

# Involving consumers in Cochrane reviews: learning from the ACTIVE project

# ACTIVE

Authors & Consumers Together Impacting on eVidenceE

# Webinar Plan

1. Welcome & introductions

2. Example of involvement

3. ACTIVE project

4. How to describe involvement

# Welcome & introductions



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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*)

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# Example of involvement: Update of a Cochrane review



Pollock et al 2014. Physical rehabilitation approaches for the recovery of function and mobility following stroke. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD001920.

Pollock et al 2015. User-involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update. Systematic Reviews 2015; 4(55); published online 20<sup>th</sup> April 2015.

Conference posters from SRR 2013 and INVOLVE 2014



# Example of involvement: **Why have involvement?**



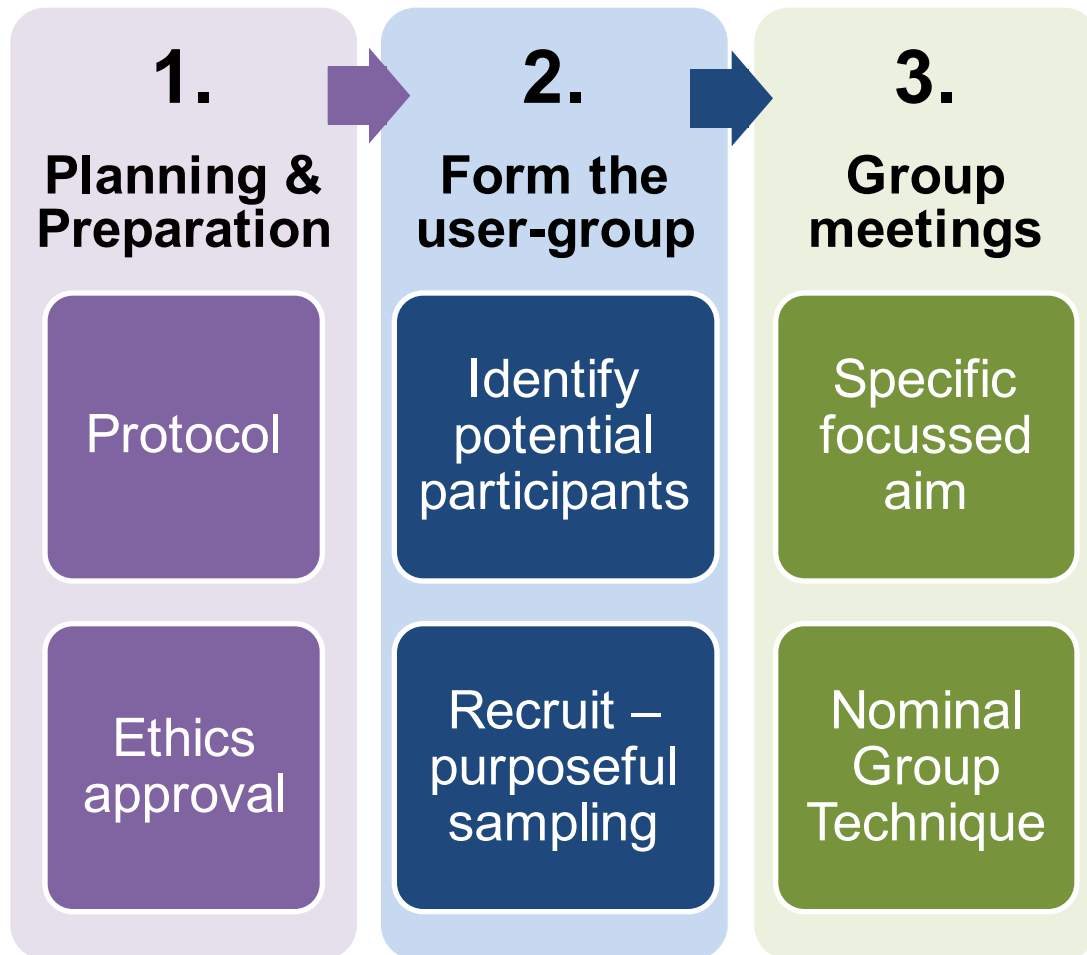
Cochrane review  
update

User-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?



