Involving consumers in Cochrane reviews: learning from the ACTIVE project
Webinar Plan

1. Welcome & introductions
2. Example of involvement
3. ACTIVE project
4. How to describe involvement
Welcome & introductions

Alex Pollock
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Welcome & introductions
Welcome & introductions

1. Who are you?
   • Consumer
   • Author
   • Researcher
   • Other *(please tell us)*

2. Why are you here?
   • I want to involve consumers in my review
   • I want to get involved in a review
   • I’m curious about what you are doing
   • I want to share my experience
   • Other *(please tell us)*
1. Welcome & introductions
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4. How to describe involvement
Example of involvement: Update of a Cochrane review


Conference posters from SRR 2013 and INVOLVE 2014
Example of involvement: Why have involvement?

**AIM:** to engage key stakeholders in an update of a Cochrane systematic review of physiotherapy treatment approaches for patients with stroke, in order to ensure clinical relevance of the completed review.
Example of involvement: What did we do?

1. Planning & Preparation
   - Protocol
   - Ethics approval

2. Form the user-group
   - Identify potential participants
   - Recruit – purposeful sampling

3. Group meetings
   - Specific focussed aim
   - Nominal Group Technique
Example of involvement: How did we get people involved?

2. Form the user-group

- Identify potential participants
- Recruit – purposeful sampling

- Networks of relevant people
- Details of interested people (Fill out a form)
- Purposefully sample (12-14 participants)

- 2-page information leaflet (including meeting dates)
- Circulated by email

- Interested people contact researchers

- Representative group (50% stroke survivors/carers, 50% physios)
Example of involvement: What did we do at meetings?

3. Group meetings

**Specific focussed aim**
- Parameters which can / cannot be changed

**Nominal Group Technique**
- Meeting ‘rules’

Meeting 1: Discuss key issues
- Discussion around issue / statement
- Voting (in silence)

Meeting 2: Agree review methods
- Vote counting

Meeting 3: Agree key messages from results
**Example of involvement:**

**How did the voting work?**

**Statement 1.** The current categories are appropriate and clinically relevant.

<table>
<thead>
<tr>
<th>Total no. responses</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree or disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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<tbody>
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<td>1</td>
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<td>2</td>
</tr>
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<td>8</td>
<td>8</td>
<td>69</td>
<td>15</td>
</tr>
</tbody>
</table>
Example of involvement: What else did we do?

1. Planning & Preparation
   - Protocol
   - Ethics approval

2. Form the user-group
   - Identify potential participants
   - Recruit – purposeful sampling

3. Group meetings
   - Specific focussed aim
   - Nominal Group Technique

4. Other group communication
   - Email
   - Tele-conference
   - Doodle poll

5. Evaluation
   - Group discussion – audio-recorded
   - Questionnaire
“...I have taken part in quite a number of things of this nature over the past 20 years and this is the first time that I have really felt that it has been successful and that I have been listened to...”

(carer of stroke survivor)

“Other Cochrane groups please copy”

(carer of stroke survivor)

“....links clinicians with researchers, allowing research to be more clinically relevant......”

(physiotherapist)
Example of involvement: What do you think?

There is a need for review authors to know more about how to involve people in a meaningful way.

- Strongly agree
- Agree
- Neither agree or disagree
- Disagree
- Strongly disagree
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ACTIVE
Authors & Consumers Together Impacting on eVidencE

Involving patients, carers, health professionals and other key stakeholders in research is considered to be beneficial to the research.

“Consumers” have been part of Cochrane since it started, and their involvement is thought to make systematic reviews of healthcare topics more useful and relevant.

There is still not much known about the best ways to involve people in systematic reviews.

ACTIVE aims to help review authors have meaningful involvement in their systematic reviews.
ACTIVE
Authors & Consumers Together Impacting on eVidencE

Find out different methods of involvement that have been used

Bring together:
* Information
* Materials
* Interviews

about **HOW** to involve people

Make this available online

Find out more: http://training.cochrane.org/ACTIVE
### Who is involved?:

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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</thead>
<tbody>
<tr>
<td>Dr Alex Pollock</td>
<td>NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK</td>
</tr>
<tr>
<td>Dr Pauline Campbell</td>
<td>NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK</td>
</tr>
<tr>
<td>Caroline Struthers</td>
<td>EQUATOR Network, University of Oxford / Consumers’ Executive</td>
</tr>
<tr>
<td>Anneliese Synnot</td>
<td>Centre for Health Communication &amp; Participation, La Trobe University, Melbourne, Australia</td>
</tr>
<tr>
<td>Dr Sophie Hill</td>
<td>Centre for Health Communication &amp; Participation, La Trobe University, Melbourne, Australia</td>
</tr>
<tr>
<td>Jack Nunn</td>
<td>Centre for Health Communication &amp; Participation, La Trobe University, Melbourne, Australia</td>
</tr>
<tr>
<td>Heather Goodare</td>
<td>Lay member, Chair, Edinburgh Health Forum; contributor to Breast Cancer &amp; Stroke Cochrane groups.</td>
</tr>
<tr>
<td>Dr Jacqui Morris</td>
<td>NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK</td>
</tr>
<tr>
<td>Richard Morley</td>
<td>Coordinator, Cochrane Consumer Group</td>
</tr>
<tr>
<td>Chris Watts</td>
<td>Cochrane Learning and Support Department</td>
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Find out more:  [http://training.cochrane.org/ACTIVE](http://training.cochrane.org/ACTIVE)
Tell us:

• About examples of user-involvement
• If you want to contribute to ACTIVE

Email:

ACTIVE@gcu.ac.uk
What kind of resources would you like?

