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

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LIFE CHANGING
World Shaping

Funded by NIHR Cochrane Programme Grant (16/114/26)

With you this morning…

Sally Crowe

Director – Crowe Associates

Crowe Associates Ltd

Committed to people development

Ruaraidh Hill

Lecturer in evidence synthesis

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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

➊ Task

➋ Approach

➌ Experience

➍ Learning

Our task

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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

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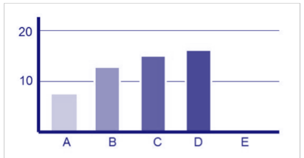
Overview - priority setting approaches

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

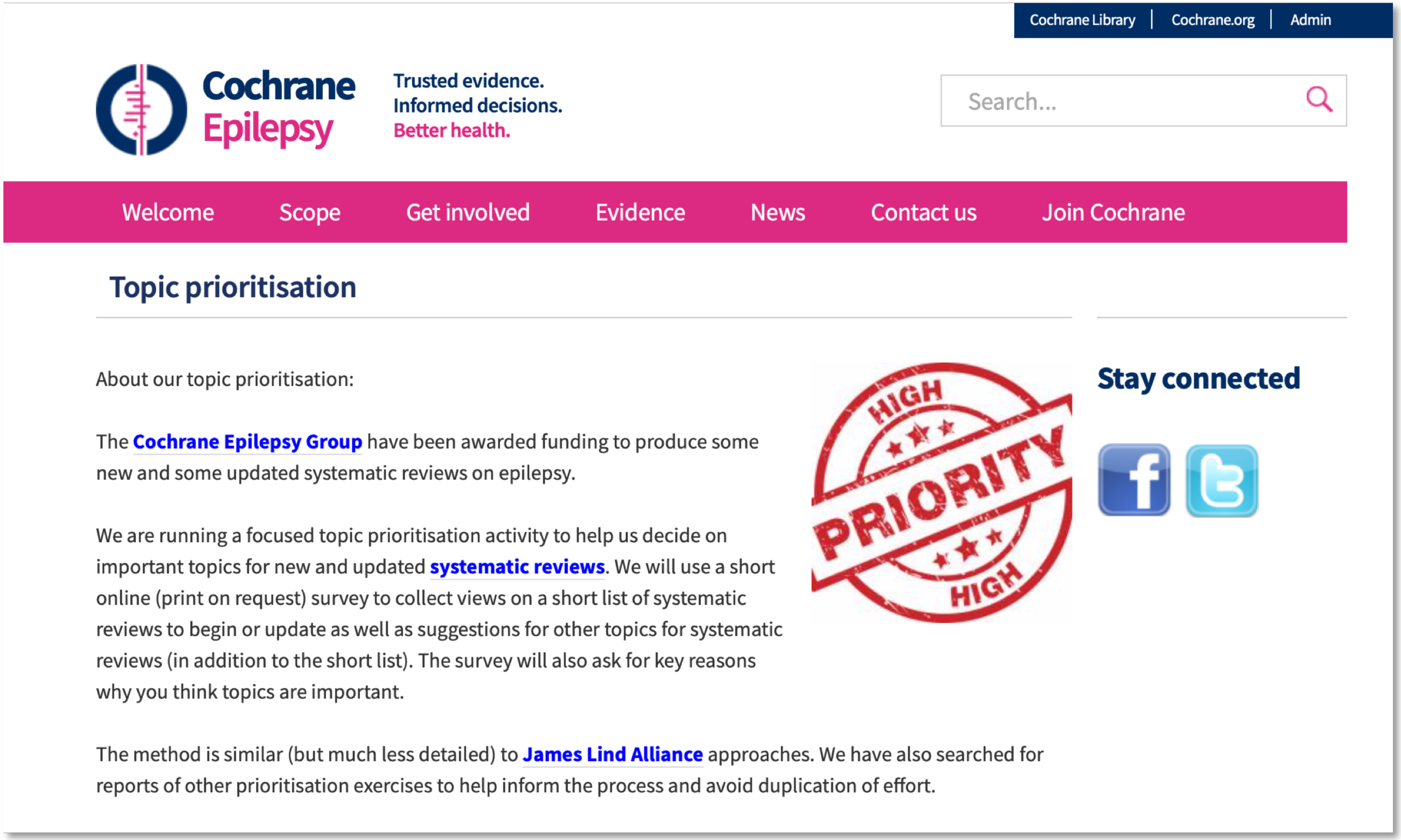
Worked closely with a small **selection** of epilepsy and Parkinson’s organisations to:

- 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)



Topic prioritisation

About our topic prioritisation:

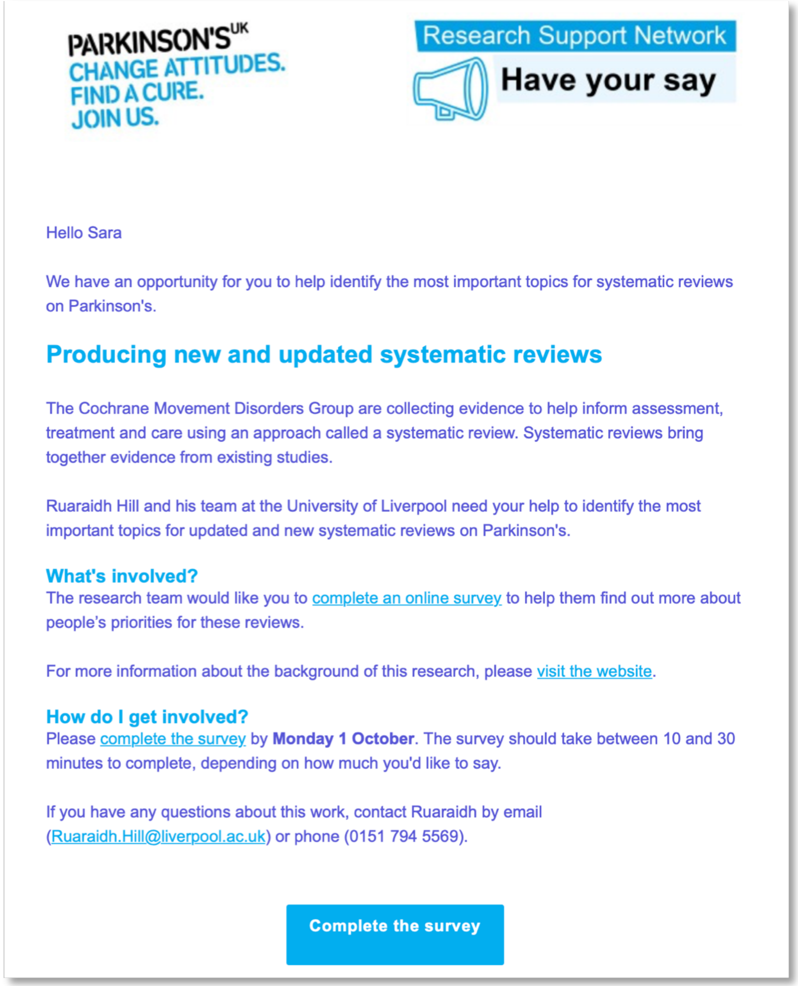
The **Cochrane Epilepsy Group** have been awarded funding to produce some new and some updated systematic reviews on epilepsy.

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)



Hello Sara

We have an opportunity for you to help identify the most important topics for systematic reviews on Parkinson's.

Producing new and updated systematic reviews

The Cochrane Movement Disorders Group are collecting evidence to help inform assessment, treatment and care using an approach called a systematic review. Systematic reviews bring together evidence from existing studies.

Ruaraidh Hill and his team at the University of Liverpool need your help to identify the most important topics for updated and new systematic reviews on Parkinson's.

What's involved?
The research team would like you to complete an online survey to help them find out more about people’s priorities for these reviews.

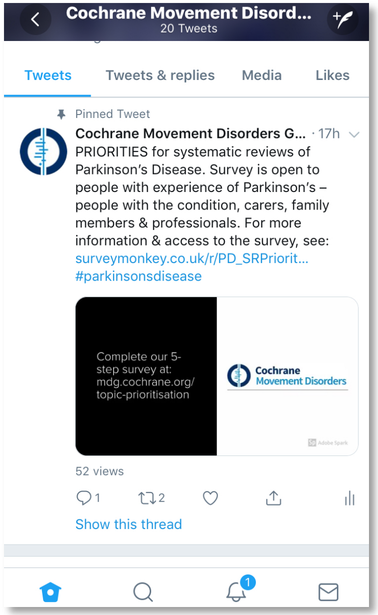
For more information about the background of this research, please visit the website.

How do I get involved?
Please complete the survey by **Monday 1 October**. The survey should take between 10 and 30 minutes to complete, depending on how much you'd like to say.