# Example of involvement:

## How did we get people involved?

**2.**

**Form the user-group**

Identify potential participants

Networks of relevant people



2-page information leaflet (including meeting dates)



Circulated by email



Interested people contact researchers

Recruit – purposeful sampling

Details of interested people (Fill out a form)

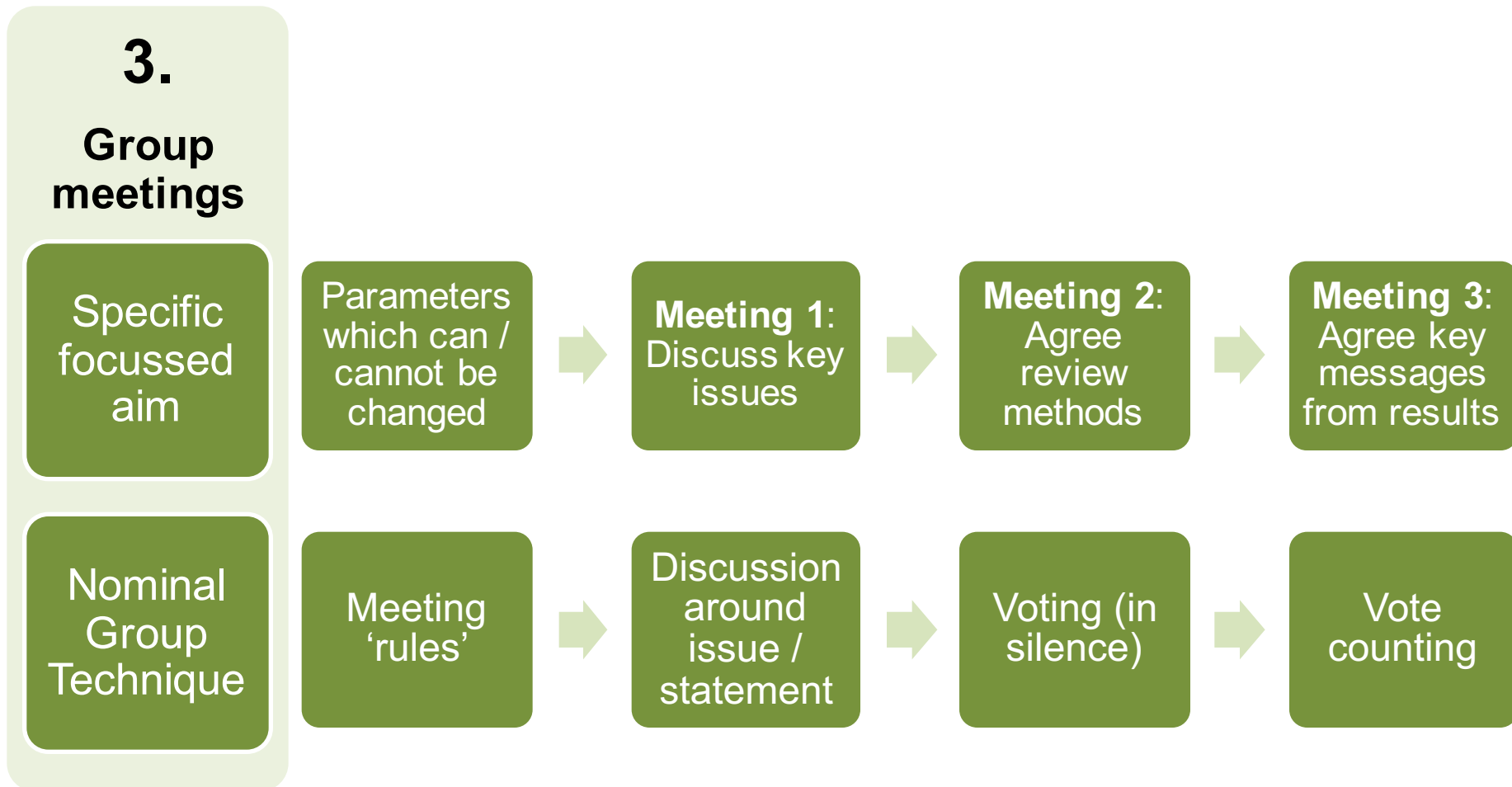


Purposefully sample (12-14 participants)



