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Co-producing a Cochrane qualitative evidence synthesis: applying real-world perspectives to full-text screening

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Disclosure

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

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Knowledge translation and co-production

Knowledge translation = transfer of knowledge from knowledge *production* to knowledge *use* (Rycroft-Malone et al 2016)

Co-production:

- "collaboration between researchers and research users in the research process" (Graham & Tetroe 2009)
- A form of *integrated* knowledge translation – knowledge is generated within the context of its use (Rycroft-Malone et al 2016)

Source: Cochrane's Knowledge Translation Framework (April 2017)

Project background

- 2017: Began Cochrane qualitative evidence synthesis with Australian stakeholder panel including consumers (n = 6), clinicians (n = 6) and health decision-makers (n = 6)
- Topic: ***Consumers and health providers working in partnership for the promotion of person-centred health services***
- During protocol stage, stakeholder panel contributed to:
  - choice of review type
  - topic selection
  - designing the selection criteria
- Many stakeholder panel members became protocol co-authors (see Merner et al 2019)
- Given high level of stakeholder and researcher enthusiasm, a method for co-producing the full-text screening step was developed

Objectives

1) to develop and pilot a co-production method for full-text screening

2) to explore the acceptability of the method to stakeholders and researchers

3) to understand the contribution of co-production of full-text screening to the relevance of the review

- Relevance: “the ‘fit’ between a body of knowledge or research approach and a specific field or issue” (Dobrow et al 2017)

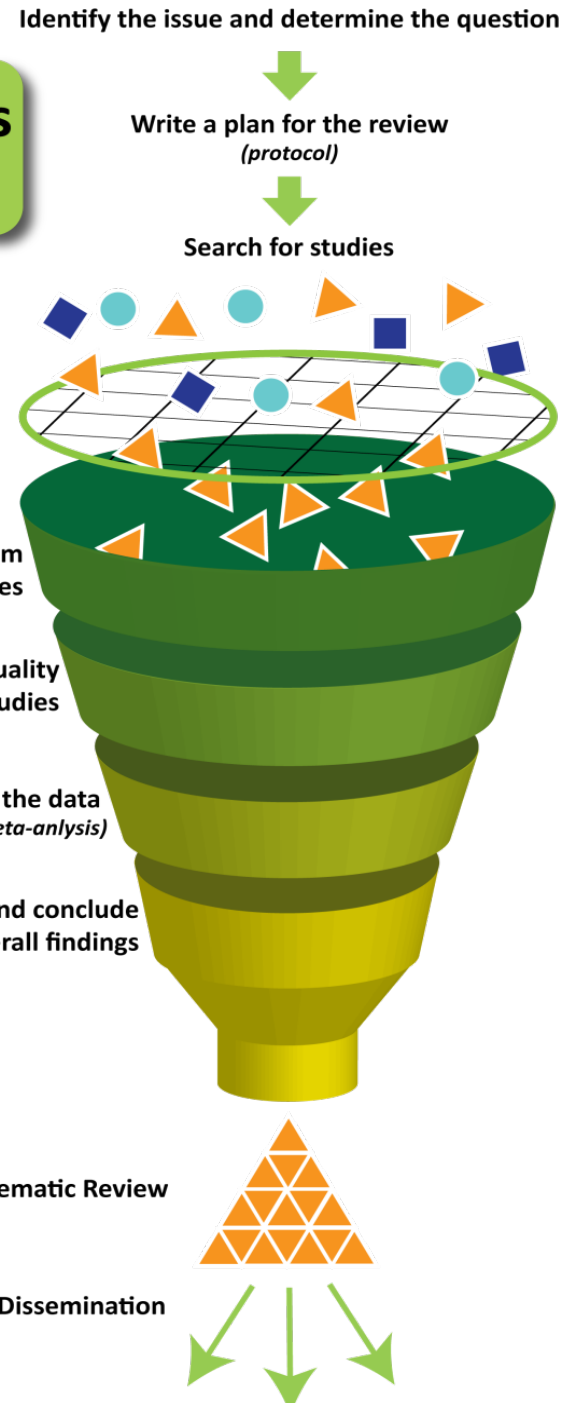
The invitation…

- Stakeholders invited to participate in a full-text screening event in Melbourne on 23 November 2018
- 11/18 stakeholders agreed to participate (including 4 consumers/carers)

The event - introduction

- Updated stakeholders on progress so far (using funnel diagram)

What ~~authors~~ we DO



IN PROGRESS

Source:
http://cccrg.cochrane.org/infographics
Developed by the Centre for Health Communication and Participation, La Trobe University

The event – how to screen

- Introduced screening using examples of how to apply the inclusion and exclusion criteria
- Gave **marked-up** and **annotated** examples of definitely in, definitely out, maybe in/out

Marked-up screening example

Definitely in: abstract view

#1927 - deFreitas 2015

de Freitas, C.

