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UK

Cochrane UK Consumer Champions project

Interim Evaluation

July 2021



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Introduction

Cochrane UK launched the Cochrane UK Consumer Champions pilot project in August 2020 with the aim of:

- developing links with a wider group and network of healthcare consumers, consumer groups and organisations
- raising awareness of evidence-based healthcare in general and Cochrane in particular
- promoting wider patient and public involvement within Cochrane groups and work

At the core of the project is a network of patients and patient advocates with lived experience of different health conditions and a key interest in evidence-based healthcare, who take on the role of Cochrane UK Consumer Champions. Their role involves planning and delivering activities of relevance to consumers and their communities. They are also involved in Cochrane projects as consumer representatives.

This report describes the results of the interim evaluation of the Cochrane UK Consumer Champions project, conducted between June - July 2021, with the aim of identifying:

- facilitators and barriers that had an impact on the project
- opportunities for improvement and learning
- the potential to expand the project and recruit a new cohort of Consumer Champions

Therefore, the interim evaluation focused on answering the following key questions:

- What evidence, if any, is there of the impact of the Cochrane UK Consumer Champions? And how can impact be measured?
- What factors have supported and hindered the implementation of the Cochrane UK Consumer Champions project? How could the implementation be improved?

To answer these questions, the project coordinators interviewed the Consumer Champions and reviewed the project documentation, including project plans and reflective journals from the Consumer Champions. The evaluation of the implementation process was underpinned by the *Normalisation Process Theory* (NPT), which provides a conceptual model to explore the factors that promote and inhibit implementation, and understand how complex interventions become embedded and integrated in practice (May and Finch, 2009).

To conclude the interim evaluation, the project coordinators list key recommendations for the future of the project.

Project overview

The Cochrane UK Consumer Champions project is led and coordinated by Emma Doble, Patient and Consumer Coordinator, and Marta Santos, Programme Support Officer.

The implementation strategy of this project involved:

- recruitment of a network of Cochrane UK Consumer Champions, with availability to dedicate 4-16 hours per month to the project
- scoping exercise at the outset to identify priorities and areas of interest
- regular meetings and contact between the project coordinators and Consumer Champions to support them in their role and shape the approach
- learning and development programme tailored to individual needs and interests
- monthly reflective journal to be completed by each Consumer Champion
- remuneration and reimbursement of expenses offered to Consumer Champions

Project timeline

The project timeline in Figure 1 illustrates the key milestones of the first months of the project, including the recruitment of the first cohort of Cochrane UK Consumer Champions.

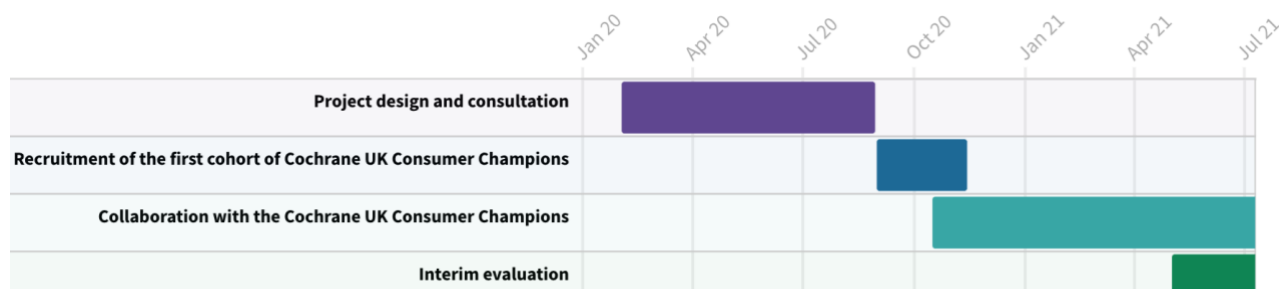


Figure 1 - Cochrane UK Consumer Champions: Project milestones.

Gantt chart template: Created by the Flourish team.

Recruitment

Between September and November 2020, we recruited four Consumer Champions: Brian Devlin, Ceri Dare, Genna White and Olivia Fulton. All the Consumer Champions had seen the role on Twitter or were contacted directly by the project coordinators for their work in patient involvement. All the Consumer Champions have significant experience in engaging with their own patient/consumer communities through social media, blogs and peer support groups. They also have some experience of research through work in patient and public involvement (PPI) or professional careers and training. The Consumer Champions bring to this project specific areas of interest and their own social networks.

