



**‘The challenges of
engagement’
Engaging with patients,
patients and priority
setting**

Thursday 21st March
Sally Crowe and Mona Nasser
Cochrane Agenda & Priority Setting
Methods Group

What is a Master Class?



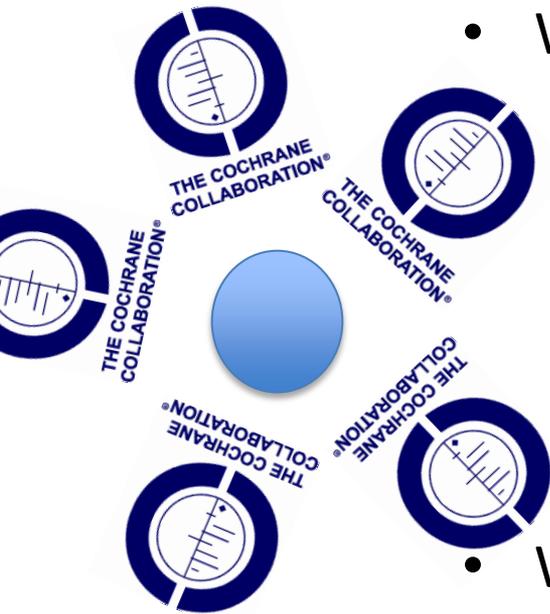
The difference between a normal class and a master class is typically the setup. In a master class, all the students (and often spectators) watch and listen as the master takes one student at a time. **The student** (typically intermediate or advanced, depending on the status of the master) **usually performs a single piece which they have prepared, and the master will give them advice on how to play it**, often including anecdotes about the composer, demonstrations of how to play certain passages, and admonitions of common technical errors. **The student is then usually expected to play the piece again**, in light of the master's comments, and the student may be asked to play a passage repeatedly to attain perfection.



website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

What are we doing today?



- What we are doing? Presentations around
 - To consider and discuss strategic approaches/models to priority setting that engages patients
 - To assess different examples of priority setting and assess the levels of patient engagement
- What are you doing?
 - Working through the hands out on reflecting how our evaluation categories apply to the four case studies that we present. Makes notes about the case studies so that you remember them

