Cochrane

Embedding consumer involvement - how do we get the evidence we need?

21st EbM-Kongress
13th – 15th February 2020

Trusted evidence.
Informed decisions.
Better health.

Cochrane

Conflicts of interest

I have no actual or potential conflict of interest in relation to this presentation

Cochrane

“Welcome to the revolution”

Cochrane

Embedding consumer involvement in research

1. The language of involvement and engagement
2. Why does involvement matter?
3. Involvement in research priority setting – the James Lind Alliance
4. Involvement in Cochrane
5. Consumer involvement in Cochrane “all talk and no action”?
6. The ACTIVE Framework for stakeholder involvement in evidence synthesis
7. Where next for involvement in Cochrane?
8. Things you can do today

Cochrane

[What's in a name? Patients, people and the power of words](#) – Evidently Cochrane

Language of Cochrane…

- Cochrane uses the term “consumers” (patients, carers and the public)
- Involvement as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (NIHR Involve)
- Engagement which might include raising awareness of research, sharing knowledge or creating a dialogue with the public about health.

Cochrane

Why is consumer involvement important?

- results in evidence that addresses consumers' needs, reduces waste in research, improves the translation of research into policy and practice, and ultimately leads to improved benefits for health systems and outcomes for patients;
- promotes transparency, accountability and trust in the way that research is produced;
- is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers.

Statement of principles for consumer involvement in Cochrane, 2017.

Stakeholder involvement in research priority setting - James Lind Alliance

Trusted evidence.
Informed decisions.
Better health.

Cochrane

James Lind Alliance

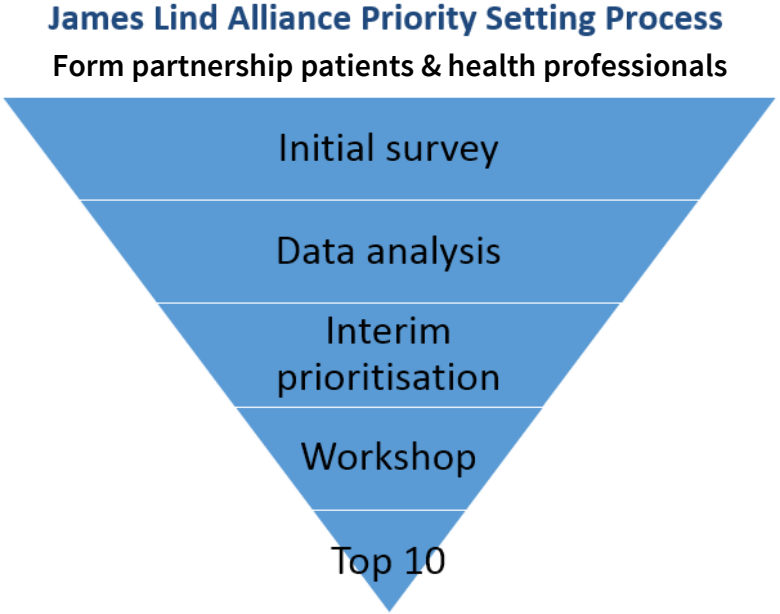
James Lind Alliance

Priority Setting Partnerships

- Established in 2004, now hosted by the UK NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Identifying treatment uncertainties & prioritising the most important for research
- Shared priorities for patients, carers and health care professionals
- Pragmatic process
- Other methods are available!