Brian Devlin: *“I’m profoundly deaf and use my social media presence to raise awareness of issues in this area. I’m also an ambassador for products and services which aim to make life easier for people with very personal and private medical conditions, including stoma care, and campaign to stop the stigma that people with stomas experience.”*

Ceri Dare: *“I have a long history of mental health problems, with a diagnosis of schizoaffective disorder. A few years ago, I developed adult-onset difficult asthma. Trying to juggle medications and treatment for both is surprisingly difficult.”*

Genna White: *“In 2012 my eldest son was diagnosed with Specific Language Impairment (SLI), now known as Developmental Language Disorder (DLD). At the time there was very little awareness about this condition and very little information available. I began researching and building a support network of peers and professionals for my son and me. In 2013 I set up a support group for parents and carers of pre-school children with speech, language and communication needs (SLCN) that was shortlisted for a Shine A Light award from The Communication Trust in 2013/14.”*

Olivia Fulton: *“I fell into patient and public involvement (PPI) in research after focusing my time on raising awareness of severe asthma. I was no longer eligible to take part in clinical trials but wanted to do something to help people with debilitating severe asthma. I never knew there was an option where I could help shape and influence research.”*

Target audience

Through the involvement of Cochrane UK Consumer Champions, this project aims to target three main groups:

- Consumers/ patients and members of the public, particularly patient groups that may not be typically represented or involved with Cochrane
- Charities and organisations directly involved with patients
- Cochrane Groups, including Cochrane UK and relevant Cochrane Review Groups

The Consumer Champions identified specific groups that they are particularly interested in reaching. These are patients and members of the public with lived experience or interest in:

- Deafness
- Stoma
- Post-traumatic stress syndrome
- Long COVID
- Speech, language and communication disorders
- Asthma
- Long-term conditions
- Critical care
- Mental health

Three of the four champions have identified social media as the main platform to reach communities of interest. In addition, one Consumer Champion is particularly interested in reaching people with low literacy, whose English is not the first language and limited access to technology and digital communication, through face-to face talks and activities. However, the latter has not yet been possible due to the pandemic.

Impact

In order to answer the question “What evidence, if any, is there of the impact of the Cochrane UK Consumer Champions? And how can impact be measured?”, it is important to understand the concept of impact.

Impact refers to longer-term goals such as “*increased use of Cochrane evidence to inform health decision making and promote behaviour change*”, that require, but transcend, the project inputs, activities, outputs or outcomes. Impacts are usually the result of multiple interventions, and it is difficult to attribute impact to a single project such as the Cochrane UK Consumer Champions (WHO, n.d.).

The logic model below illustrates some examples of inputs, activities, outputs, outcomes and how these can lead to achieving impact.

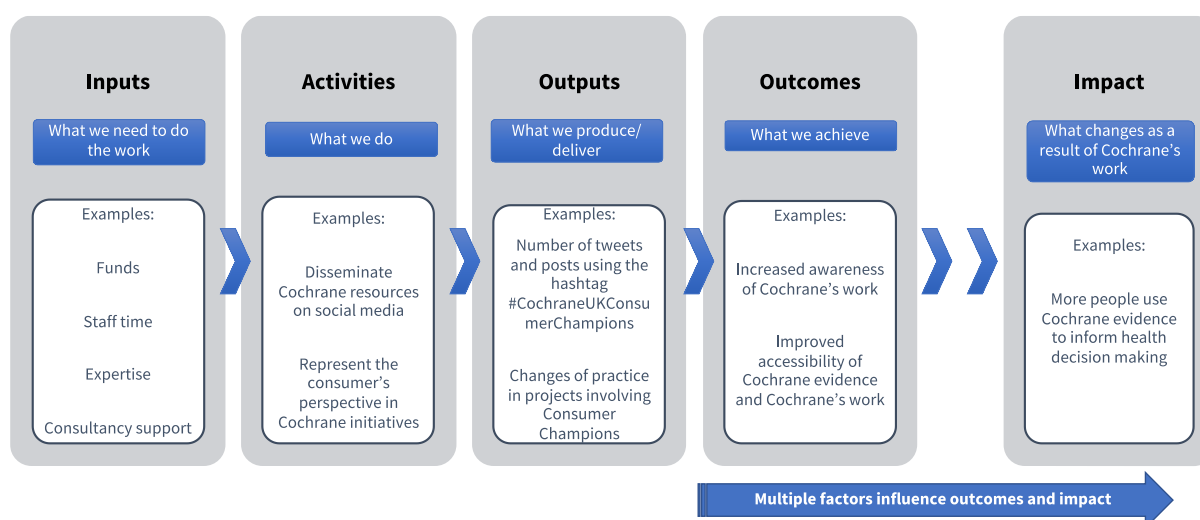


Figure 2 – Logic model – Cochrane UK Consumer Champions project.

Inputs include the resources that support the project implementation (WHO, n.d.).

Activities include actions that the Cochrane UK Consumer Champions perform to achieve the project's goals (WHO, n.d.).

Outputs are first-level results, such as number of social media posts, number of impressions and engagements, quantification of activities (WHO, n.d.).

Outcomes include second-level results that occur from outputs. These can be changes in the target audience knowledge as a result of exposure to the work of Cochrane UK Consumer Champions but can also be influenced by other factors. These changes will influence impact (WHO, n.d.).

For the interim evaluation, we will focus on the activities and outputs that resulted from the involvement of Consumer Champions.

Activities and Outputs

Activity 1: To develop and conduct a survey within the communities of the Cochrane UK Consumer Champions

In April 2021, the Consumer Champions developed and conducted a survey aimed at understanding the baseline knowledge and perception of Cochrane within their communities, and to identify preferred platforms and formats for accessing health information. This survey was also an opportunity to raise awareness of Cochrane as it provided further information to all the respondents at the end of the survey.

Of 76 respondents, 63% had heard of Cochrane and 37% had never heard of Cochrane. Less than 5% were part of the Cochrane Consumer Network. The results of the survey can be found in [Appendix 1](#).