Aiming for inclusion: a case study of motivations for involvement in mental health-care governance by ethnic minority users

Health Expectations Oct 2015;18(5):1093-1104
2015 Oct

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DOI: 10.1111/hex.12082

Objective To examine the motivations for involvement in mental health-care governance by socially disadvantaged ethnic minority users. Design and setting A qualitative case study approach was employed to investigate the involvement of minority north-eastern users in mental health-care governance at CAPS Pedro Pellegrino in Rio de Janeiro, Brazil. Semi-structured interviews with minority Northeasterners (n = 12) and institutional stakeholders (n = 26) were complemented by participant observation of user assembly and user movement meetings. Findings Minority Northeasterners express both individual and collective motivations for involvement in mental health-care governance. Individual motivations include the desire to increase social interaction, acquire meaningful social roles and overcome the stigma attached to mental illness. Collective motivations include the intent to improve the responsiveness of mental health care and achieve social justice for people with mental problems. Taken together, these motivations demonstrate a strong aspiration by users to promote their social inclusion and the inclusion of others who also experience marginalization. Results also reveal that the involvement of long-term participants is driven mostly by collective goals while early-stage participants focus predominantly in dealing with individual concerns. This is at odds with the mutual incentives theory, which postulates that collective motivations prevail over individual motivations in explaining user involvement. Conclusion Groups historically excluded from decision-making processes may identify social inclusion as the core goal of their involvement. Initiatives aiming to increase user participation in health-care governance must address the range of motivations driving the involvement of users, instead of focusing solely on issues related to health-care management and provision.

Annotated screening example

Definitely in: further information from full-text

- Governance committee, user assembly and user movement meetings included service users (patients and carers), health professionals, health service administrators
- Met more than once (actually over a period of years)
- Met face to face
- Made decisions about service design and delivery to improve patient centred care, user experience

(deFreitas, 2015)

The event – doing the full-text screening

2 x 45 min small group sessions:

- stakeholders assigned to groups (at least one consumer, clinician and health decision-maker in each)
- no one had previously read the papers (including the researchers)
- each group used a **screening sheet**
- following discussion within the group, consensus was reached about inclusion/exclusion

Example of screening sheet

**To be included a study must be rated yes (Y) for each of the following criteria:

Criteria	Y	N	Unclear
1. **Is there at least one consumer in an advisory or representative capacity?** Rate as "Y" if at least one partnership participant is a: • consumer or patient representative, • consumer consultant, • consumer with an acute or chronic condition, • carer or family member, or • consumer organisation member. Rate as "N" if all partnership participants are: • health policy makers, • health service managers/administrators, • health professionals, • university academics, teaching or research staff, or • in any other non-consumer role.			

Results

- On the day, 20 full-text articles were screened
- After the day, stakeholders screened over 120 articles (many by one stakeholder!)
- A researcher independently 'second-screened' each article, showing a high level of agreement

Stakeholder evaluation of process

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The information I received before coming helped me understand what was expected of me before I came				5	5
The materials and resources used during the meeting helped me understand my role and make a contribution					9*
I felt that my contributions were heard and valued					10

* Only 9 responses to this question

Evaluation (continued)

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My participation in the meeting helped to strengthen my personal or professional networks				4	6
My participation in the meeting helped to increase my understanding of the steps involved in producing a Cochrane Review					10

Reflections from the stakeholders

- **Positive aspects**
  - Understanding the Cochrane process (n=7)
  - Opportunity for discussion about the review (n=5)
  - Meeting other panel members and researchers (n=4)
  - Learning a new skill (n=2)
  - Openness of the researchers (n=1)
- **Suggestions for improvement**
  - Could expect more of the panel (n=3)
  - Include other voices (n=1)

Reflections from the researchers

- Verified researchers were “on the right track” with the review
- Benefited from brainstorming solutions to “sticky” screening issues
- The multi-faceted health system experiences of stakeholders helped the researchers improve how they applied the selection criteria, so the studies selected would reflect 'real-world' practice

Discussion

- This co-production method was successful in involving stakeholders in review production
- Built the capacity of researchers and stakeholders to value each other's perspective, and also encouraged a "value-added" communal perspective (Kothari et al 2013)
- Successful co-production should "face internally as well as externally"; relationships in the collaboration are critically important (Greenhalgh et al 2016, Rycroft-Malone et al 2016)
- Process of co-production may be more important than the tangible outcome, development of "team identity", social or relational capital (Kothari et al 2013)

Conclusions

1. We developed and piloted a successful co-production method for full-text screening
2. The method was acceptable to stakeholders and researchers
3. The contribution of co-production of full-text screening to the relevance of the review:
   - "Value-added" communal perspective
4. Something "more" has been created: "team identity" and social and relational capital may extend beyond the life of the current project

Thank you to our stakeholder panel

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Susan Biggar
Noni Bourke
Renee Chmielewski
Leia Earnshaw
Marie Gill
Fiona Martin
Louise McKinlay
David Menzies
Nancy Messino
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Naomi Poole
Nora Refahi
Lorraine Smith
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Cheryl Wardrope

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