Cochrane

James Lind Alliance Method



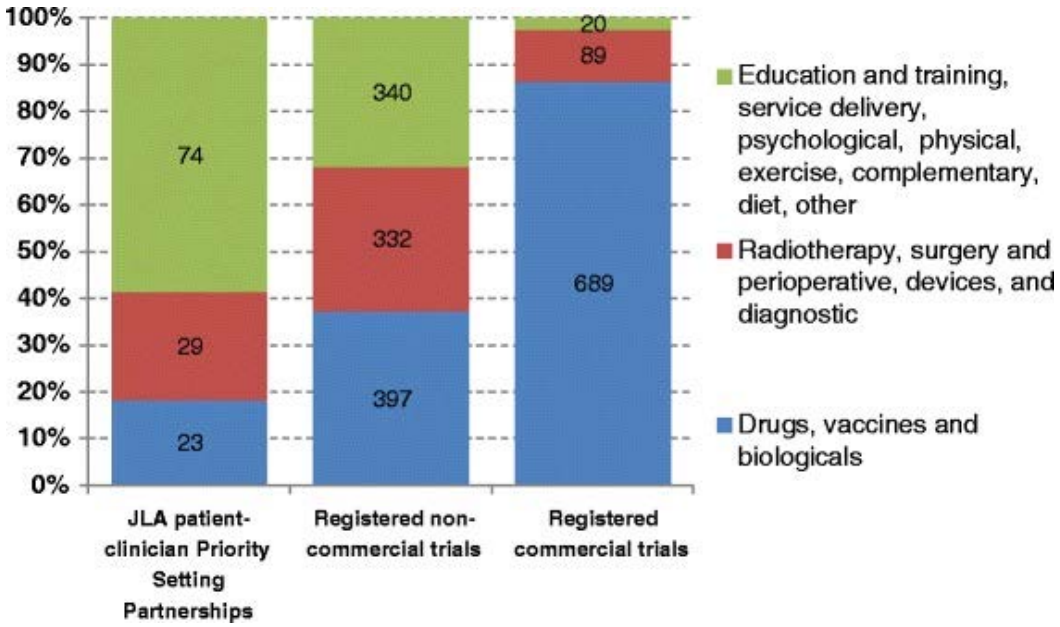
http://www.jla.nihr.ac.uk/

Cochrane

JLA Priority Setting Partnerships

- Over 100 completed or underway
- Topics from Acne to Womb Cancer
- Others have used the JLA method (e.g. Cochrane Tobacco Addiction Group, and Cochrane Communications and Consumer Group)
- Majority UK based, but increasingly more widely (e.g. Canada, Netherlands) and some international in scope

Mismatch between patients', clinicians' and the research communities' priorities



Crowe, S., Fenton, M., Hall, M. *et al.* Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. *Res Involv Engagem* **1,** 2 (2015). https://doi.org/10.1186/s40900-015-0003-x

Impact of the JLA top ten

Changing the research culture

- Canadian Dementia PSP (2017) influenced the Canadian Governments national Dementia Strategy
- Multiple Sclerosis PSP (2013) –changed the MS Society's funding priorities and way it works with partners

Changing funders priorities

- UK NIHR funding streams give higher priority to research questions emerging from PSPs

Changing Cochrane

- Pressure Ulcers PSP (2015) and Neuro-oncology PSP (2017) resulted in a suite of Cochrane systematic reviews to answer priority questions

More than a Top 10 - How James Lind Alliance Priority Setting Partnerships transform research, people and organisations Sally Crowe and Kristina Staley, 2019

Cochrane

Embedding consumer involvement in Cochrane

Trusted evidence.
Informed decisions.
Better health.

Cochrane's Knowledge Translation Strategy

Key audiences consumers and the public

https://community.cochrane.org/review-production/knowledge-translation

Cochrane Consumer Network

- Formed 1994
- 1600+ volunteers across 89 countries
- Patients, carers and the public, + supporters
- Led by its own members
- 50% UK
- 75% English speaking, developed world

Consumers in governance

Rachel Plachcinski and Helen Bulbeck sit on Cochrane's governing Council

https://community.cochrane.org/organizational-info/people/cochrane-council

Cochrane

Involvement in evidence production

Cochrane policy to involve consumers throughout organisation and all review stages

- ✓ Consumer invovement at Review Group level
- ✓ Consumer peer reviewers
- ✓ Writing/editing plain language summaries
- ✓ Language translation

In reality, varied activities, levels of engagement and experiences for consumers across Cochrane. Ground-breaking in 1993 but lagging behind best practice by mid-2010s – hence ACTIVE project