The Consumer Champions are currently developing a strategy to compile and share Cochrane resources with the aim of raising awareness to Cochrane. The results of the survey will be taken into consideration to shape their approach.

Activity 2: To disseminate Cochrane resources and initiatives on social media

The Consumer Champions use Twitter as the main social media platform to disseminate relevant resources and engage with their communities (total of 4037 followers on Twitter). One Consumer Champion is more established on Facebook and shares content with her community, in particular the Facebook groups “Developmental Language Disorder support” and “Raising Awareness for Developmental Language Disorder (DLD)”, with a total of 3500 members.

The Consumer Champions have decided to use the hashtag “CochraneUKConsumerChampions” to track their engagement and highlight their role within Cochrane UK. Since starting the project, the Consumer Champions have published over 100 posts and tweets using this hashtag, or similar. Cochrane UK began using the hashtag “CochraneUKConsumerChampions” in December 2020. From December 2020 to June 2021, tweets from the @CochraneUK account including this hashtag have had:

- 31294 impressions (this is an indication of the number of screens the tweets will have been presented on)
- 228 engagements (this is the number of times anyone engaged with the content)
- 26 retweets
- 55 clicks on the links contained within the tweet

Below are examples of some of the tweets posted by the Cochrane UK Consumer Champions:

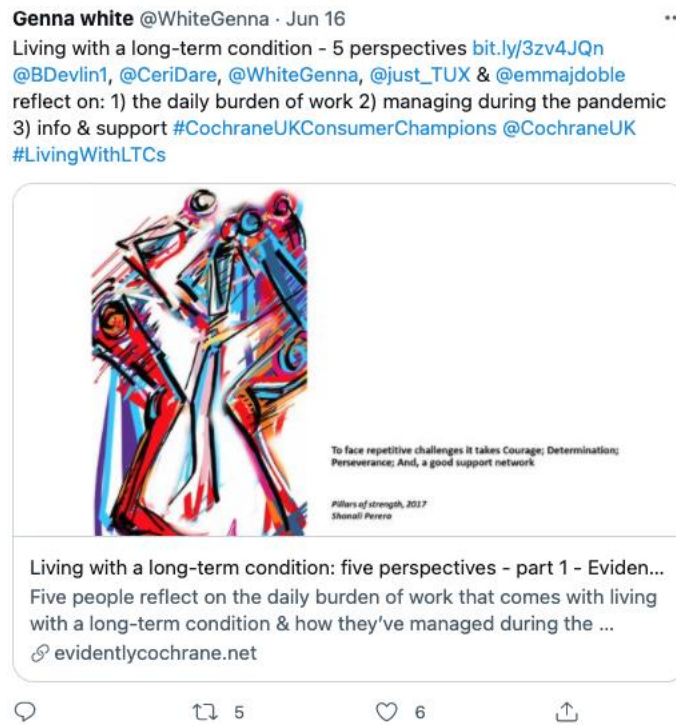


Figure 3 - Tweet by Genna White (3647 impressions, 57 engagements, 5 retweets - 18th June 2021).

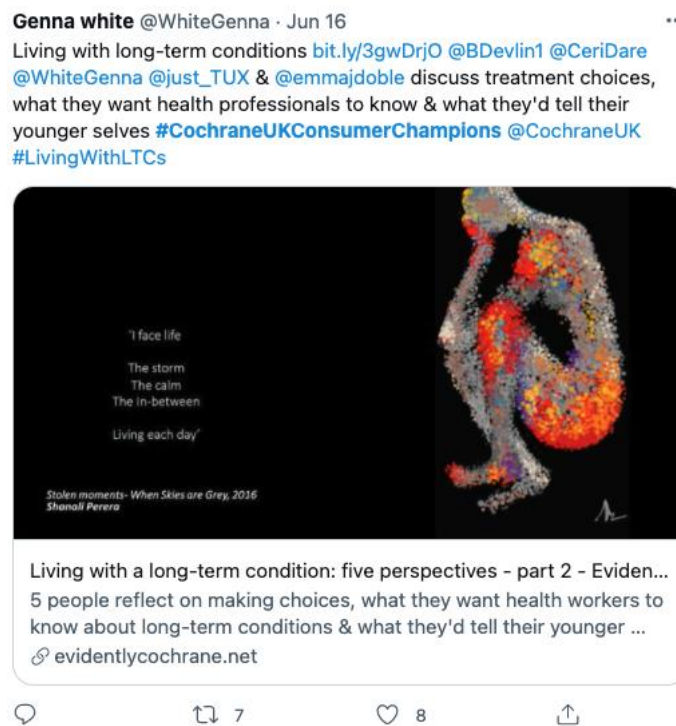


Figure 4 - Tweet by Genna White (6728 impressions, 73 engagements, 7 retweets - 18th June 2021).

