

Welcome!

- 1. Introductions and polls (i) Tell us who you are (ii) What is your experience of involvement?
- 2. Involving people in the work of Cochrane (Richard)
- 3. ACTIVE: Background & key findings (Pauline)
- 4. Developing the e-learning (Chris)
- 5. An introduction to the resource (Pauline)
- 6. Using the resources vignettes (Pauline)
- 7. Discussion
 - How can we disseminate the resources?
 - What else can we do next?
 - Is there anything we can add or do better?
- 8. Question and answer session





Involving people in the work of Cochrane

- Involving people in the work of Cochrane goes back to 1993
- Formation of Cochrane Consumer Network 1995
- Over 1700 consumers (patients, carers and others) currently volunteer to help
- Consumer Structure & Function Review 2015 showed uneven practice across network
- Review Groups, authors & consumers asked for support



"The involvement of consumers is essential."

"Consumers help to inform decisions made around identification and prioritization of patient important topics and outcomes."

"We need to find a way to involve consumers more fully."

"We need to find a way to involve consumers more fully in our activities."



Supporting consumer involvement in Cochrane

- Cochrane Consumer Delivery Plan identifies 8 ways to support consumer involvement in Cochrane, including:
- Statement of Principles for consumer involvement establishes a framework for involvement
- Need to build resources to support authors and review groups

The Statement of Principles for Consumer Involvement in Cochrane

Consumer involvement in Cochrane - the Statement of Principles

The purpose of consumer involvement in Cochrane

Cochrane is a global independent network of researchers, professionals, and people interested in health, including healthcare consumers. Cochrane's healthcare consumers are made up from a wide range of people, including patients (or people with personal experience of a healthcare condition), health and social care service users, caregivers and family members. Also included are people who represent or are advocates for patients and carers. What unites them all is their search for high quality, unbiased information about health conditions and treatments. Consumer involvement is vital to Cochrane's work as it:



- (i) promotes transparency, accountability and trust in the way that research is produced;
- (iii) 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;
- (iii) is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers.





Supporting author teams and Review Groups to involve people

- Online learning resource for systematic review authors
- Aims to support you in getting people involved in the production of your reviews
- Evidence and practical suggestions for finding and involving people throughout the review process
- Useful resources, guidance documents, interviews about first hand experiences, and links to case studies and examples of good practice
- Supported throughout by the evidence base identified through the ACTIVE research project.

Covers:

- Essentials for good practice
- Finding people to involve
- Methods of involving people in systematic reviews
- When and how to involve people:
- Learning from examples
- Comes with practical support

