

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

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

Trusted evidence.
Informed decisions.
Better health.



Conflicts of interest

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



“Welcome to the revolution”



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

Tangled terminology....

Engagement

Consumer Involvement

Service User and Carer Community

Co-Produced Knowledge.
Creating knowledge and impact together



Collaborative Knowledge Production

patient and public involvement ('PPI')

Partnering with Consumers and Carers

consumer and community

public involvement

HEALTHCARE DECISION MAKERS

PARTICIPATORY ACTION RESEARCH

POLICY MAKERS

From Research to Co-creation

KNOWLEDGE TRANSLATION

Collaborating with consumers



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.



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.



James Lind Alliance



**James
Lind
Alliance**

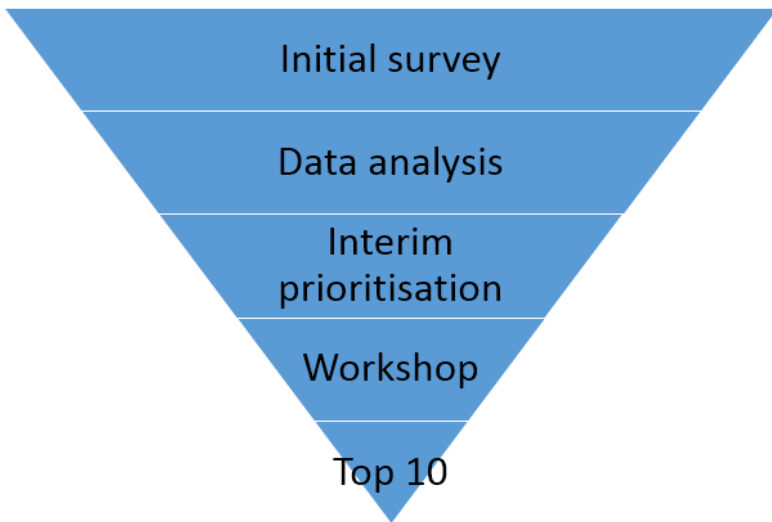
Priority Setting Partnerships

- 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!

James Lind Alliance Method

James Lind Alliance Priority Setting Process

Form partnership patients & health professionals

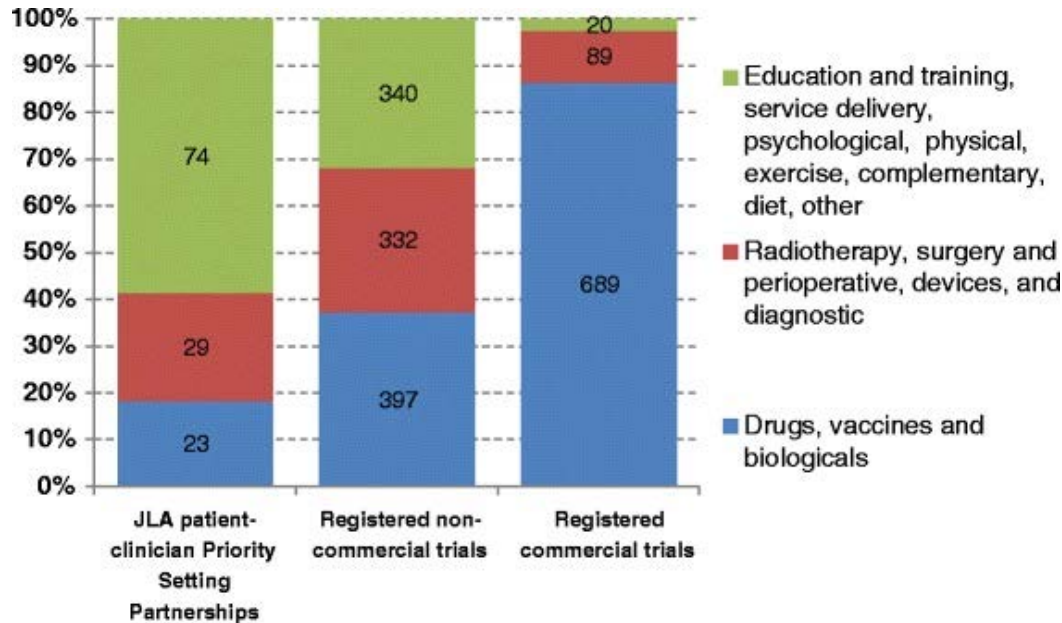


JLA Priority Setting Partnerships

- 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 Government's 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