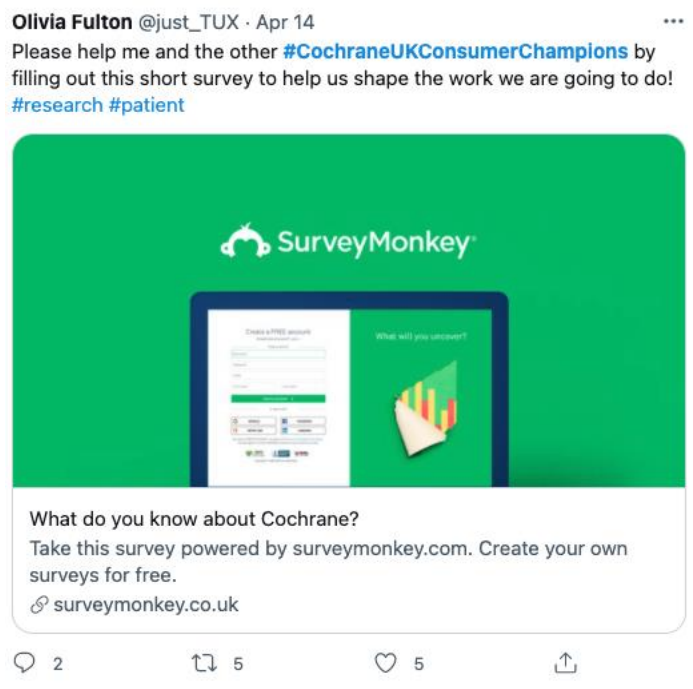


Figure 5 - Tweet by Olivia Fulton (**5143 impressions, 5 retweets** - data from 28th June 2021).



Figure 6 - Tweet by Olivia Fulton (**8326 impressions, 9 retweets** - data from 28th June 2021).



Figure 7 - Tweets by Brian Devlin (combined total of **8365 impressions, 200 impressions, 18 re-tweets, 78 link clicks** - data from 28th July 2021).

One Consumer Champion described an example of when they perceived to have made a difference by raising awareness of a health problem and Cochrane evidence:

“I keep on re-tweeting things. Nine times out of ten, they won’t land anywhere, but occasionally they do make a difference. [...] There was a blog recently, and somebody from the States picked up and said: “My God, I wish I’d known this, this is amazing” [...] so I think it’s just that sort of using whatever little bit of influence I have on Twitter or whatever. And I do think that these things matter to people.” – Cochrane UK Consumer Champion, July 2021

Besides posting on social media, the Consumer Champions engage directly with consumers and healthcare professionals via private messaging.

“Also, there’s a lot of doctors and nurses that follow me and, if there’s something that I think that they’ll be interested in, I’ll DM them, or direct message them with whatever it is that Cochrane is doing” – Cochrane UK Consumer Champion, July 2021

Activity 3: To represent the consumer’s perspective within Cochrane and relevant organisations

a. Twitter Chats

The Consumer Champions have participated and contributed to conversations on Twitter on relevant topics:

- “Involving patients in online events and research”, #InvolvingPatientsOnline, hosted by Emma Doble for The BMJ (December 2020)

- “Language Matters: the use and misuse of language when talking about long-term conditions”, #LanguageMatters, hosted by Cochrane UK (June 2021)



Figure 8 – Tweet by Olivia Fulton, in response to the twitter conversation #LanguageMatters.

b. Blogging

The Consumer Champions and Emma Doble, Patient and Consumer Coordinator, have co-produced two blogs on “Living with Long-Term Conditions: five perspectives” for [Evidently Cochrane](#), published in June 2021. The two blogs had a total of 1614 views (data from 28th July 2021).

A Consumer Champion has also written a blog on “Attending (online) conferences as a patient” on 2nd March 2021, in anticipation of Virtually Cochrane. The blog was published on her personal blog and had 613 views (data from 28th June 2021).

c. Events

From October 2020 to April 2021, the Consumer Champions and the project coordinators were involved in the organisation of [Virtually Cochrane](#) to ensure that the consumers’ voice was represented. One Consumer Champion represented the group and the consumer’s perspective from the early stages of planning the event and was involved in the following activities:

- Participation in regular meetings with the organising committee

- Proposal of relevant topics and speakers for the programme of the event, and strategies to engage consumers
- Planning the session “Better health decisions. Using Cochrane evidence in shared decision-making” and participation as a panel member in the live session

All the Consumer Champions were also involved in:

- Reviewing the communication materials and strategy to improve their accessibility and inclusivity. As a result of their input, the Cochrane UK team adapted the language of the registration form and communication materials, and made changes to the images and pace of the promotional video
- Preparation of a presentation for the Project Hub and a drop-in meeting during the event

The Consumer Champions felt that their perspectives and input were valued during Virtually Cochrane:

“I’m so grateful to have been able to attend and participate in Virtually Cochrane. Thank you so much Marta Santos and Emma Doble for looking after the Cochrane UK Consumer Champions so well” – Cochrane UK Consumer Champion, April 2021

“I think the discussion around the way that the Cochrane Reviews are presented with the Plain English Summary. I thought that was quite important to me actually [...] I felt empowered enough to be able to say that, and I think it was. I got a very, very positive response from her (member of the Cochrane Governing Board).” – Cochrane UK Consumer Champion, July 2021

The number of registrations from patients, members of the public and carers was **20 times higher than in 2019**. It is important to note that the transition to a virtual event may have also contributed to the increase of registrations.

d. Dissemination

The Consumer Champions have contributed to the evaluation of Cochrane’s Plain Language Summary Project, by completing a comprehensive survey directed to consumers. This survey aimed to identify what makes Cochrane’s Plain Language Summaries easy or difficult to understand, and what can be done to improve them.

a. Collaboration with Cochrane Review Groups

Three Consumer Champions have established contact with a Cochrane Review Group. Two Consumer Champions peer-reviewed a Cochrane Review.