Representative group (50% stroke survivors/carers 50% physios)

# Example of involvement: What did we do at meetings?

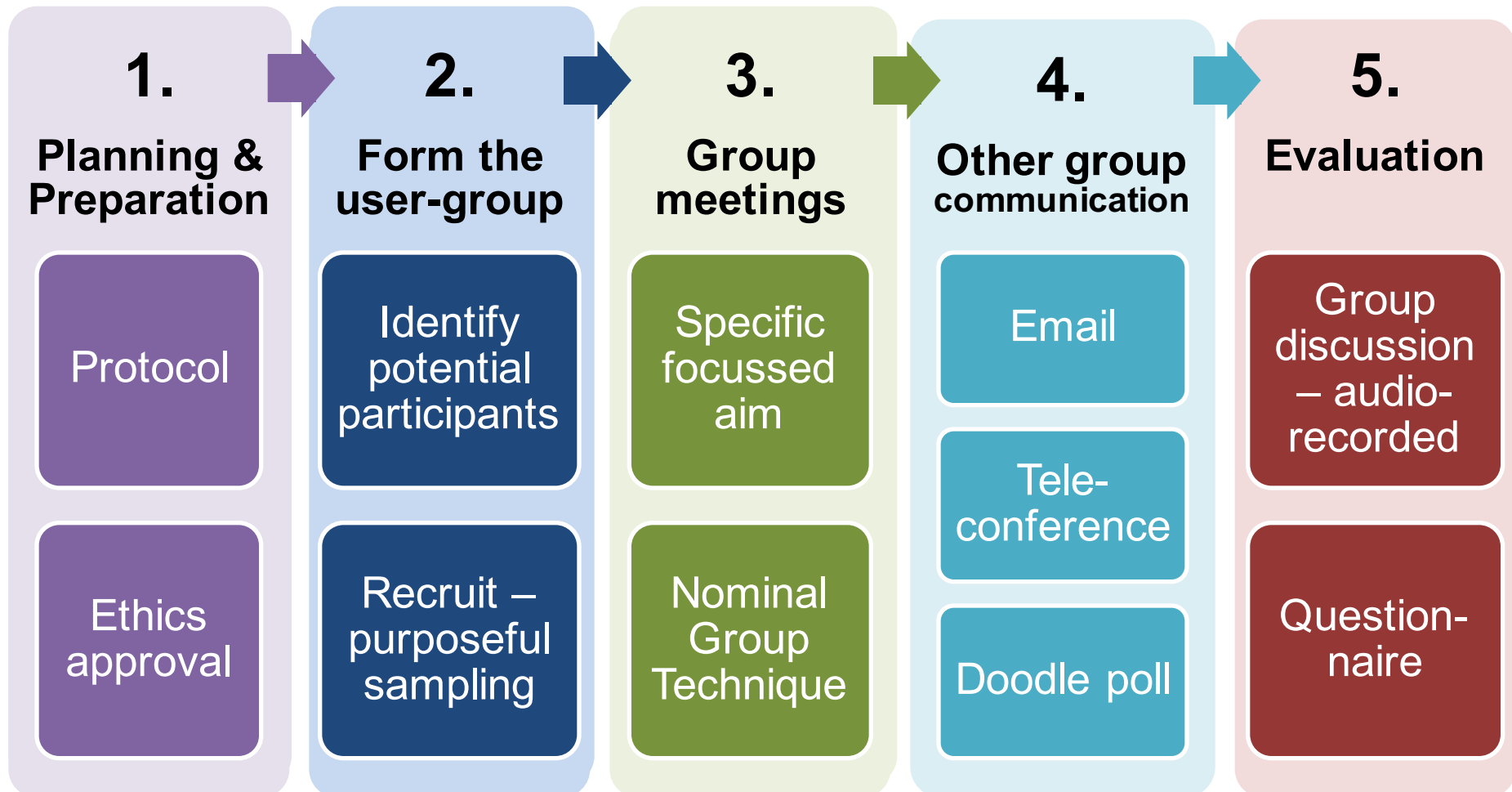


# Example of involvement: How did the voting work?

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

Total no. responses	Strongly agree 1	Agree 2	Neither agree or disagree 3	Disagree 4	Strongly disagree 5
n=13	0	1	1	9	2
%100	0	8	8	69	15