If you have any questions about this work, contact Ruaraidh by email (Ruaraidh.Hill@liverpool.ac.uk) or phone (0151 794 5569).

Promotion (3)

Do you have experience of Parkinson's disease?



Cochrane Movement Disorders G... · 17h

PRIORITIES for systematic reviews of Parkinson's Disease. Survey is open to people with experience of Parkinson's – people with the condition, carers, family members & professionals. For more information & access to the survey, see: surveymonkey.co.uk/r/PD_SRPriorit... #parkinsonsdisease

Complete our 5-step survey at: mdg.cochrane.org/topic-prioritisation

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

https://spark.adobe.com/video/Qhc6vEwBg6Eaa

Promotion (4)

Cochrane
Epilepsy

Survey coming soon

Trusted evidence.
Informed decisions.
Better health.

Epilepsy Action
@epilepsyaction

Parkinson's UK, NIHR Research, and 3 others follow

The UK's leading member-led epilepsy charity, providing information for the 600,000 people with epilepsy in the UK and anyone with an interest in the condition

Leeds, UK epilepsy.org.uk
Joined November 2008

2,157 Following 25.2K Followers

Epilepsy Action @epilepsyaction · 11h
If you're inspired by #GBBO😱 to grab a whisk and avoid soggy bottoms, you can change lives by getting together for a tea break to support people with epilepsy! 🍰 👌 Sign up today and you'll get everything you need - epilepsy.org.uk/teabreak

Cochrane @cochranecollab

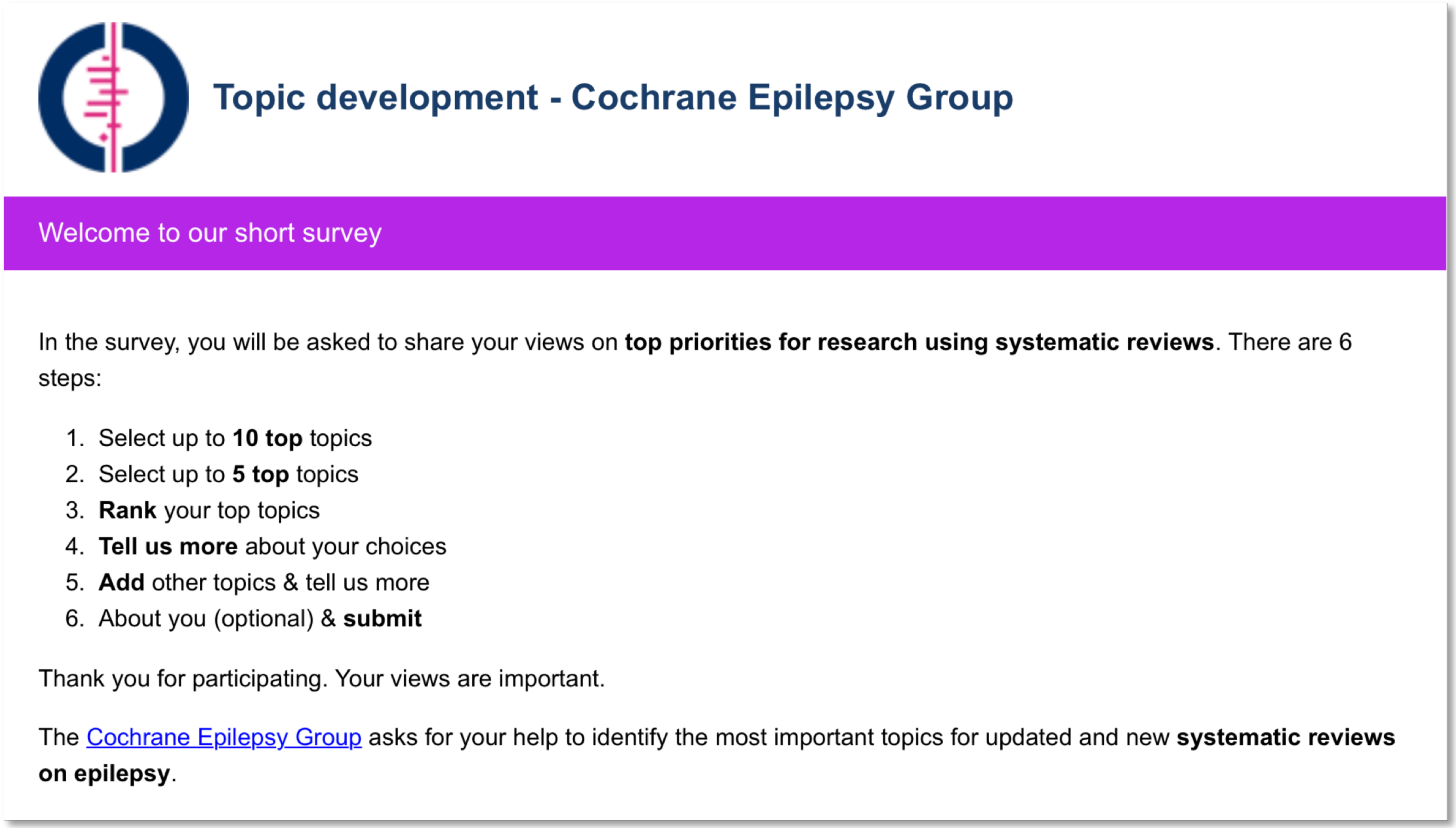
Have your say! Help @CochraneMDG set the priorities for future systematic reviews of Parkinson's Disease! Survey open to people with experience of #Parkinsons – people with the condition, carers, family members & professionals.buff.ly/2p7VwKS