Activity 4: Share Cochrane’s tasks with consumers and promote involvement with Cochrane

Two Consumer Champions have shared consumer peer review tasks from Cochrane TaskExchange with their communities.



Figure 9 – Tweet by Brian Devlin (590 impressions, 4 engagements – data from 28th July 2021).

Implementation and Monitoring

The evaluation of the implementation process (described in page 4) was underpinned by a theoretical model – Normalisation Process Theory (NPT). NPT identifies four mechanisms through which participants contribute to implementation processes: coherence; cognitive participation; collective action; reflective monitoring (May and Finch, 2009).

We have analysed these four mechanisms and constructs based on the interviews conducted with the Cochrane UK Consumer Champions from June to July 2021, the monthly reflective journals and project documentation. This analysis only reflects the input of 3 out of 4 Cochrane UK Consumer Champions due to the long-term absence of one of the Consumer Champions.

i) Coherence

Coherence is the sense-making work that participants do individually and collectively when they are faced with the problem of operationalising a set of practices (May and Finch, 2009). Sense-making requires:

1. Participants to distinguish the intervention from current ways of working
2. Participants to collectively agree about the purpose of the intervention
3. Participants to individually understand what the intervention requires of them
4. Participants to construct potential value of the intervention for their work (May and Finch, 2009)

Key considerations and findings:

- The Cochrane UK Consumer Champions are the first cohort of Consumer Champions and were involved in shaping the role based on their individual interests and skillset.
- The Consumer Champions reported difficulties in understanding the role, aims, objectives and expected outcomes at the beginning of the initiative.

“I was initially quite overwhelmed by size of Cochrane, understanding where I fit and how I was going to contribute.” - Cochrane UK Consumer Champion, November 2020

“It was confusing to know what the role was at first” - Cochrane UK Consumer Champion, December 2020

“There are so many different areas that could be looked at but trying to decide on the top priority is tricky.” - Cochrane UK Consumer Champion, June 2021

The project coordinators expected a period of familiarisation with the organisation and the role that would be shaped in collaboration with the Consumer Champions. For this reason, we planned several meetings with key individuals, shared resources and allocated time in the first months to focus on learning more about the organisation and the role. These actions have shown to be fruitful as the Consumer Champions developed a greater understanding of the role and what it entails in the first 3 months of the initiative. They consider that the workshop with Sally Crowe, meetings with Martin Burton, the Cochrane UK team and the Consumer Champions were crucial to gain a better understanding of the organisation and the role.

“Having video calls with the other champions and other Cochrane members where we discussed this has really helped. [...] I have found the workshops with Sally Crowe really insightful and informative, and they have provided me with the clarity to take the next steps in my journey as a Cochrane Consumer Champion and reassured me that I have an important contribution to make.” - Cochrane UK Consumer Champion, November 2020

“I spent a lot of time background reading and trying to understand how Cochrane is structured and how it works. I think I have an angle on that now. I am much more confident ‘describing’ Cochrane UK now. It’s an enormous organization and is very complex. The breakthrough was understanding the difference between Cochrane Central and Cochrane UK.” - Cochrane UK Consumer Champion, December 2020

“After meeting the other Champions and discussing with Sally I got some clarity as to what our role as a Champion is.” - Cochrane UK Consumer Champion, December 2020

“I found the team meeting with Martin useful. I gained a better understanding of the structure of Cochrane and how it has developed, and how the success of my role will be measured.” - Cochrane UK Consumer Champion, January 2021

During the interviews conducted in July 2021, the Consumer Champions clearly defined their role and the purpose of the project.

- The regular meetings with the project coordinators were important to help the participants distinguish their role from the voluntary role of Cochrane consumers and make sense of the specific tasks and responsibilities. As an example, we have discussed that the participation in peer-reviewing Cochrane Reviews would be considered a learning exercise and opportunity to network with relevant Cochrane Review Groups, however, these would not be the primary focus of the Consumer Champions Project.
- The Consumer Champions expressed a belief in the value of consumer involvement.

“They [Cochrane UK Consumer Champions] bring the lived experience and can highlight where/ how changes can be made to help products become more user friendly to the patient population.” – Cochrane UK Consumer Champion, July 2021

“They [Cochrane UK Consumer Champions] represent the consumer, their voice and their lived experience. These elements can be missing from health research but they are vital for ensuring that research is meaningful to the people that it concerns.” – Cochrane UK Consumer Champion, July 2021

ii) Cognitive participation

Cognitive participation is the work that the participants do to build and sustain the practices and intervention (May and Finch, 2009). It requires:

- Key individuals to drive the intervention forward
- Participants to agree that the intervention should be part of their work
- Participants to buy in to the intervention
- Participants to continue to support the intervention (May and Finch, 2009)

Key considerations and findings:

- The Consumer Champions identified the project coordinators as the key individuals that drive the intervention forward and support them in their role.