- Real-life examples of involvement in reviews
- Personal stories about involvement
- Practical templates for planning involvement (e.g. meeting agenda, ethics application)
- Guidance on reporting
- Tool to measure impact
- Other

(tick all that apply)
Webinar Plan

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4. How to describe involvement

- **WHO is involved?**
- **WHEN does involvement occur?**
- **HOW much involvement?**
WHO is involved?

Cochrane “Consumer”:

• Difficulty finding a shared definition

• “A healthcare consumer is any actual or potential recipient of health care. Healthcare consumers who use Cochrane evidence are generally patients, carers and family members, or people interested in remaining healthy who are seeking information about a health condition or treatment for personal use.”
WHO is involved?

Public involvement:

- INVOLVE definition:
  - Patients, potential patients, carers
  - People who use health and social care services
  - People from organisations that represent people that use services

- “there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services”.

INVOLVE (2012) Public involvement in systematic reviews: Supplement to the briefing notes for researchers. INVOLVE, Eastleigh
WHO is involved?

Stakeholders:

• “People whose primary job is not directly in research”:
  • Patients, their families and caregivers
  • Individuals representing patient groups
  • Policy makers
  • Clinicians

Camden 2015 Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts, Disability and Rehabilitation, 37:15, 1390-1400, DOI:10.3109/09638288.2014.963705
WHO is involved?

ACTIVE definitions:

**Stakeholder:** *any potential knowledge user whose primary job is not directly in research.*
This includes people who are:

- patients, potential patients, family and carers
- people who use health and social care services
- people from organisations that represent people who use services
- people with a professional role in health and social care
- policy makers and managers

**Consumer:** *any actual or potential recipient of health or social care, their carers and family members*
4. How to describe involvement

WHO is involved?
WHEN does involvement occur?
HOW much involvement?
WHEN does involvement occur?
WHEN does involvement occur?

**Continuous involvement**
- People are involved at all stages of a review
- e.g. as an author, or on an advisory group

**One-time involvement**
- People are involved at one specific stage
- e.g. developing a question, writing a lay summary

**Multiple-time involvement**
- People are involved at two or more specific stages of the review

**Combined involvement**
- A combination of continuous plus one- or multiple-time involvement
4. How to describe involvement

- **WHO is involved?**
- **WHEN does involvement occur?**
- **HOW much involvement?**
  - Continuous involvement
  - One-time involvement
  - Multiple-time involvement
  - Combined involvement

**HOW much involvement?**
HOW much involvement?

More involvement

Less involvement

Color Temperature in Kelvin Scale

UV

Higher Frequency

Lower Frequency

Wavelength (nm)
## HOW involved are they?

<table>
<thead>
<tr>
<th>Term</th>
<th>Type of involvement</th>
<th>Example methods</th>
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<tbody>
<tr>
<td>CONTROL</td>
<td>User-led</td>
<td>User-researchers</td>
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<td></td>
<td>User-control</td>
<td>Review team members</td>
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<tr>
<td>COLLABORATION</td>
<td>Devolved user-control</td>
<td>Consensus methods</td>
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<tr>
<td></td>
<td>Explicit involvement in decision making</td>
<td>Data extraction &amp; analysis</td>
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<td></td>
<td>Involvement in decision making implied</td>
<td>Advisory group members</td>
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<td>CONSULTATION</td>
<td>Workshop</td>
<td>Workshops</td>
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<td>Interviews. Focus groups</td>
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<td></td>
<td>Written</td>
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<tr>
<td>MINIMAL</td>
<td>Participant</td>
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</table>
4. How to describe involvement

- **WHO is involved?**
- **WHEN does involvement occur?**
- **HOW much involvement?**
  - Continuous involvement
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- **More involvement**
- **Less involvement**
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The table represents the level of control and collaboration across different stages of the process. The icons indicate the level of engagement and decision-making.
Can you fill a gap / give an example for any of these stages:

- Develop question, plan methods, write & publish protocol
- Develop search, run search, select studies
- Collect data, analyse data
- Assess risk of bias
- Interpret findings, write & publish review

(tick all that apply)
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YOUR COMMENTS & THOUGHTS?
ANY QUESTIONS?

ACTIVE@gcu.ac.uk