website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

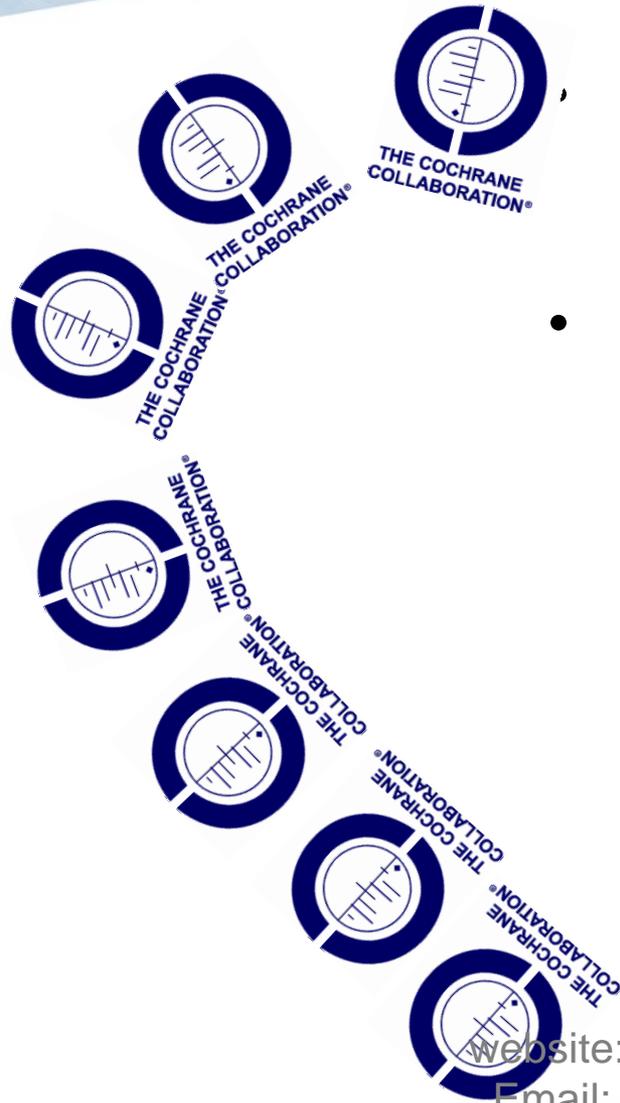
What is Research Priority Setting

a collective activity for deciding which uncertainties are most worth trying to resolve through research.

- uncertainties considered may be problems to be understood or solutions to be developed or tested; across broad or narrow areas (Sandy Oliver)

Website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk



Decision Making & Bias

- As a decision making tool
 - To make more transparent and accountable approaches to manage the research portfolio and Developing systematic approaches to engage with stakeholders or use data to inform the processes
- To lead to better Research
 - Managing Biased/Skewed Research Agenda
 - Lots of studies on drug-placebo and limited studies on drug-common therapy also applies here, Lack of research on important clinical questions with everyday implications (which affects 80% of the dental research literature), Duplication of research in one area and lack of research in another area



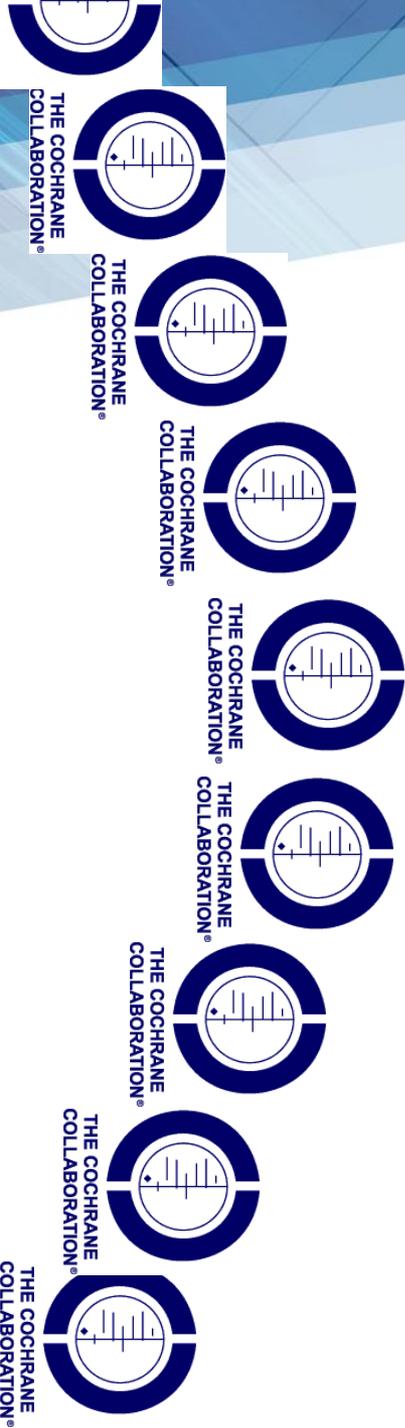
Case study 1 Data Driven Approach

Burden of Disease Approach:

- Measuring burden of Disease for example DALYs (disability adjusted life years), QALYs (quality adjusted life years), HEALYs (healthy life years), DALE (disability adjusted life expectancy)
- Analysing risk factors
- Comparing our current knowledge on managing these conditions with the risk factor assessment
- Cost effectiveness analysis

website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk





Case study 2 Stakeholder engagement with quantitative ranking

Child Health Priorities

- Setting up the objective conceptual framework on which the project is set up.
- Forming an expert task force that defines common definitions, context, timeline and broad domain of health research and then the health research priorities
- All experts rank the studies based on criteria that are derive from the conceptual framework
- Summary scores of the priorities
- Program Budgeting and marginal analysis

website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

Case study 3 Organizational structure to support a Research Priority Setting Exercise