“Marta and Emma are sensitive and kind, and skilled, leaders and I trust their judgement fully in telling me the areas that they think I’ll have most effect in.” – Cochrane UK Consumer Champions, February 2021

“Emma and Marta. They keep me on track and support me to do my role as a consumer champion.” – Cochrane UK Consumer Champion, June 2021

- The Consumer Champions expressed their belief that it is right for them to be involved and that they can make a valuable contribution:

“There are a lot of people who have had very hard lives, who maybe got children with special needs and they just choose to engage with me, and I seem to have quite a big day following so ... I think that I can bring Cochrane to people that wouldn’t normally have any knowledge” – Cochrane UK Consumer Champion, July 2021

“I think I feel fully embedded into Cochrane just now. I’ve met some truly lovely people and have felt valued throughout. I feel that my opinion is always valued and respected” - Cochrane UK Consumer Champion, January 2021

“I’m really enjoying my time in Cochrane UK. Easily the best thing I’m doing just now. As before I feel that, in the things I’m involved with, my opinions are sought out and valued.” - Cochrane UK Consumer Champion, February 2021

“I contributed to the long-term health condition series about my experience [...]. I found the exercise really valuable - it enabled me to recognise that sharing my knowledge and experience may help other people navigate their own health journey.” - Cochrane UK Consumer Champion, March 2021

-
- Throughout the project, the Consumer Champions have shown to have the capacity and willingness to collectively and individually contribute to the work involved in this initiative.

“I’m also getting a clearer insight into how the other champions are active within their respective communities. I really enjoy speaking with everyone and developing ideas together.” - Cochrane UK Consumer Champion, January 2021

iii) Collective action

Collective action relates to the operational work involved in the intervention (May and Finch, 2009). It requires:

- Participants to perform the tasks required by the intervention
- Participants to maintain their trust in each other’s work and expertise through the intervention
- The work of the intervention to be appropriately allocated to participants
- The intervention to be adequately supported by its host organisation (May and Finch, 2009)

Key considerations and findings:

- The Consumer Champions are proactive in identifying opportunities of their interest and undertake the tasks required by the intervention. Each Consumer Champion has dedicated an average of 4 to 8 hours per month to this project. However, two Consumer Champions have had to temporarily suspend their active involvement for periods of time due to medical reasons and personal circumstances.
- The project coordinators have identified specific tasks that require more consistent involvement from the Consumer Champions:

- To identify relevant and accessible Cochrane resources to share with their own communities and develop a strategy to disseminate these resources.
- To analyse the results of the survey “What do you know about Cochrane” and reflect on the findings to inform how to best engage with their communities.
- Cochrane UK supports the Consumer Champions and the initiative by allocating two project coordinators, funding training and development opportunities organising regular meetings and support, and remuneration to the Consumer Champions. When the Consumer Champions were asked about what further support could be offered to them, as part of the interviews conducted in June/ July 2021, they mentioned:

“Everyone I have had contact with at Cochrane UK has been really supportive so I would say continue doing what you’re doing” - Cochrane UK Consumer Champion, June 2021.

“I think the level of support is phenomenal. I think it is really good. [...] I can't think of a single thing that I need more than I'm getting really from yourself from the others. I think it would be good sometime, when the lockdowns are all over and so on, to meet together as a group. So I get to know people a little bit better, but that's some time away. But I can't think of a single thing other than that really.” – Cochrane UK Consumer Champion, July 2021.

- From November 2020, the Consumer Champions participated in several learning and development activities to improve their knowledge about the organisation, develop skills and set individual and collective goals. In particular, the Consumer Champions participated in:
 - An introductory workshop followed by meetings with the Cochrane UK team
 - Access to Cochrane’s training resources and an introductory booklet highlighting the most relevant resources
 - Monthly meetings with the project coordinators with additional follow-up to share additional resources based on individual learning needs
 - Dissemination Training course delivered by the Cochrane’s Knowledge Translation team (one Consumer Champion only)
 - Peer-reviewing Cochrane systematic reviews.
- The role is tailored to the Consumer Champions’ profile. The Consumer Champions have been actively involved in shaping the role based on their interests and strengths. The project coordinators maintain regular contact with the Consumer Champions to discuss upcoming activities or projects and ensure that tasks are adequately allocated.

iv) Reflective monitoring

Reflective Monitoring is the appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them (May and Finch, 2009). It requires:

1. Participants to access information about the effects of the intervention
2. Participants to collectively assess the intervention as worthwhile
3. Participants to individually assess the intervention as worthwhile
4. Participants to modify their work in response to their appraisal of the intervention (May and Finch, 2009)

Key considerations and findings:

- The Consumer Champions have been involved in the evaluation and the report will be shared and discussed with them.
- During the interviews conducted in June/ July 2021, two Consumer Champions reported that evaluating the impact of their involvement is challenging, which may affect how they perceive their contribution.
- The project coordinators meet with the Consumer Champions regularly and make changes as a result of the individual and communal appraisal. The project coordinators proposed setting up individual development plans with long-term goals however this has not been achieved. The regular meetings with the Consumer Champions have focused on setting up short- to medium-term goals (1-3 months) and tasks.
- The Consumer Champions are asked to complete monthly reflective journals to monitor the engagement in activities and reflect on the potential impact resulting from the involvement of the Cochrane UK Consumer Champions. The Consumer Champions have been less consistent with completing the journals.

