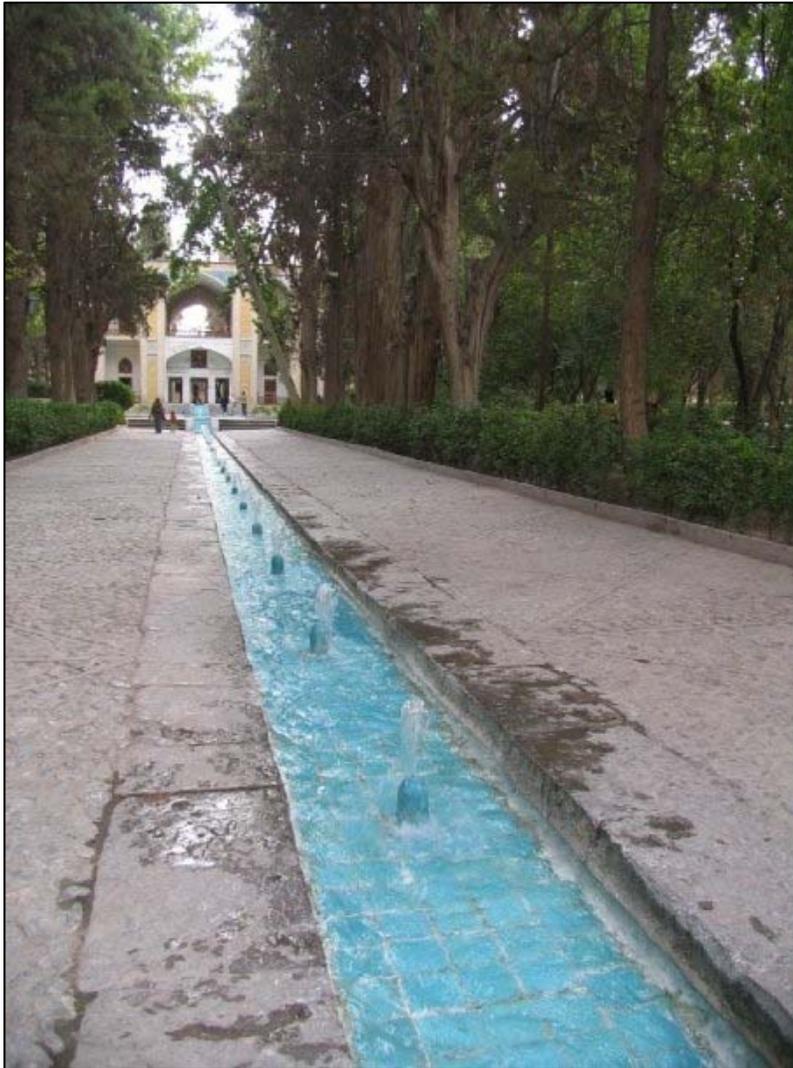


The Cochrane Collaboration & James Lind Alliance

Join our discussion priority setting

- A Cochrane Collaboration discussion forum on priority setting
- A discussion group on Methodspace www.methodspace.com/group/priority-setting-and-agenda-setting-methodology





*Let the goal to reach
perfection, but be
content with a little
progress toward
perfection everyday*

(BKS Iyengar)

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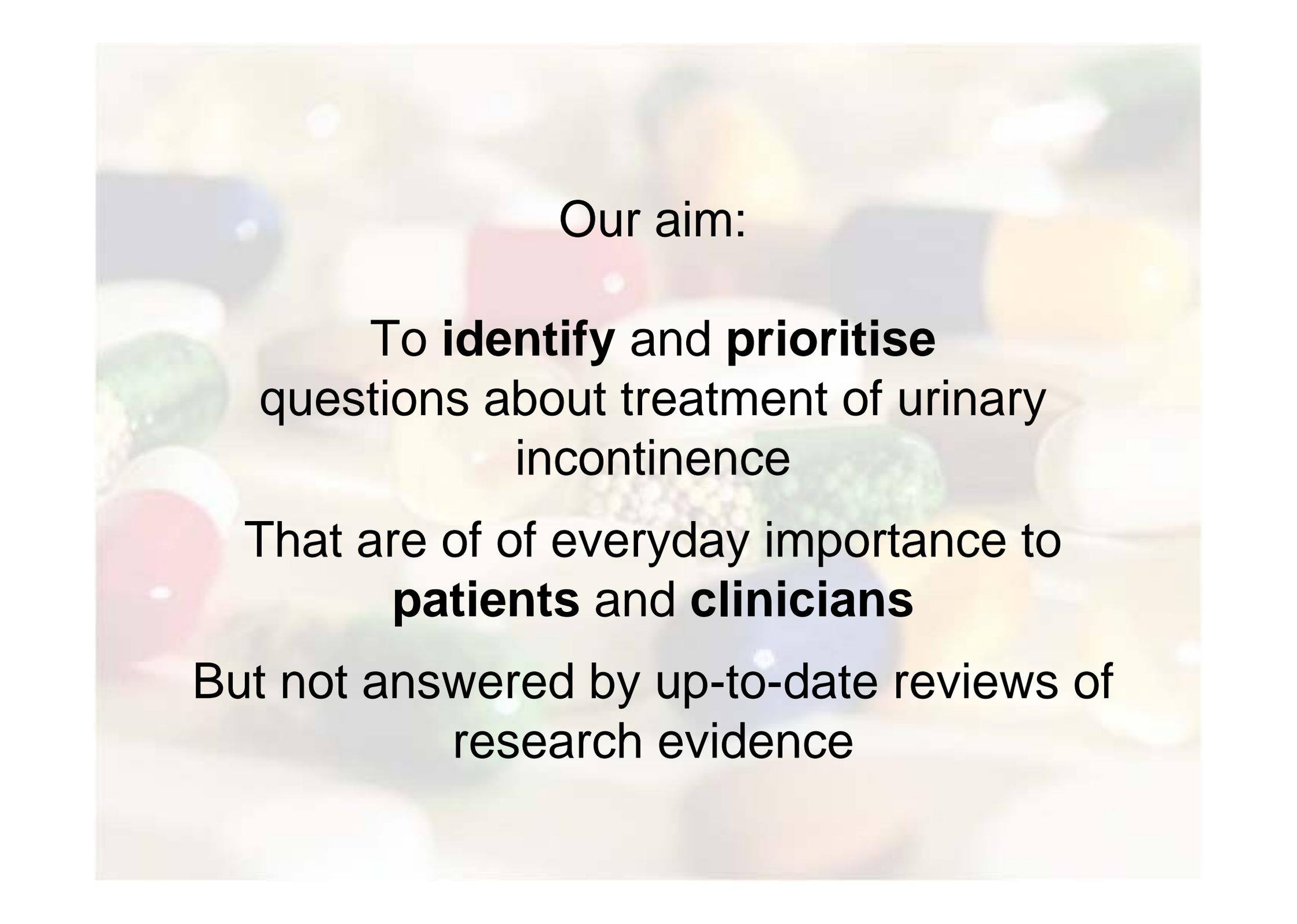


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**Stimulating research
development: the effect of a
patient-clinician partnership
that identified and prioritized
research needs in urinary
incontinence**

Brian Buckley
on behalf of the JLA PSP on UI



Our aim:

To **identify** and **prioritise**
questions about treatment of urinary
incontinence

That are of everyday importance to
patients and **clinicians**

But not answered by up-to-date reviews of
research evidence

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graph TD; A[Initiation] --> B[Consultation]; B --> C[Collation]; C --> D[Prioritisation]; D --> E[Dissemination];
```

Initiation

Consultation

Collation

Prioritisation

Dissemination

Initiation

Identification of potential partner organisations

Recruited 13 clinician orgs, 8 patient orgs

↓
Consultation

↓
Collation

↓
Prioritisation

↓
Dissemination

Initiation



Consultation

Harvesting uncertainties from organisations



Collation



Prioritisation



Dissemination