PenCLAHRC

- Locality Leads, PenPIG and capacity building workshops
- Online collection question using a web-based question formulation tool
- Stage 1 - executive group prioritisation – 6 locality leads and 7 theme leads prioritising the topics based on transparent criteria
- Evidence synthesis team provides a briefing
- Stage 2 – large stakeholder group meeting with discussions and then voting (three votes 1 point, two votes 2 point)
- Unclear questions/Insufficient information goes back to the preparation team and prioritised in the next session

website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

Mona



website: <http://capsmg.cochrane.org>
Email: mona.nasser@pcmd.ac.uk



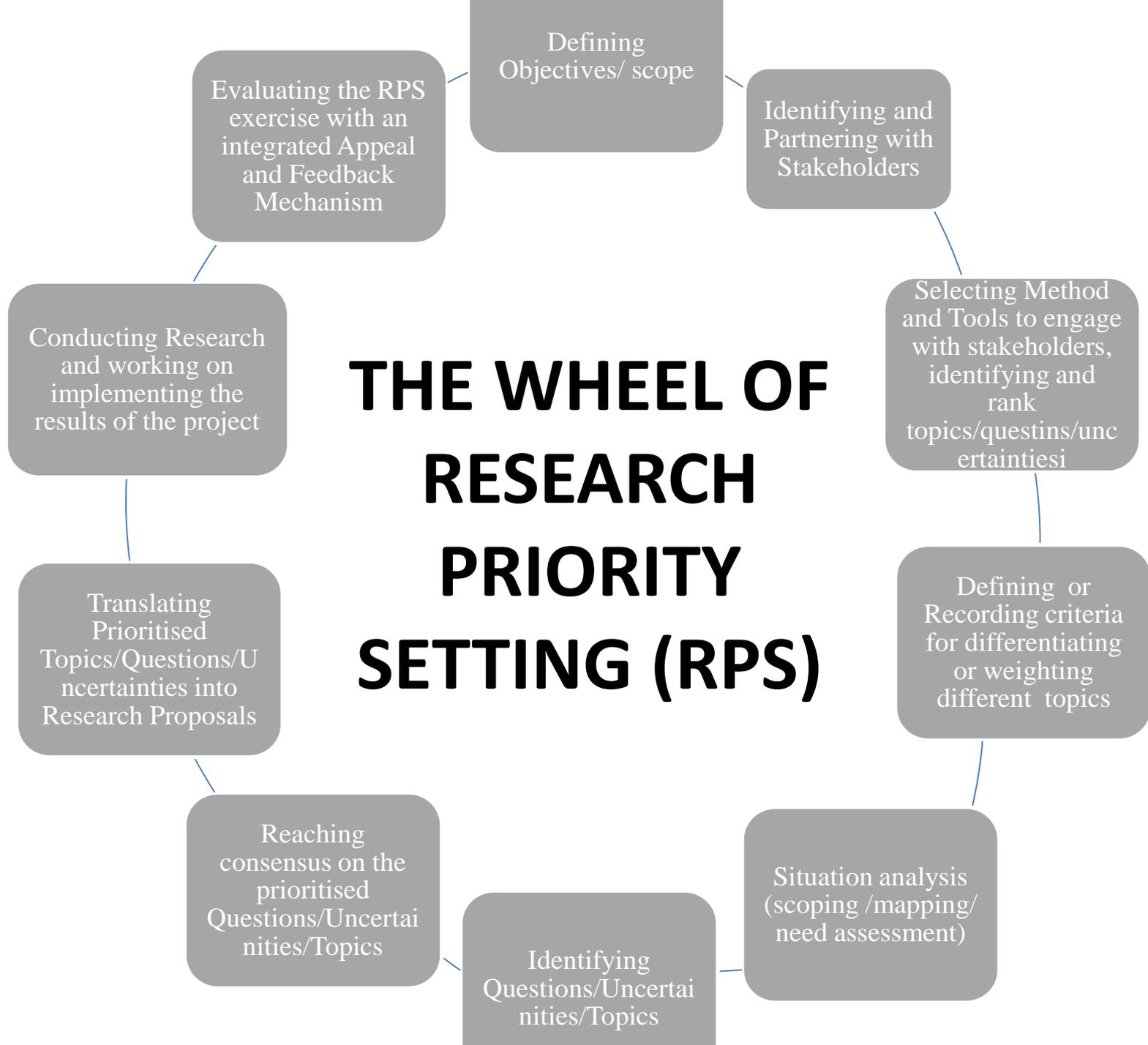
Discussion Question

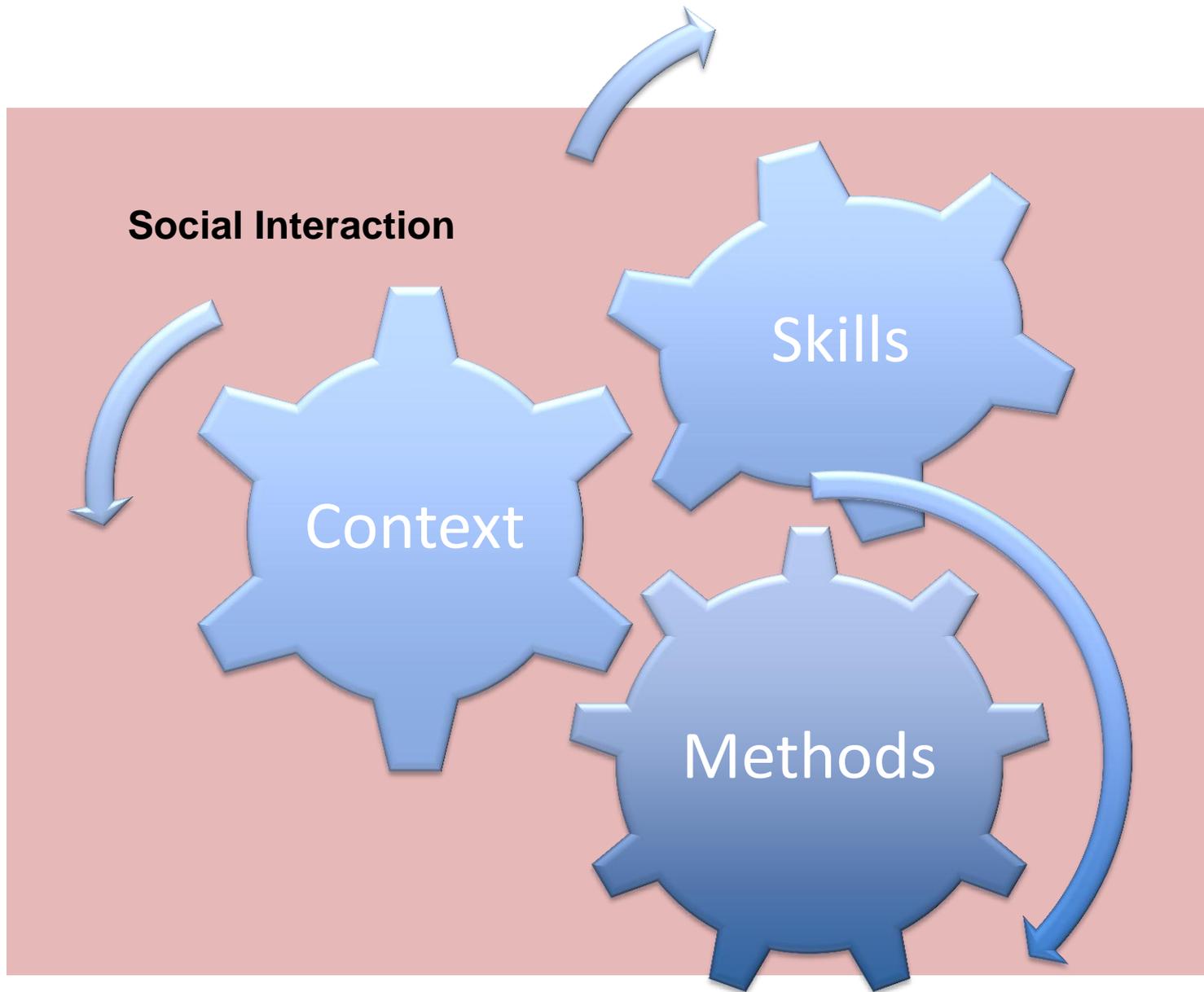
How can groups in the collaboration build on existing partnerships that have already been established?

