Topic refinement for Cochrane Reviews – reaching stakeholders: a case study

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With you this morning…

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Our partnership

Cochrane Epilepsy

Cochrane Movement Disorders

epilepsy action

PARKINSON'S UK

CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

www.epilepsy.org.uk

www.parkinsons.org.uk
This presentation

We aim to share our experience of

- Thinking through and developing an approach to topic refinement
- Stakeholder engagement
- Developing web-based surveys and promoting participation
This presentation – how we did it

1. Task
2. Approach
3. Experience
4. Learning
Our task
Our task

Seek stakeholder’s preferences for Cochrane systematic reviews to be produced as part of programme grant

- **topics** relating to interventions and care
- **outcomes** used or aspects of care for consideration in the reviews

We call this **topic refinement**
Our approach
Overview - priority setting approaches

**Technical**

Use of existing data e.g. disease prevalence, economic burden, other measures
Scoring and use against matrix of criteria
Gap analysis or identified need e.g. Guidance and policy plans, commissioning health services
Systematic review of existing priority sets
Horizon and environmental scanning
Cochrane criteria (e.g. downloads) or editorial decisions

**Interpretive**

Surveys to generate/rank/validate priorities (Delphi or other)
Using ‘free text’ data to inform above
Creating/enriching scenarios to inform research topics and priorities
Discussion among informed stakeholders to generate and or agree priorities; workshops, meetings.
Accessing patient narratives, help line data and proxy sources of perspectives
Approach

Developed and piloted a 2 web-based surveys using SurveyMonkey (Advantage subscription):

- Epilepsy
- Parkinson's Disease

Worked closely with a small selection of epilepsy and Parkinson’s organisations to:
  - Develop, test, improve the surveys
  - Market, engage and provide information to stakeholders

Developed a social media strategy and digital content:
  - /Priorities webpage on our Cochrane Groups’ sites
  - Text for tweets, handles (Twitter users) to target, retweet requests, hashtags
  - Visuals to support engagement (banners, slideshows)
Promotion (1)

[Image]

Cochrane Epilepsy

Welcome Scope Get involved Evidence News Contact us Join Cochrane

Topic prioritisation

About our topic prioritisation:

The Cochrane Epilepsy Group have been awarded funding to produce some new and some updated systematic reviews on epilepsy.

We are running a focused topic prioritisation activity to help us decide on important topics for new and updated systematic reviews. We will use a short online (print on request) survey to collect views on a short list of systematic reviews to begin or update as well as suggestions for other topics for systematic reviews (in addition to the short list). The survey will also ask for key reasons why you think topics are important.

The method is similar (but much less detailed) to James Lind Alliance approaches. We have also searched for reports of other prioritisation exercises to help inform the process and avoid duplication of effort.
Promotion (2)

- Epilepsy Action and Parkinson’s UK facilitated access to their ‘research interested’ networks using targeted direct mail:
  - EA 8000 list members
  - PDUK 4500 list members
- Our Cochrane groups emailed members (authors, consumer experts)
Do you have experience of Parkinson's disease?

https://spark.adobe.com/video/LojNYUy3nLoli

https://spark.adobe.com/video/Qhc6vEwBg6Eaa
Survey coming soon


Promotion (4)
The survey

Welcome to our short survey

In the survey, you will be asked to share your views on top priorities for research using systematic reviews. There are 6 steps:

1. Select up to 10 top topics
2. Select up to 5 top topics
3. Rank your top topics
4. Tell us more about your choices
5. Add other topics & tell us more
6. About you (optional) & submit

Thank you for participating. Your views are important.

The Cochrane Epilepsy Group asks for your help to identify the most important topics for updated and new systematic reviews on epilepsy.
The survey – some features/ functions

General approach
- Mix of closed form, ranking and open form items on topics
- Prioritisation using a sequence of selecting:
  - top 10 → then top 5 → then ranking the top 5

Technical details*
- Used the survey platform’s response ‘carry forward’ functionality
- Topics initially presented to respondents in random order
- Survey split into ‘pages’ to allow data capture without respondents reaching end page
- Demographic questions at end and deliberately restricted in detail

* WARNING – if you ask me about these, I will talk your ears off
Our experience
Reach

- Open globally, but largely UK-based respondents
- Over 1000 respondents:
  - 569 started the epilepsy survey
  - 470 started the Parkinson’s survey
- Majority of respondents were people with the condition:
  - 59% epilepsy
  - 78% Parkinson’s
- Few responses from professionals
Responses – top 5 topics (epilepsy, PD)
Perspectives shared – Epilepsy

Preconception counselling for women – why is this important to you (127 responses)?