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Initiation

Consultation

Collation

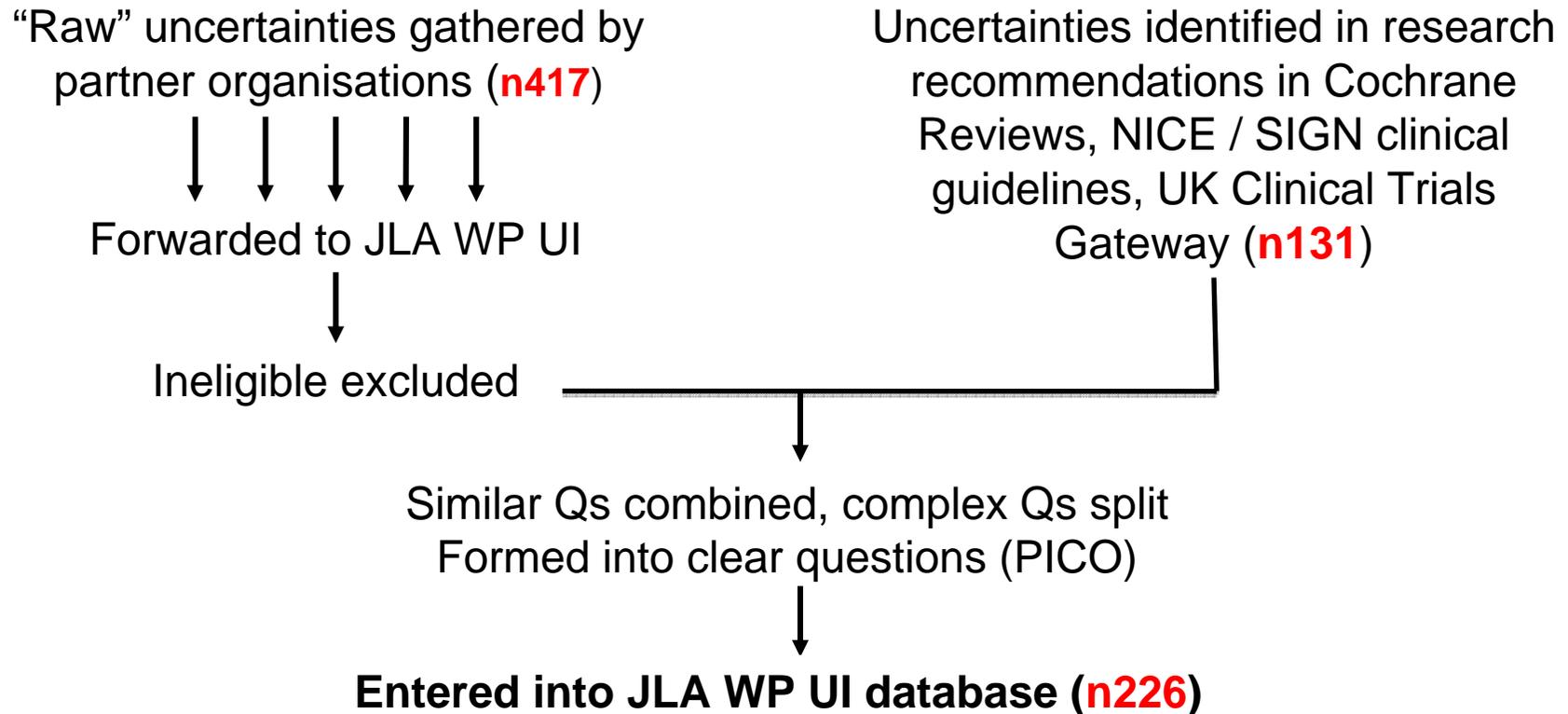
Questions gathered from partner orgs

Unanswered questions from existing sources

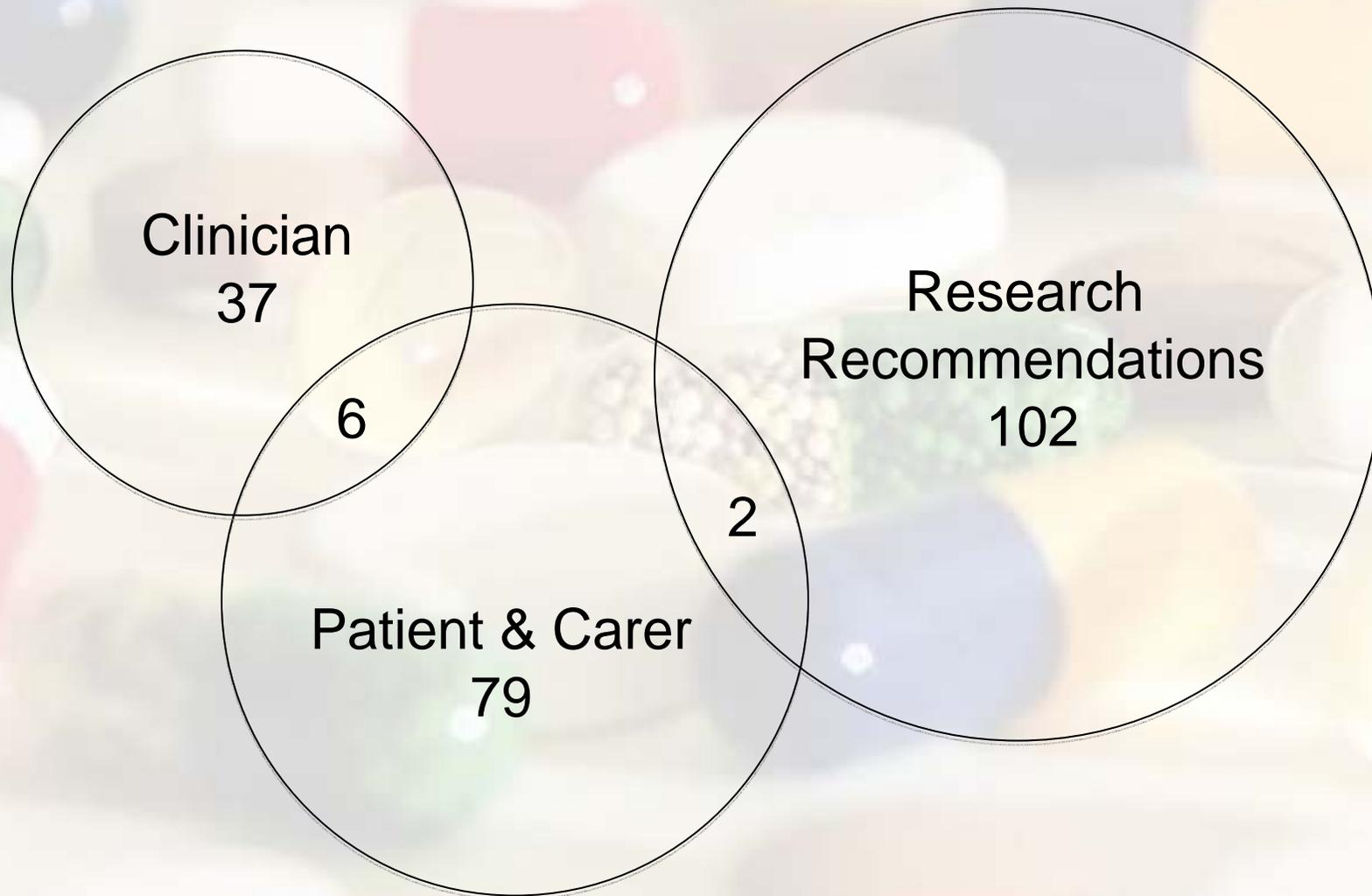
Prioritisation

Dissemination

Consultation and collation of uncertainties



226 questions after refining



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graph TD; A[Initiation] --> B[Consultation]; B --> C[Collation]; C --> D[Prioritisation]; D --> E[Dissemination]; D --- D1[Phase 1: participating organisation consultation]; D --- D2[Phase 2: consensus meeting];
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Initiation

Consultation

Collation

Prioritisation

Phase 1: participating organisation
consultation

Phase 2: consensus meeting

Dissemination

Prioritisation Phase 2 consensus meeting



Top ten topics

- 1. Optimal pelvic floor muscle training regimens?**
- 2. Guidance and training for GPs in UI management?**
- 3. Treatment of mixed stress & urge incontinence**
- 4. Optimal management regimens for neurogenic bladder dysfunction?**
- 5. Treatment of mixed frequency & urgency**
- 6. Usefulness of urodynamic testing in informing treatment decisions?**
- 7. Optimal treatment SUI following failed tape surgery?**
- 8. Optimal treatment/s for daytime UI in children?**
- 9. Disposable versus reusable catheters for intermittent use?**
- 10. Concurrent or sequential surgery for prolapse and SUI?**

Initiation



Consultation



Collation



Prioritisation



Dissemination

Schedule of prioritised Qs to funders