website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

THE WHEEL OF RESEARCH PRIORITY SETTING (RPS)





website: <http://capsmg.cochrane.org>
Email: mona.nasser@pcmd.ac.uk

Before Starting a Priority Setting Exercise

Defining the scope/level of RPS

Setting up systems to collect the required data to inform the RPS exercise

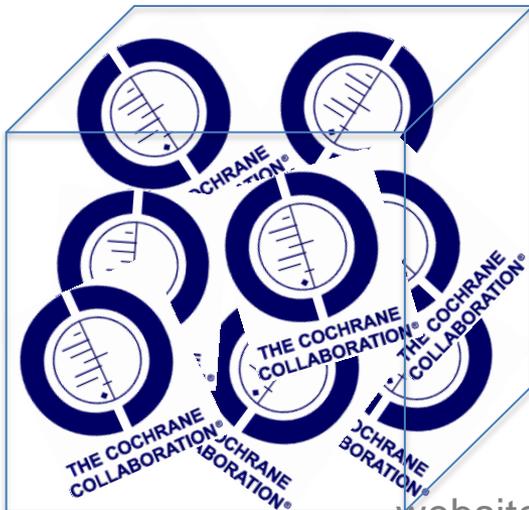
Building the group to establish partnerships with stakeholders

Capacity Building

Clarity and transparency of the objectives

Available Resources and timeline

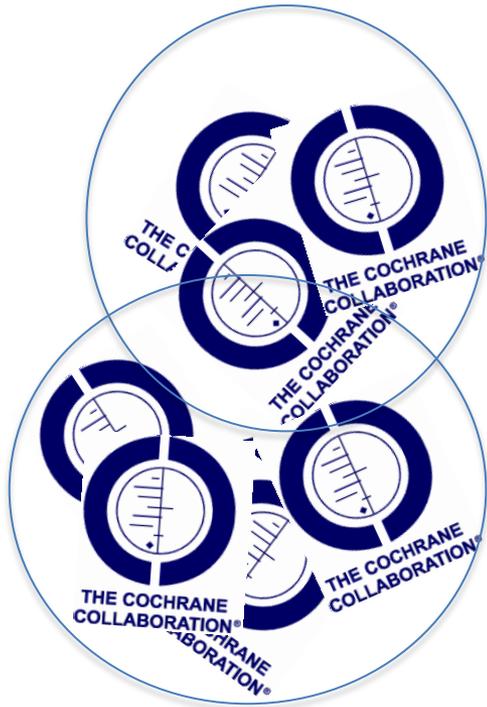
Conceptualizing research question/topic



website: <http://capsmg.cochrane.org>

Email: mona.nasser@pcmd.ac.uk

Categorization of Research Priority Setting Exercises



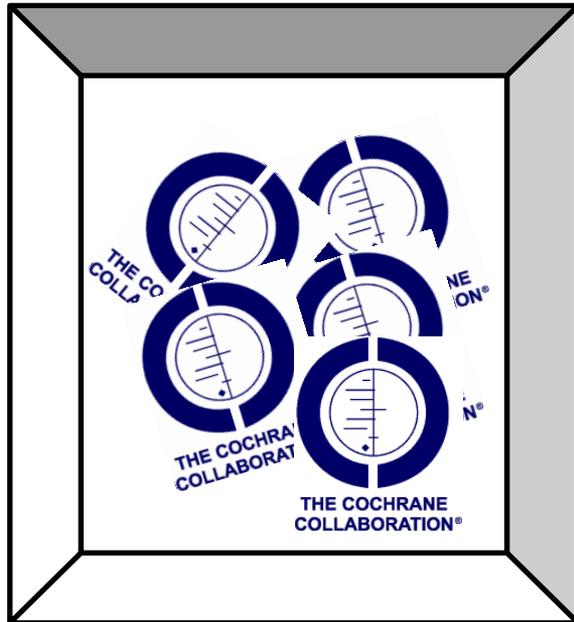
(a) technical assessment (b) interpretive assessment

(a) identifying research topics (b) ranking research topics

(a) Retrospective/gap finding approach (b) foresighting and visionary approach

(a) Quantitative ranking (c) Building consensus

Frameworks to evaluate Research Priority setting Exercises



Accountability of Reasonableness: Relevance, Publicity, Appeals, Enforcement (Martin 2003)

Sibbald's 2009 framework for successful health priority setting exercises (process elements): Stakeholder Engagement, Use of explicit process, Informational management, consideration of values and context, revision or appeal mechanisms.

Good Practice in Research Priority Setting

Preparatory work

- Context
- Use of comprehensive approach
- Inclusiveness
- Information gathering
- Planning for implementation

Decision on priorities

- Criteria
- Methods for decision on priorities