Embedding consumer involvement in Cochrane

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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>

Involvement in evidence production

Cochrane policy to involve consumers throughout organisation and all review stages

- ✓ Consumer involvement 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

Knowledge Translation



Patients Included conferences



Cochrane Crowd

Our crowd is made up of valued contributors who curate high-quality health evidence.

Volunteers from around the world help us identify the research we need to determine if a treatment or diagnostic test works.



Why join us?
Everyone has a reason.

- I'm keen to be part of a thriving community that's passionate about improving health.
- I want to develop a track record of contributing to a global leader in health evidence.
- I want to make a difference for people with health issues like me.
- I want to develop my research skills and keep up-to-date in my clinical area.

How does it work?
With volunteer power and a crowdsourcing algorithm.

Volunteers screen health research citations and decide whether they should be included in our clinical trials database.


A crowdsourcing algorithm determines how many volunteers need to agree that a citation should be included in the database.

Our team of experts review any citations the crowd can't agree on.



How will it help?
You can make a difference.

More and more health research is published every day. You can help us meet the growing challenge of identifying the research we need to produce high-quality and up-to-date health evidence. And that will lead to better health outcomes for everyone.



Trusted evidence.
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Better health.

Login Sign up

Follow YouTube

You can make a difference!

Become a Cochrane citizen scientist. Anyone can join our collaborative volunteer effort to help categorise and summarise healthcare evidence so that we can make better healthcare decisions.

Give it a try

15552
Contributors

146
Countries

3851009
Classifications

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)

Involvement in review production

Project ACTIVE

Authors and **C**onsumers **T**ogether **I**mpacting on **eV**idence**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

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>

Involving People

About ACTIVE 5 mins ●

Essentials for good practice 15mins ●

Finding people to involve 15mins ●

Methods of involving people 15mins ●

When & how to involve people 10mins ●



When and how to involve people



Case studies by levels of involvement

KEY:

 Patients, carers and their families involved

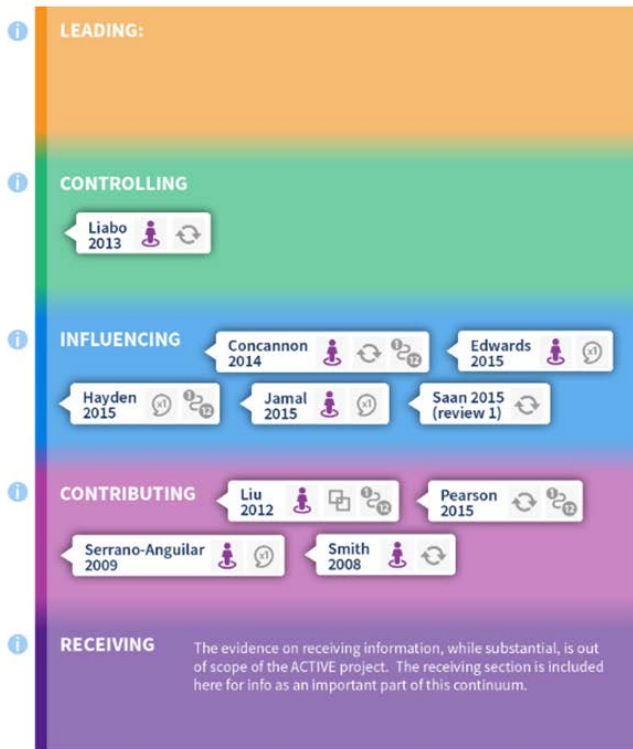
Approach to involvement

 Continual involvement

 One-time involvement

 Combined approach

 Top and tail approach



TaskExchange



Why TaskExchange?