# Example of involvement: What else did we do?



# Example of involvement: How did it go?

*“...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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**nmahp-ru**  
Nursing, Midwifery and Allied Health Professions Research Unit  
CHIEF SCIENTIST OFFICE

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.




Improving health through research

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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>

# ACTIVE

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## Who is involved?:

Dr Alex Pollock	NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK
Dr Pauline Campbell	NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK
Caroline Struthers	EQUATOR Network, University of Oxford / Consumers' Executive
Anneliese Synnot	Centre for Health Communication & Participation, La Trobe University, Melbourne, Australia
Dr Sophie Hill	Centre for Health Communication & Participation, La Trobe University, Melbourne, Australia
Jack Nunn	Centre for Health Communication & Participation, La Trobe University, Melbourne, Australia
Heather Goodare	Lay member, Chair, Edinburgh Health Forum; contributor to Breast Cancer & Stroke Cochrane groups.
Dr Jacqui Morris	NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK
Richard Morley	Coordinator, Cochrane Consumer Group
Chris Watts	Cochrane Learning and Support Department

Find out more: <http://training.cochrane.org/ACTIVE>



# ACTIVE

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Tell us:

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

Email:

ACTIVE@gcu.ac.uk

# ACTIVE

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## 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)*

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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*





# WHEN does involvement occur?



Trusted evidence.  
Informed decisions.  
Better health.