Published Neurourology & Urodynamics

How to assess impact?

Funders – application process is confidential

Research register databases – time delay

Peer consultation – selective and limited

Cochrane Incontinence Group

	Research development	Research funded	New (N) or updated (U) review	In HTA process
Pelvic floor training	✓		U	✓
GP training or guidance				
Mixed stress & urge UI	✓	✓	N	✓
Neurogenic bladder management		✓		✓
Mixed frequency & urgency				
Effectiveness of urodynamics		✓		
Failed tape surgery			N	
Daytime UI in children		✓✓	N	
Disposable/reusable catheters	✓			✓
Concomitant SUI &			■	

Role of research bodies

Several topics have been accepted into the prioritisation process of national funding body – but a difficult process – danger of specificity of topics being lost

Adopted by academic research groups:

- International Consultation on Incontinence Research Society
- The Pelvic Floor Clinical Studies Group

Role of researchers

- Research groups excluded from PSP - conflicted
- But overlap of clinicians/patient orgs/researchers
- Initially, most research dev by those involved
- But impact has spread outwards
- So excluding research groups from submitting or prioritising topics seems sensible
- But keeping them in touch with the process works
- Peer-reviewed publication provides valuable ref for applications

Role of Cochrane group

The Cochrane Incontinence Group was involved at the start of the PSP and was kept in contact

Several new reviews are under way and at least one is now being updated that cover prioritised topics