5:08 pm - 2 Oct 2018

4 Retweets 2 Likes

Ruaraidh Hill @RuaraidhHill · 2 Oct 2018
Replying to @cochranecollab @CochraneMDG
Link working well - near to 500 responses, largely people with Parkinson's, sharing priorities for #systematicreviews. With your help we can get over 500! Please RT & See: surveymonkey.co.uk/r/PD_SRPriorit…

The survey



Topic development - Cochrane Epilepsy Group

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**.

Preview topic development - Cochrane Epilepsy Group

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

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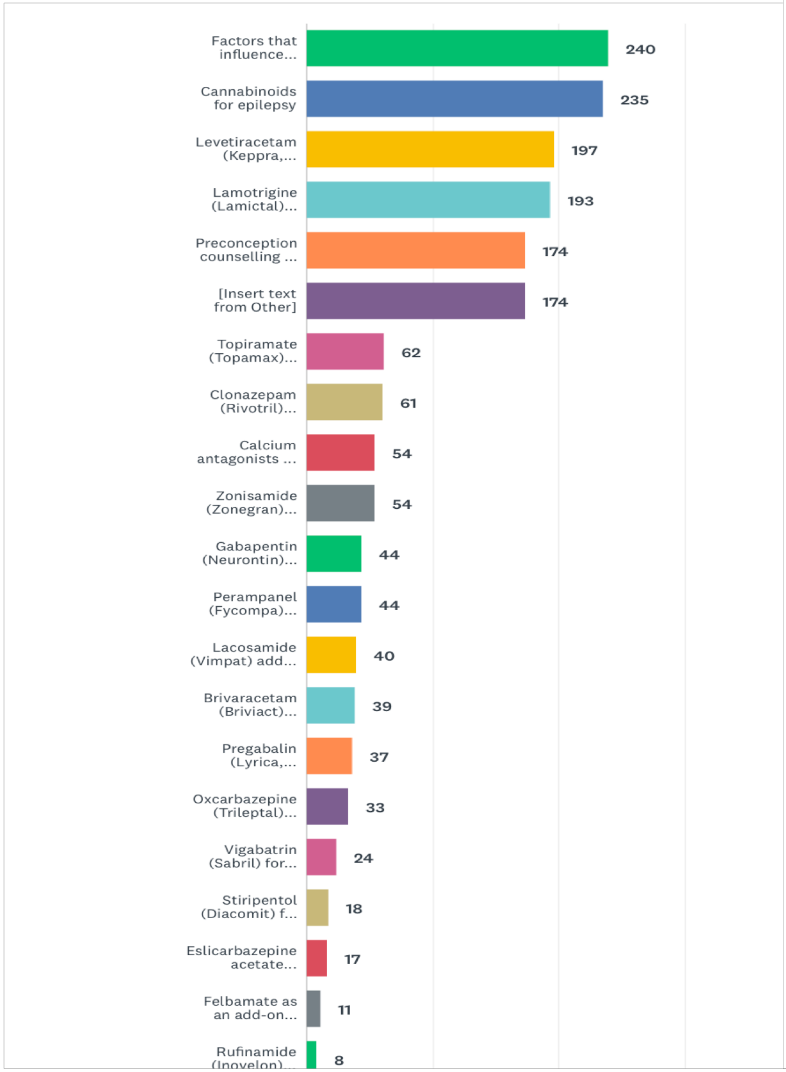
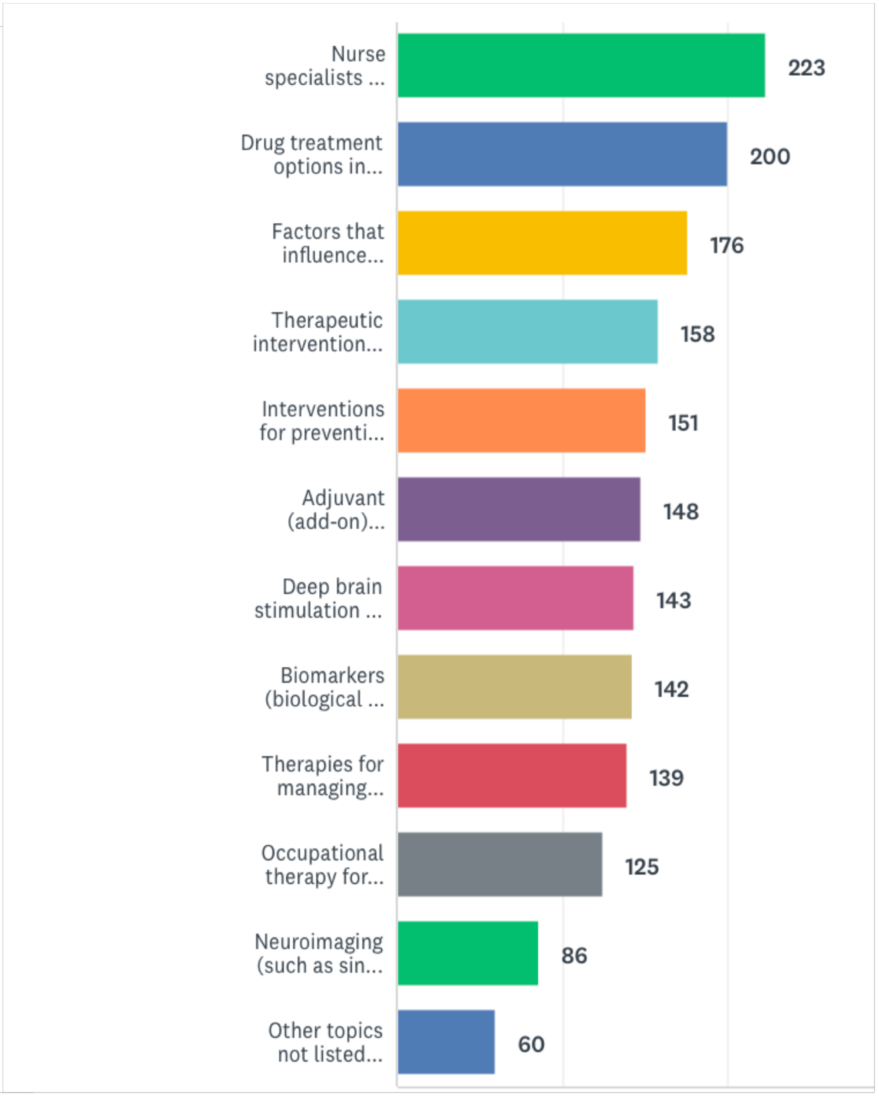
Reach

- 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

Governance – team to develop the process	✓	Shortlist by Cochrane groups, with external stakeholder reps. Refinement involved external experts & stakeholder reps.
Stakeholder engagement – external & internal to Cochrane	✓	External: people with lived experience via in email & social media - reasonable numbers & diversity, some health professionals. Internal: via Cochrane group authors email, Consumer Facebook & KT group
Documentation & **dissemination**	UNDER CONSTRUCTION	Process & findings to be written-up & disseminated (webinar soon). Priorities informed programme planning
Currency & **timeframe**	✓	Current for 2018-21

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
4. Learning

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

Declaration of interests, funding and acknowledgements

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	Received consultancy payment for her work on this project
Ethics	Methods and content approved by Health and Life Sciences Research Ethics Committee (3087)
Funder	National Institute for Health Research - Cochrane Programme Grant (16/114/26).
We acknowledge	the 1039 people who told us what was important to about systematic reviews in epilepsy and Parkinson’s Disease, our partners and Programme teams in CEG and CMDG

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A member of the Russell Group