Cochrane

Knowledge Translation

Cochrane

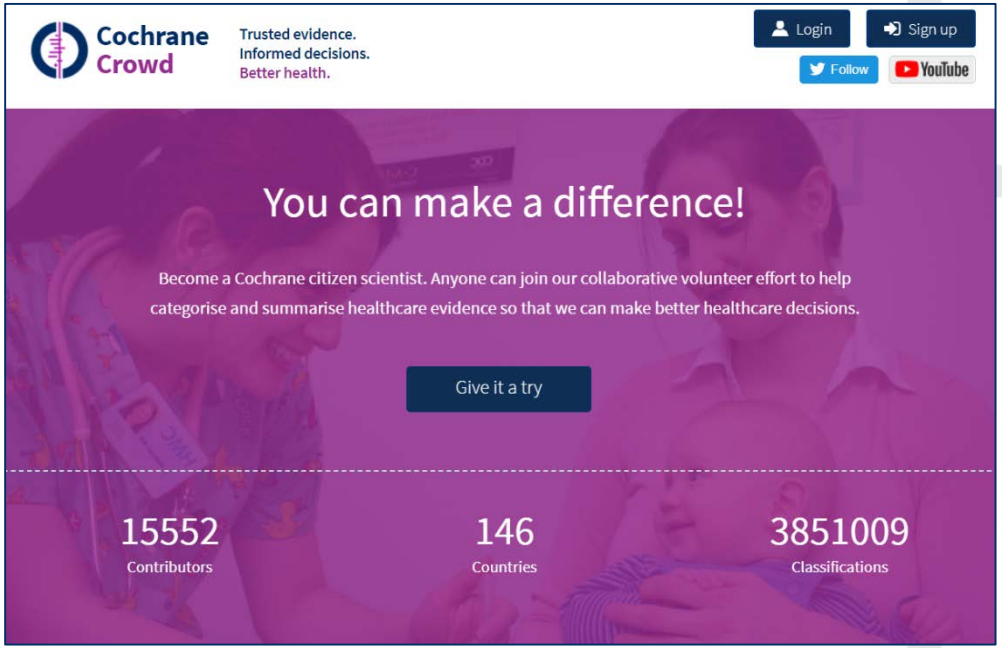
Patients Included conferences

Patients Included

Patients Included is a Trademark of the REshape & Innovation Center

Cochrane

Cochrane Crowd



https://crowd.cochrane.org/index.html

Cochrane

Consumer involvement in Cochrane – “all talk and no action”?

2 studies that addressed consumer involvement in Cochrane protocols and reviews

(i) First assessed extent of consumer involvement in the development of Cochrane intervention protocols and reviews during a 12 month period leading up to February 2017. Found only 9.8% protocols and 14.8% of full reviews reported any consumer involvement.

(ii) Second study found 17% reviews in 12 months leading up to February 2018 involved consumers. In 44% of these reviews, the roles of the consumers were specified as authors, referees, and editors, but in remaining reviews, it was typically unclear to what extent, and at what stage of the review process the consumers were involved

(Flodgren GM, Bidonde J 2017, 2018 Cochrane Colloquium abstracts)

Cochrane

Involvement in review production
Project ACTIVE

Authors and **C**onsumers **T**ogether **I**mpacting on e**V**idenc**E.**

- ACTIVE brought together relevant evidence, information resources, and examples of active involvement in successfully completed reviews and report on these.
- A systematic review to find reports of active involvement in published reviews, looked for any materials or resources which authors involving people in their reviews have developed and used.
- Interviewed people who have been involved - as authors or consumers - in reviews where there was active involvement
- Developed a framework for approaching stakeholder involvement in evidence synthesis

Cochrane

ACTIVE framework

- When was there involvement?
- How much involvement was there?
- Who was involved?
- How were people recruited? (Open or closed)
- Nature of the approach (one time, continuous, combined)
- Methods (Direct Interaction, no direct interaction)

Pollock, A., Campbell, P., Struthers, C. et al. Stakeholder involvement in systematic reviews: a scoping review. Syst Rev 7, 208 (2018). https://doi.org/10.1186/s13643-018-0852-0

Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S., … Morley, R. (2019). Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. Journal of Health Services Research & Policy, 24(4), 245–255. https://doi.org/10.1177/1355819619841647