“I think pregnancy is a big worry for women with epilepsy so researching possible ways to reduce these anxieties and ensure women are supported is important.”

“This will be an issue for my daughter as she wants to have kids, but has not yet reached a satisfactory level of seizure control.”

Cannabinoids – why is this important to you (175 responses)?

“People are going nuts about CBD, presuming it will work for them and taking any form of cannabis that they can. It’s so dangerous and even the CBD alone - we don’t know the long-term effects of it.”

“Lots of positive opinion and would like to see more evidence.”
Perspectives shared – Parkinson’s Disease

Nurse specialists – why is this important to you? (161 responses)

“Evidence that nurse specialists are cost effective need to be persuasive so that there is a Parkinson's nurse for everyone with Parkinson's and that posts of Parkinson's nurses do not come under threat from financial cuts.”

“Good PD nurses are worth so much to PD people someone who understands and we can talk openly and honestly.”

Therapies for managing anxiety – why is this important to you (106 responses)

“…Socially limiting so patient opts out and enters a vicious downward cycle.”

“Anxiety has been the most distressing element on a day to day basis of my Parkinson's. Even being unable to walk properly is easier to deal with.”
### How did we do? Cochrane KT guidance

<table>
<thead>
<tr>
<th>Governance</th>
<th>Shortlist by Cochrane groups, with external stakeholder reps. Refinement involved external experts &amp; stakeholder reps.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholder engagement</td>
<td>External: people with lived experience via email &amp; social media - reasonable numbers &amp; diversity, some health professionals. Internal: via Cochrane group authors email, Consumer Facebook &amp; KT group</td>
</tr>
<tr>
<td>Documentation &amp; dissemination</td>
<td>Process &amp; findings to be written-up &amp; disseminated (webinar soon). Priorities informed programme planning</td>
</tr>
<tr>
<td>Currency &amp; timeframe</td>
<td>Current for 2018-21</td>
</tr>
</tbody>
</table>
How did we do? REPRISE checklist

1. **Context and scope** – UK based, interventional questions, SRs, epilepsy and Parkinson’s disease, medium term priorities.

2. **Governance and team** – internal team, could have had more external members, some team members experienced in priority setting.

3. **Inclusion of stakeholders** – lived experience and specialist professionals (limited information), aim for 300 in each survey, no reimbursement for participation.

4. **ID and collection of topics** – previous prioritisation exercises, online survey, gathering topics in addition to set for prioritisation, known unknowns.

5. **Prioritisation of topics** – individual ‘forced’ online ranking, exclusions of other questions yet to be determined.

6. **Outputs** – Epilepsy ranked set, Parkinson’s Disease less clear priorities.

7. **Evaluation and feedback** – currently in this phase.
Our learning
Learning....(1)

- Navigating from ‘gold’ to ‘good’
- **Staging** approaches – topic shortlists, web-based approaches, workshops held in reserve
- **Focused** engagement with a selection of stakeholders
- **Engaging** target audience in testing and improvement of surveys
- Integrating other **topic research**
- **Defining** ‘systematic review’ – not easy!
Learning…(2)

- Managing *information shared* by people with a condition
- Choosing *digital tools*
This session

1. Task
2. Approach
3. Experience
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Your views…

- In what ways could we have done this better?
- Was the approach **good enough**?
- What would you want to know in a report/publication?
- How should we disseminate?
- Is the lack of professional respondents an issue?
Next steps

- Further analysis
- Exploring free text for outcome preferences – mapping with review protocols/ updates
- Extension with expanded topic list for multinational stakeholders?
- Cochrane Learning Live webinar – coming soon
- Publication for dissemination and transparency – summary on Cochrane Groups’ webpages at very least in addition to funder’s report
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Ruaraidh
Financial – non personal, non specific interest. Delivered educational workshops on health economics, medicines management and HTA for cancer specialists – unrestricted sponsorship by pharmaceutical industry and industry association (March 2019). Not specific to topics presented.

Cochrane author

Sally
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