## New Cochrane Review Ecosystem

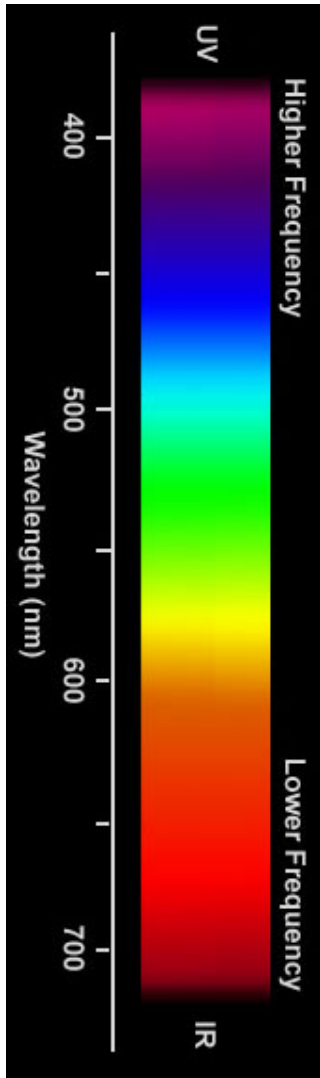




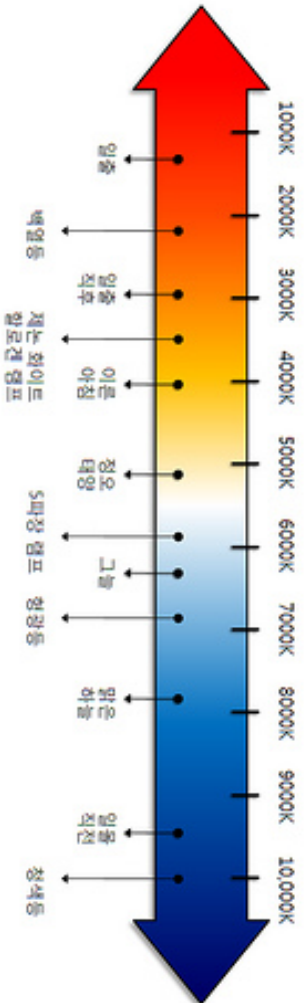





# HOW much involvement?



**Color Temperature in Kelvin Scale**  
광원의 종류와 색온도



# HOW involved are they?



Term	Type of involvement	Example methods
<b>CONTROL</b>	User-led	User-researchers
	User-control	Review team members
<b>COLLABORATION</b>	Devolved user-control	Consensus methods
	Explicit involvement in decision making	Data extraction & analysis
	Involvement in decision making implied	Advisory group members
<b>CONSULTATION</b>		Workshops
		Interviews. Focus groups
		Written
<b>MINIMAL</b>	Participant	Qualitative research

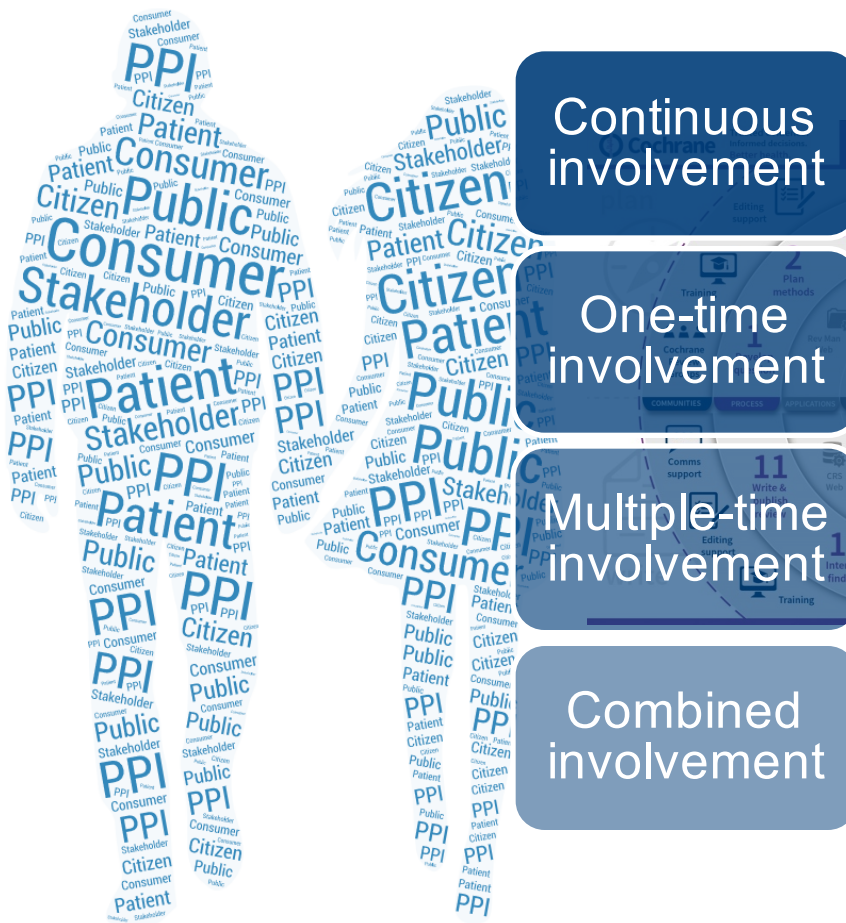
# 4. How to describe involvement

Continuous involvement

One-time involvement

Multiple-time involvement

Combined involvement



		1. Develop question	2. Plan methods	3. Write & publish protocol	4. Develop search	5. Run Search	6. Select studies	7. Collect data	8. Assess risk of bias	9. Analyse data	10. Interpret findings	11. Write & publish review
CONTROL												
COLLABORATION	Devolved control	😊	😊	😊	😊	😊	😊	😊		😊		
	Explicit decision making	😊			😊	😊	😊				😊	😊
	Implicit decision making	😊	😊	😊	😊	😊	😊	😊			😊	😊
CONSULTATION		😊	😊	😊				😊	😊	😊	😊	😊
MINIMAL					😊	😊	😊					

# 4. How to describe involvement

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](mailto:ACTIVE@gcu.ac.uk)

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