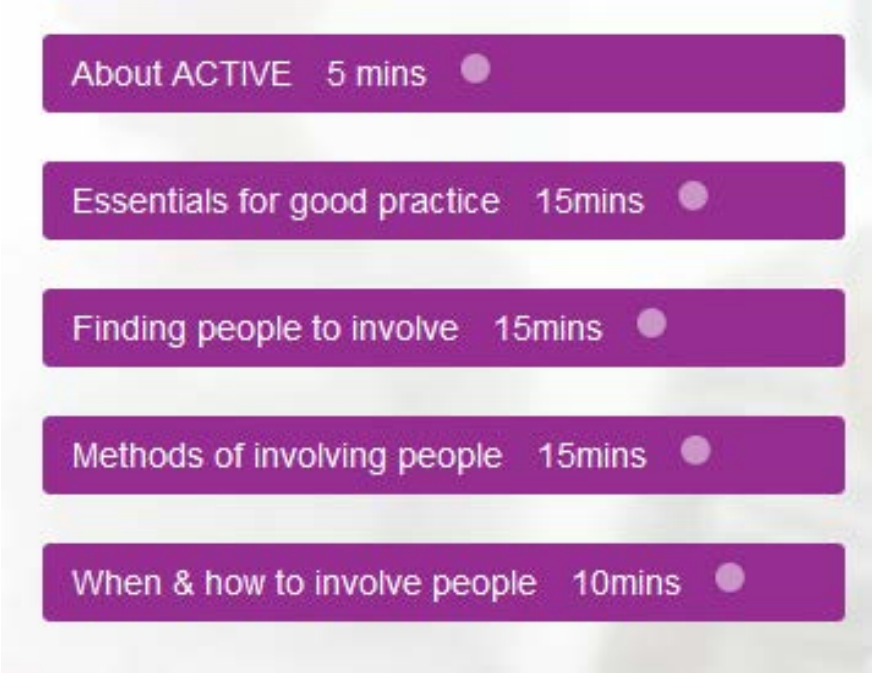
Involving People

Free online learning for systematic review authors who want to involve people in reviews