After prioritisation

- Evaluation
- Transparency

References

- Nasser M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews. *J Clin Epidemiol*. 2012 Apr 19
- Lomas J, Fulop N, Gagnon D, Allen P. On being a good listener: setting priorities for applied health services research. *Milbank Q*. 2003;81(3):363-88. Review.
- Montorzi G, de Haan S, IJsselmuiden C. Priority Setting for Research for Health: a management process for countries. . ISBN 92-9226-039-1<tel:92-9226-039-1>; Council on Health Research for Development (COHRED); 2010.
- Viergever RF, Olifson S, Ghaffar A, Terry RF. A checklist for health research priority setting: nine common themes of good practice. *Health Res Policy Syst*. 2010 Dec 15;8:36.
- Nasser M, Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *J Clin Epidemiol*. 2013 Mar 8.
- Nasser M, Welch V, Ueffing E, Crowe S, Oliver S, Carlo R. Evidence in agenda setting: new directions for the Cochrane Collaboration. *J Clin Epidemiol*. 2013 Jan 8.
- Whear R, Thompson-Coon J, Boddy K, Papworth H, Frier J, Stein K. Establishing local priorities for a health research agenda. *Health Expect*. 2012 Dec 6. doi: 10.1111/hex.12029. [Epub ahead of print] PubMed PMID: 23216859.

Sally Crowe
Sandy Oliver
David Moles
Vivian Welch
Erin Ueffing
Alessandro Liberati
Iain Chalmers
Peter Tugwell
Brian Buckley
Ian Shemilt

Reshma Carlo
Gabriela Montorzi
Ken Stein
Peter Sawicki
Mike Clarke
Kalipso Chalkidou
David Moles
Liz Kay
Edward Wilson
Janneke Elberse
Jodie Doyle

Rebecca Armstrong
Roberto D'Amico
Kalipso Chalkidou
David Tovey
Harriet MacLouse
Rachel Marshall
Pam Carter

website: <http://capsmg.cochrane.org>
Email: mona.nasser@pcmd.ac.uk