Some of this work is definitely in response to PSP

Conclusions

PSP successfully developed and employed methodology

Appears effective in informing research development

Challenges:

- Maintaining impetus / impact
- Should prioritised questions be more specific and carefully constructed?
- How to measure impact?

Thank You

Thanks to all participating organisations and their members.

***The JLA PSP on UI was supported by the Cochrane Collaboration
Prioritisation Fund and by the participating organisations.***

***The James Lind Alliance is funded by the Department of Health and
Medical Research Council***



PRIORITISING AND UPDATING COCHRANE REVIEWS: NHS ENGAGEMENT AWARD

Authors: David Tovey, Toby Lasserson and Rachel Marshall

Agenda



- NHS Engagement Award – “fit for purpose”
 - Rationale
 - Elements of the project
 - Progress to date
 - Proposed outputs

Rationale



- “>2000 reviews “out of date”
- 2 year “one size fits all” approach needs to be re-evaluated
- CRGs have limited resources and so need to have the tolls to decide where to expend their efforts

Elements of the project



Three aims:

1. To identify those reviews that NHS stakeholders regard as the most important to update.
2. To assist CRGs in identifying the reviews in which the meta-analysis' conclusions would be most prone to change if the review was updated"
3. To explore whether selected strategies (including search initiatives) can be centralised in delivering updated reviews that have been identified as a priority topic by CRGs.