https://training.cochrane.org/involving-people

Cochrane

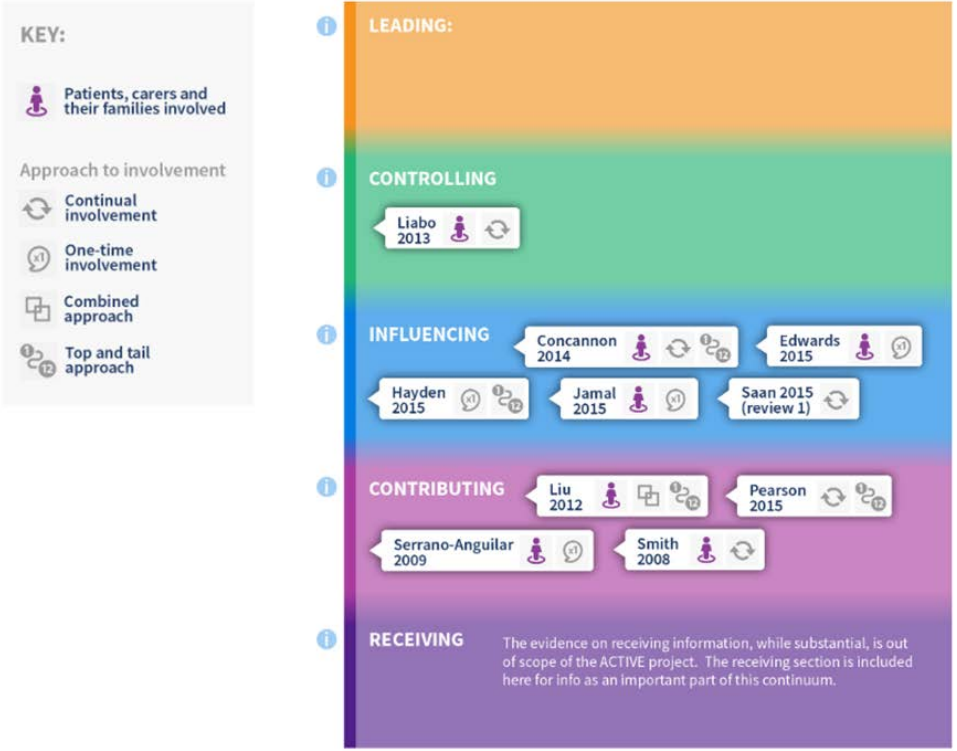
Involving People



Cochrane

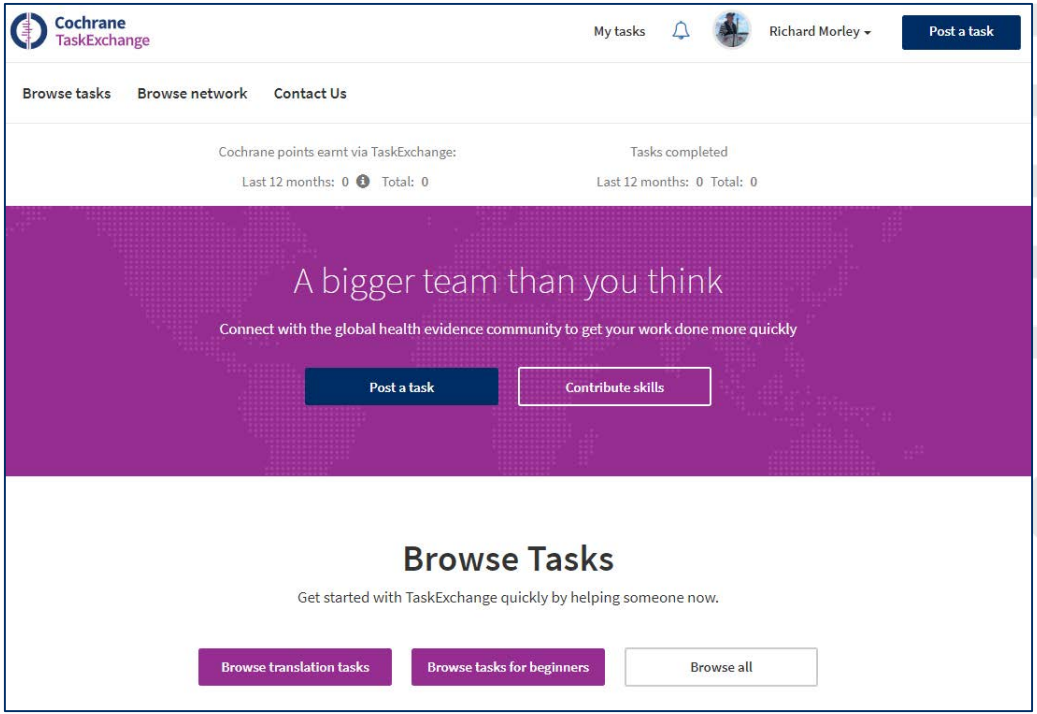
When and how to involve people

Case studies by levels of involvement



Cochrane

TaskExchange



Cochrane

Cochrane Evidence Essentials

Module 1: Evidence-based medicine

Eleni tells us how a healthcare puzzle of her aunt's inspires her to begin to find out about evidence-based medicine. She learns what evidence-based medicine is, why it matters and how evidence and practice are being championed and improved.

30 min Login required

Module 2: Randomized controlled trials

Hearing that her aunt needs medical help increases Eleni's interest in where healthcare evidence comes from. She learns how clinical trials can be controlled and randomized, and what's needed to make sure randomized controlled trials are well run.

45 min Login required

Module 3: Introduction to systematic reviews

Eleni wants to know where the most reliable healthcare evidence can be found and decides to explore systematic reviews. She learns about different kinds of systematic reviews, their advantages and limitations, how they're done and what's in each section of a finished review.

45 min Login required

Module 4: Understanding and using systematic reviews

Eleni visits her aunt, who has a blood clot in her leg as a result of a 13-hour flight. Eleni wants to find out what she can do to avoid developing the same condition herself. She learns how to find a relevant Cochrane Review, understand its results and use it to make a shared decision with a healthcare professional.

45 min Login required

4 free to access modules covering:

1. Introduction to EBM
2. Clinical Trials
3. Systematic Reviews
4. Understanding Cochrane evidence and shared decision making

In English but to be translated from 2020 into Croatian and German

https://training.cochrane.org/essentials

Cochrane

An international network for public involvement and engagement in health and social care research

255 members worldwide

@globalPPINet

https://consumers.cochrane.org/

Cochrane

Where next for Consumer involvement?

1. Build the evidence base: ACTIVE 2 – 1. Best practice for methods of involving stakeholders in systematic reviews 2. Best practice for reporting stakeholder involvement in systematic reviews 3. Impact of involving stakeholders in systematic reviews
2. Review of future of consumer involvement post 2020 – current. Greater support for authors, consumers, KT and involvement infrastructure
3. Monitor and evaluate impact of Cochrane's KT work - developing theories of change

Cochrane

Join the revolution!

1. Sign up for the James Lind Alliance newsletter
2. Join the Cochrane Consumer Network and sign up for Cochrane consumer newsletter
3. Follow Cochrane Consumers @cochraneconsumr and on Facebook
4. Join the International PPI Network
5. Consider this conference becoming a Patients Included event

Cochrane

Thank you!

Richard Morley rmorley@cochrane.org

Twitter @cochraneconsumer @rmengagement

Web: consumers.cochrane.org

Training: training.cochrane.org

Evidence Essentials:https://training.cochrane.org/essentials

International PPI Network @globalPPINet