Overall, the implementation strategy has shown to be successful and created a strong foundation to maximise the contribution of the Cochrane UK Consumer Champions.

v) Costs

To implement the project, Cochrane UK allocated funds for four Cochrane UK Consumer Champions. Two of the four Consumer Champions have not claimed any fees to accommodate personal circumstances. The table below includes the estimated costs of involving and remunerating all four Cochrane UK Consumer Champions. It was estimated that the Consumer Champions who collaborated voluntarily dedicated 4 hours per month to the project.

The external consultancy fees are the costs involved in planning and delivering workshops and specialised consultancy services in Patient and Public Involvement (PPI).

The infrastructural costs and direct input from the Cochrane UK team were not included in this the interim evaluation.

Description	Total amount (October 2020 – June 2021)
Four Cochrane UK Consumer Champions – remuneration for involvement	£3150
External consultancy fees	£14380
Total costs	£17530

Table 1 - Costs associated with the implementation of the Cochrane UK Consumer Champions (October 2020 - June 2021).

Recommendations

Project coordinators:

- To review or complete the individual development plans in collaboration with the Consumer Champions
- The regular meetings between the Consumer Champions and the project coordinators will be shortened from 1 hour to 30 minutes and focus on discussing the plan for the upcoming month. The reflective journals will be used to report on the involvement in key activities, outputs (including time dedicated to each activity), and reflection;
- To provide further support in understanding the role and Cochrane as an organisation to future Consumer Champions. This might involve an introductory meeting with Martin Burton, Director of Cochrane UK, and inclusion of additional resources in the support booklet
- To introduce yearly appraisals to formally discuss whether the involvement in the project continues to be fruitful and viable for each Consumer Champion. Furthermore, the continuity of involvement in the project will be reviewed after two years of being involved in the role;
- To review the support booklet for Consumer Champions to highlight key resources to further support the understanding of Cochrane as an organisation

Cochrane UK Consumer Champions:

- To complete the reflective journal in anticipation of the regular meetings with the project coordinators
- To identify individual long-term goals and activities

Conclusion

The Cochrane UK Consumer Champions project has been a first step for Cochrane UK to expand its connections and work with consumers. This project has involved a lot of learning and development as part of the process. The consumer champions have achieved an incredible amount considering the short time they have been involved in the project and with Cochrane. Involving wider groups of consumers in Cochrane, and evidence-based healthcare more generally, is often sought and this project has highlighted how this can be done by involving consumers openly, supporting them through the work and co-designing and delivering the things which matter most to them. As we conclude this first year of learning and reflection, we look towards recruiting a new group of champions to expand the project and create a second cohort.

As the project expands and the Consumer Champions collaborate with more projects, it would be important to conduct a comprehensive evaluation that includes feedback from members that were involved with, and may benefit from, the contribution of the Consumer Champions.

References

May, C. and Finch, T., 2009. Implementing, embedding, and integrating practices: an outline of normalization process theory. *Sociology*, 43(3), pp.535-554.

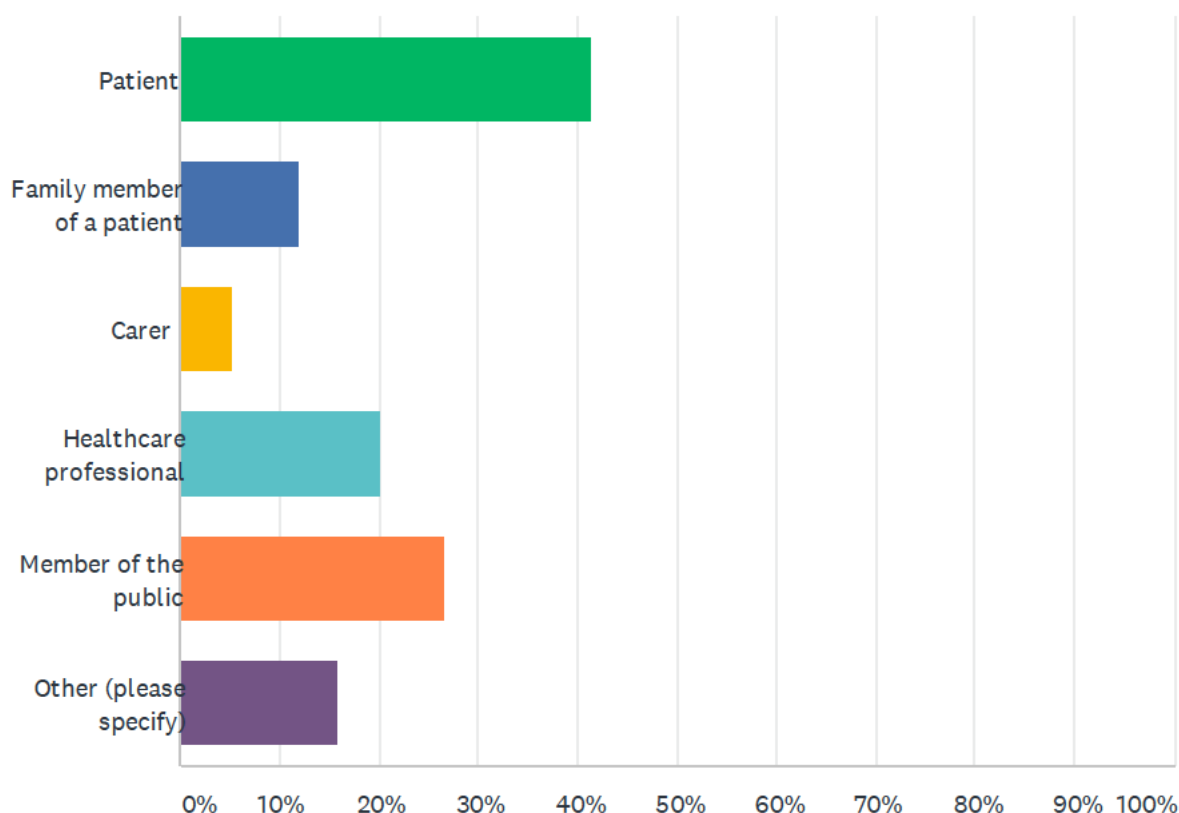
WHO (n.d.). *Evaluate campaigns and other complex communication interventions*. [Online]. Available at: <https://www.who.int/about/communications/evaluation/campaigns-evaluation> (Accessed: 2nd May 2021).

