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Identifying patient important outcomes in systematic reviews – the Cochrane Consumer Network

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I will cover:

- Consumer involvement in Cochrane
- 2015 Consumer Structure and Function Review
- Consumer Delivery Plan to 2020 Priorities
- Consumers and outcomes – 3 case studies
- Consumers, outcomes and reducing waste in research
- An international network on public involvement & engagement in health & social care research (PPI)

and argue:

- Consumer involvement in Cochrane is strong, but limited in scope
- What there is remains little reported
- Some evidence of a mismatch between patient identified outcomes and those used in Cochrane reviews
- Opportunities exist to build on our work

Consumer involvement in Cochrane

- Cochrane is a global network of researchers, clinicians and consumers (37K in 137 countries) that produces high quality, unbiased health evidence
- Since 1993 consumers have been involved in a wide variety of ways, including working with Cochrane's authors, Review Groups, Fields and Centres
- A growing community of more than 1,467 (1,338 in 2015) people. 300 to 500 consumers actively contribute in a 12 month period
- Includes patients (or people with personal experience of a healthcare condition), health and social care service users, care-givers and family members, and people who represent or who are advocates for patients and carers
- United by their search for high quality, unbiased information about health conditions and treatments

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2015 Consumer Structure and Function Review

Conclusions

- ✓ Cochrane pioneered the involvement of consumers in systematic reviews
- ✓ Over 1330 *Archie* registered consumers
- ✓ Active core of between 300 and 500 regularly involved
- ✓ Examples of best practice across the network
- ✓ Something to celebrate

- Practice across Cochrane varies significantly
- Consumer role largely restricted to peer review
- Not kept pace with expectations/practice outside Cochrane
- Review Groups and authors want support to involve consumers
- Consumers want more to do
- Structures do not presently support effective consumer involvement

Consumer Delivery Plan to 2020 Priorities

1. Develop and adopt a statement of principles about consumer involvement in Cochrane
2. Integrate consumer involvement and representation in all levels of Cochrane decision-making groups
3. **Support consumer involvement throughout the entire review production and evidence dissemination process (NB outcomes)**
4. Contribute to the development of the Cochrane Membership plan to ensure the it offers maximum opportunities for consumer membership and involvement
5. Build on current and develop new, programmes of training and support for Cochrane consumers
6. Improve communication with Cochrane consumers
7. Build effective external partnerships
8. Increase awareness of evidence-based medicine and the use of Cochrane evidence when making health decisions in the worldwide consumer community

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Consumers and outcomes (1)

Hard to identify activity in published literature

Literature searches for the Consumer SFR identify consumers had been involved in identifying outcomes in systematic reviews e.g.

- Kelson (1999) identifies case studies from the Pregnancy and Childbirth and Musculoskeletal CRGs
- Ghersi (2002) as an important impact of consumer involvement in the Breast Cancer Group
- Coon (2015) End-user involvement in a systematic review of quantitative and qualitative research of nonpharmacological interventions for attention deficit hyperactivity disorder delivered in school settings
- Not routinely reported in Cochrane reviews

Consumers and outcomes (2)

"Identification of outcomes important for patients, public and practitioners"

UK Cochrane Centre, co-ordinated by Sally Crowe

Exploring cost effective ways of involving stakeholders that are robust and evidence-based

- Cochrane Airways (Asthma) partnership with Asthma UK inc. F2F + Facebook survey + creative methods
- ENT Disorders Group (Chronic Rhinosinutitus) online survey – no patient group to work with, social media + email
- Pregnancy & Childbirth Group (Breastfeeding) mined experiential data (Healthtalk) 51 interview transcripts analysed

Lessons: (1) challenge of developing effective methods (2) validated existing outcomes but also clear differences between patient preferred outcomes and reviews

http://training.cochrane.org/resource/CLL-webinar-consumers-terrified

Consumers and outcomes (3)

Wounds research for patient benefit: a 5-year programme of research Cullum *et al* (2016)

Aims

- University of York/Cochrane Wounds Group NIHR Programme Grant
- To explore the experiences of complex wound care; identify which outcomes matter; compare these with those reported in wounds research
- A prioritised list of research questions in pressure ulcer prevention and treatment

Methods

- semi structured interviews with people affected by complex wounds and desirable treatment outcomes
- a systematic review of the design and conduct of RCTs of complex wound treatments
- research priority setting in pressure ulcer prevention and treatment (James Lind Alliance Pressure Ulcer PSP)

Results

- Most patients and health professionals identified *healing* of the complex wound as the primary treatment goal – not reflected in wounds research

Consumers, outcomes and reducing waste in research - some lessons

- Consumer involvement in Cochrane reviews is not often reported and Involvement of patients in identifying outcomes in Cochrane reviews is under-reported
- Where it happens, consumer involvement in identifying important outcomes is not systematic and reveals mismatches between outcomes desired by patients and those used in RCTs and systematic reviews
- Chalmers and Glasziou http://researchwaste.net/
- Opportunities exist for Cochrane to contribute to reducing waste in research by more systematically involve consumers in identifying important outcomes and help set the agenda, including in “empty” reviews where necessary
- Cochrane, COMET and core outcomes sets

Consumers, outcomes and reducing waste in research – opportunities for collaboration

- **Join the conversation** - Cochrane Forums https://forums.cochrane.org/c/consumers
- **Engage consumers** - Cochrane Membership – Spring 2017
- **Involve consumers** - Task Exchange http://taskexchange.cochrane.org/
- **Support researchers** - Project ACTIVE – developing resources for Cochrane authors (funded by Cochrane Training and supported by Consumer Network) http://training.cochrane.org/ACTIVE
- **Collaborate** - COMET and Cochrane – developing COS
- **Collaborate more**! - An international network on public involvement & engagement in health & social care research (PPI)

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International network on public involvement & engagement in health & social care research

- Exciting time for patient and public involvement and engagement in health and social care research
- A growing and important movement, creating better research with patient and public benefit
- Well established in some countries, and rapidly developing in many others
- Opportunity to bring together institutions, associations and individuals, whose purpose is to advance and promote public involvement and engagement in research

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COMET Initiative
INVOLVE
Royal College of Nursing
WARWICK MEDICAL SCHOOL

Thank you!

Web – www.consumers.cochane.org

Twitter - @cochraneconsumr

Facebook – https://www.facebook.com/groups/188375461224285/

Cochrane Forums - https://forums.cochrane.org/c/consumers

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