Co-applicants with CEU



- Sally Hopewell, (Alex Sutton, Yemisi Takwoingi)
- Tamara Rader, Jessie McGowan, Information specialists, Institute of Population Health, Ottawa
- Cochrane Musculoskeletal Review Group
- Bazian Ltd

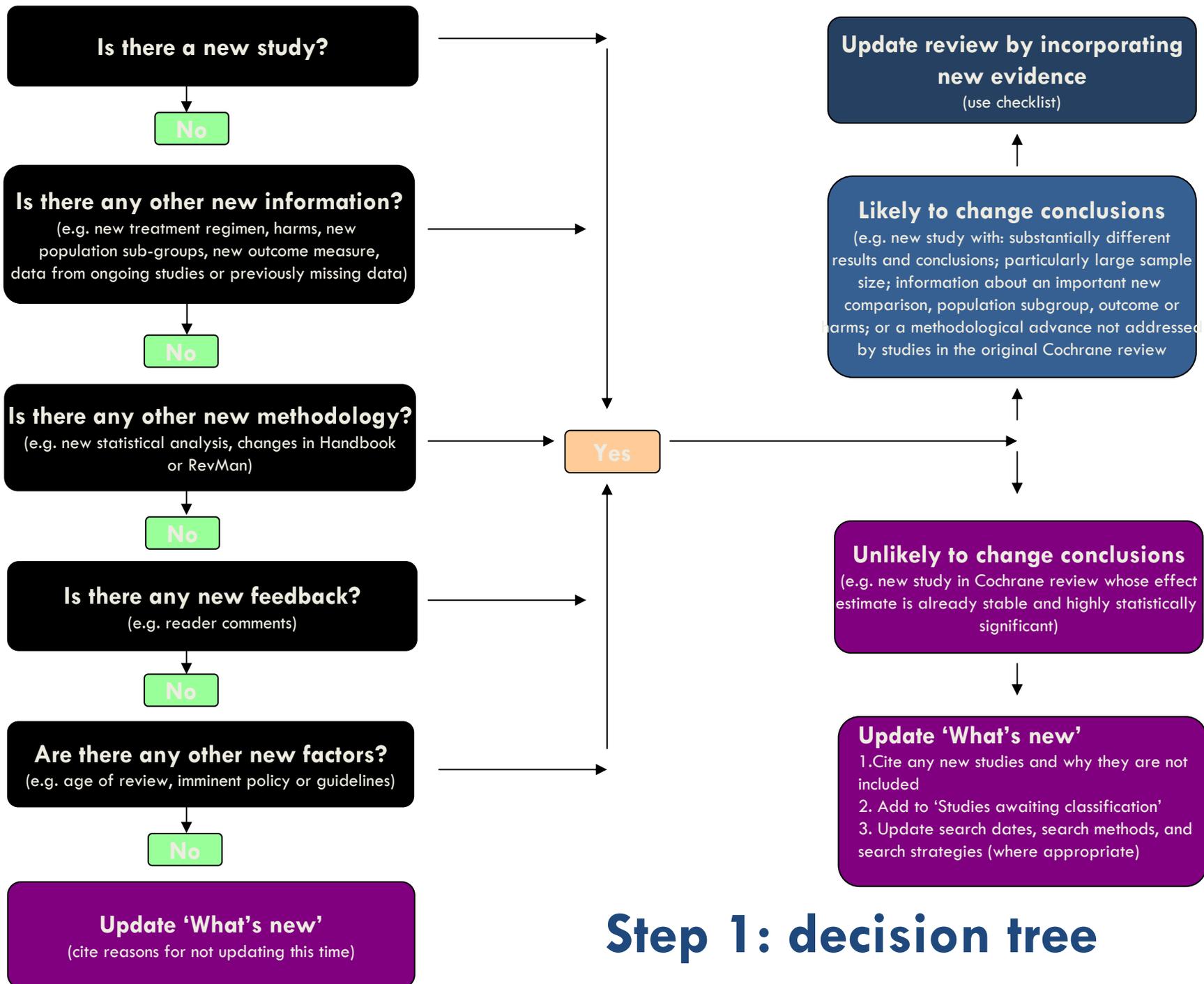
Progress to date: identifying reviews important to the NHS

- Two panel meetings held with NHS representatives; third meeting due to be held December 2010 (meetings held by Bazian, our collaborator in the project).
- Results of the first two panel meetings:

NHS criteria for updating	
1) Strategic importance	5) Emerging evidence
2) Patient importance/ impact	6) Potential clinical impact/disruptive technology
3) National Spend	7) Remaining uncertainty in the review area
4) Burden of disease	8) Health inequality

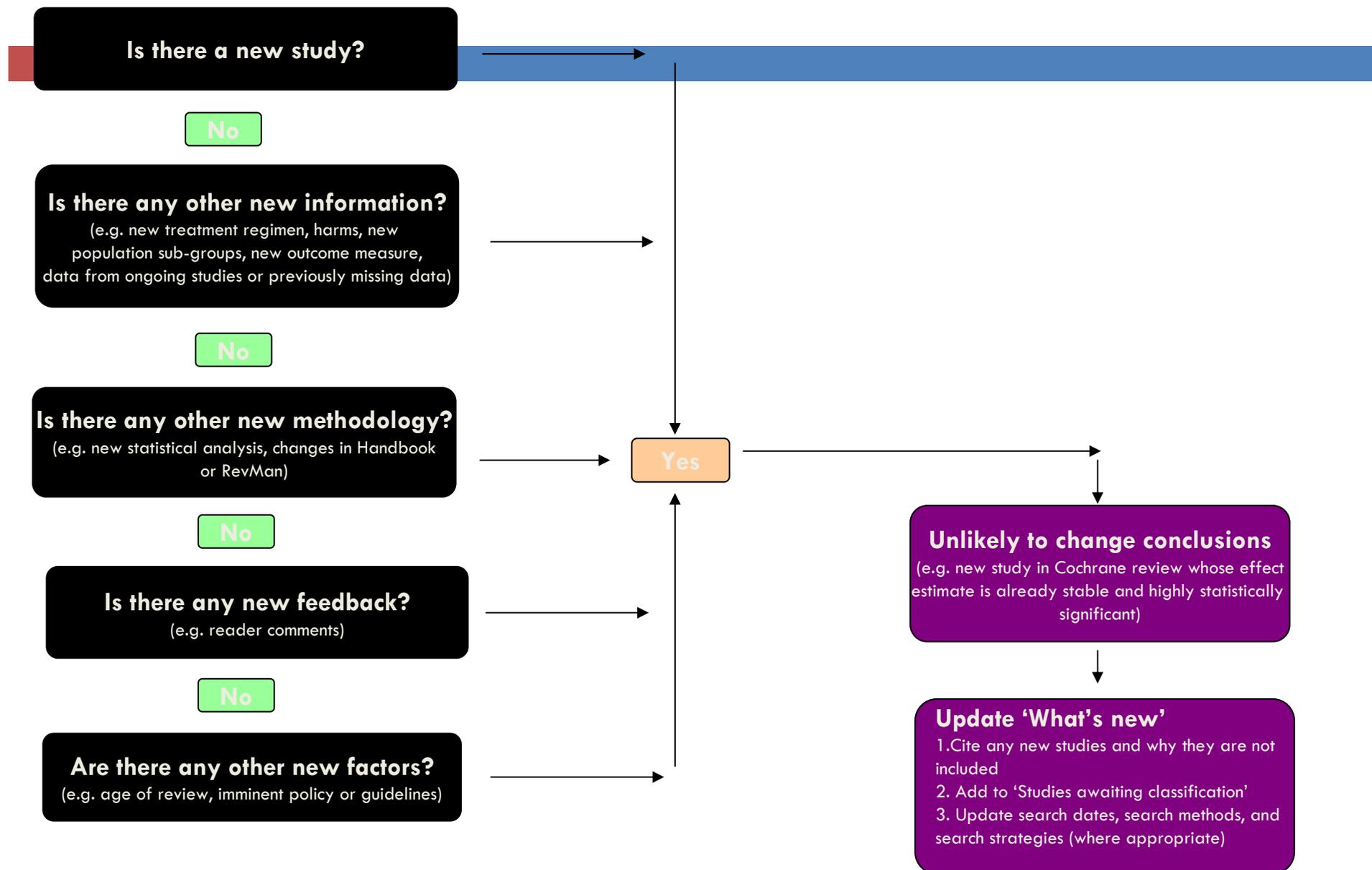