Because it should be easy to help out on a review

1. login to TaskExchange

2. create your profile

3. browse the list of tasks to find the tasks that interest you

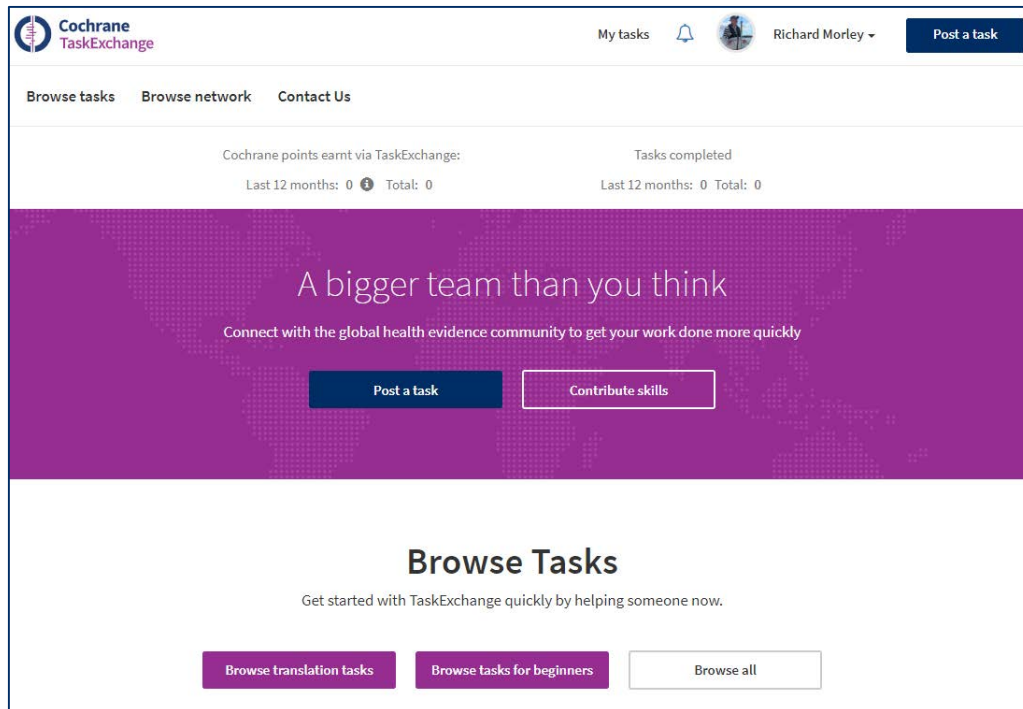
4. see what reward is offered



5. receive notifications when tasks are posted that are relevant for you

6. let TaskExchange connect you with people who need help


7. Success! complete your task and help finish a review

Find out more or give us feedback:
taskexchange.cochrane.org
@task_exchange | taskexchange@cochrane.org



Cochrane TaskExchange My tasks   Richard Morley [Post a task](#)

[Browse tasks](#) [Browse network](#) [Contact Us](#)

Cochrane points earned via TaskExchange: Last 12 months: 0  Total: 0

Tasks completed Last 12 months: 0 Total: 0

A bigger team than you think

Connect with the global health evidence community to get your work done more quickly

[Post a task](#) [Contribute skills](#)

Browse Tasks

Get started with TaskExchange quickly by helping someone now.

[Browse translation tasks](#) [Browse tasks for beginners](#) [Browse all](#)

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>

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



255 members worldwide

@globalPPINet

<https://consumers.cochrane.org/>

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

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**

Thank you!

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Twitter [@cochraneconsumer](https://twitter.com/cochraneconsumer) [@rmengagement](https://twitter.com/rmengagement)

Web: consumers.cochrane.org

Training: training.cochrane.org

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

International PPI Network [@globalPPINet](https://twitter.com/globalPPINet)