Progress to date: identifying reviews most prone to instability

- Research project aiming to combine elements of the previous “qualitative” updating tool and a quantitative “simulation” model developed by Alex Sutton and colleagues
- Statistical model factors in effect size, number of trials/events to calculate relative risk of instability to calculate the probability that the meta-analysis’ conclusions would change if the review was updated
- Proposed outputs:
 - ▣ Ranking of reviews in order of instability
 - ▣ Identify the likely number of participants/events that would be needed to change conclusions

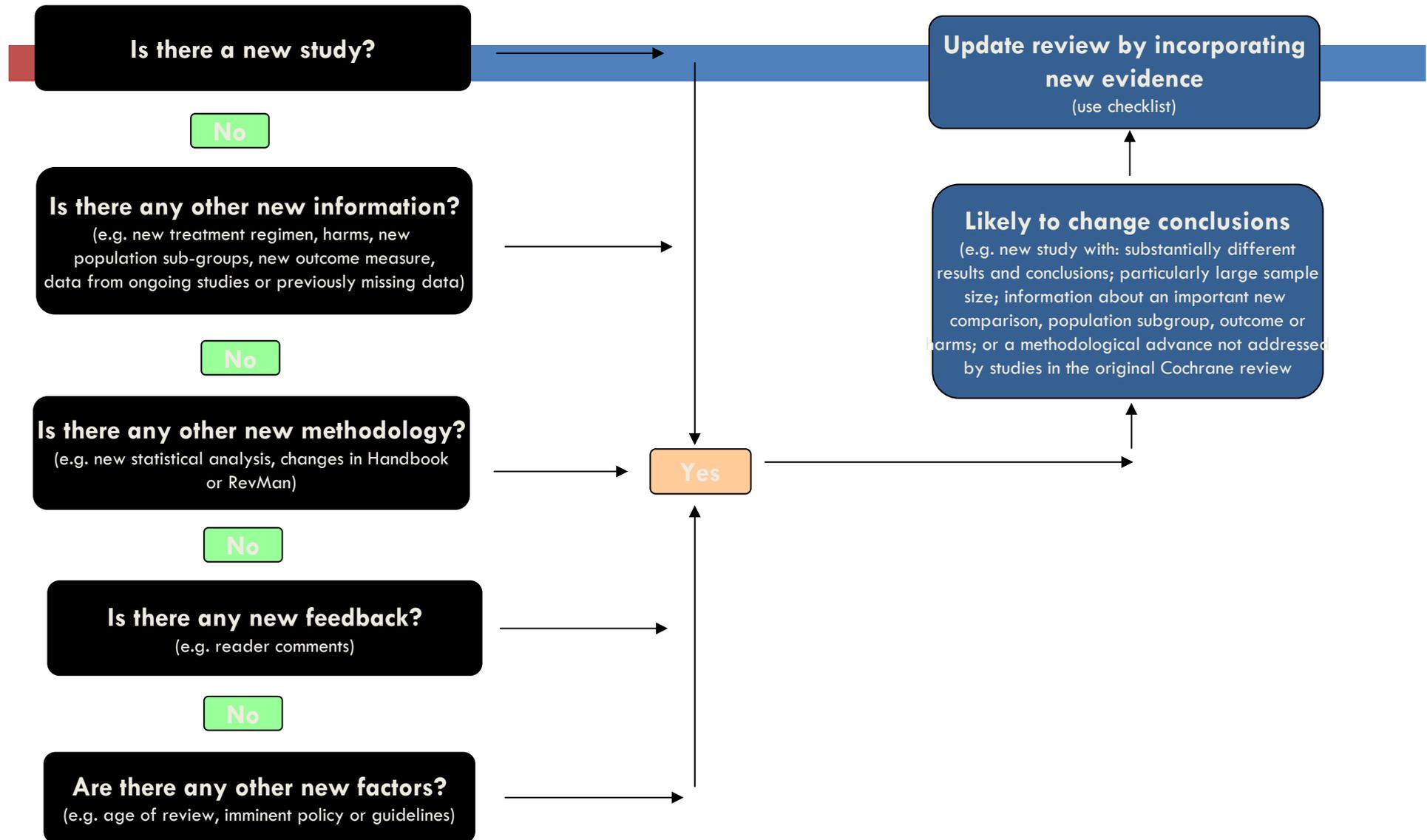


Step 1: decision tree

Trigger *unlikely* to change conclusions



Trigger *likely* to change conclusions



Strategic issues: prioritising updates

Current Categories

- Default (active)
- Stable
- Withdrawn

Straw man?

- Current
- Not being updated
- Retracted

Strawman continued

Category	Explanation / sub-category	Free text allowed
Current	Up to date	
	Update pending - low risk of instability	
	Update pending - high risk of instability	New research team sought*
No longer being updated	Stable	
	Low priority	
	Historical interest only	
	Superseded [link]	
Retracted	[Used for scientific misconduct]	

How might prioritisation work: stakeholders' perspectives



- How important is the question?
 - ▣ Condition – health impact, topical, urgency, inequalities, spend
 - ▣ Intervention – cost, uncertainties, potential benefit, new evidence

How might prioritisation work: CRGs' perspectives

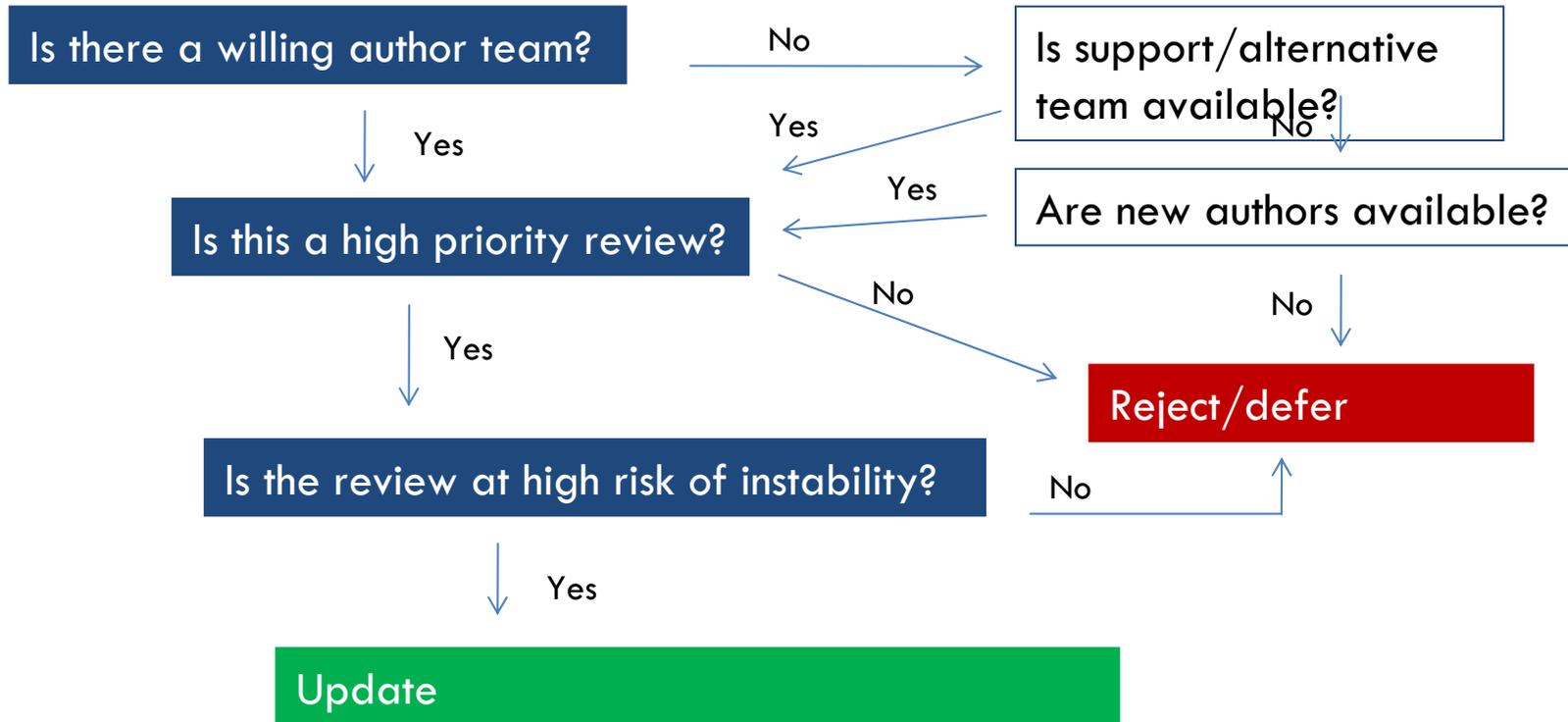


Is there a willing author team?

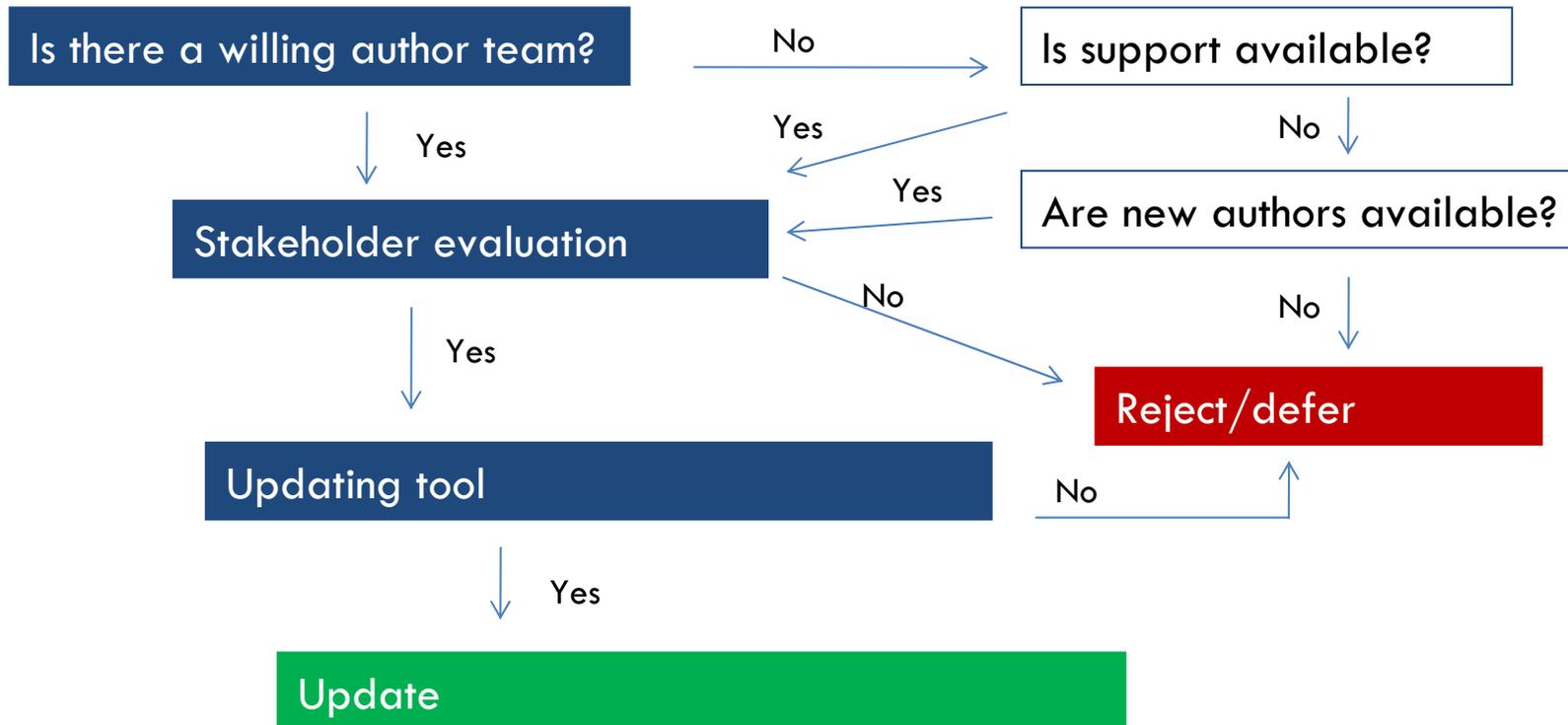
Is this a high priority review?

How likely is the review to be unstable?

How might prioritisation work: CRGs' perspectives



How might prioritisation work: CRGs' perspectives



Summary



- Very early days in this project
- End-point will be a report to the CC in 12 months describing options
- Stakeholder engagement important: this is one model
- Any feedback/ideas at this stage?

Discussion points



- Are we thinking along the right lines?

- How can we move forward?
 - ▣ Working group on labels

- Is it reasonable to set targets for updating?