Appendix 1

Survey Results

What do you know about Cochrane?

Q1 – How would you describe yourself? (n=75)



Other:

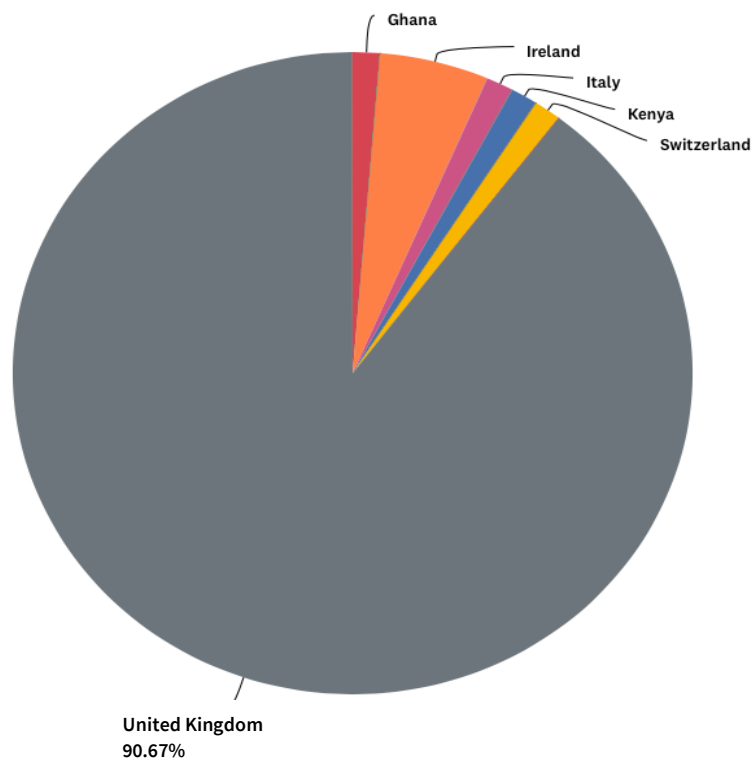
- Member of Cochrane UK
- Professor of Pharmacology
- Researcher
- Student SLT
- Student healthcare professional
- Informaticist
- Retired HCP
- And ex healthcare professional
- Patient & researcher
- Retired healthcare professional
- Wellbeing coach (complimentary health therapies)

Q2 - What is/ are your health area(s) of interest (e.g. asthma, diabetes,...)? (n=75)

arthritis disease mental health Depression
 disorders chronic **Diabetes** syndrome
Asthma Thyroid medicine cancer health bowel
 care communication disorders



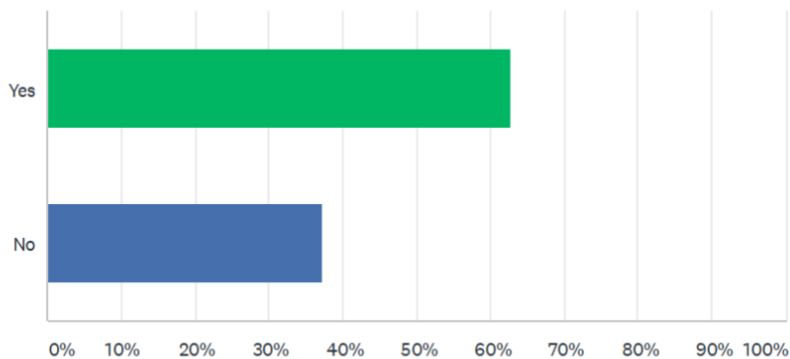
Q4 - In what country do you live? (n=75)



Q5 - Have you heard of Cochrane? (n=75)

Q5 Have you heard of Cochrane?

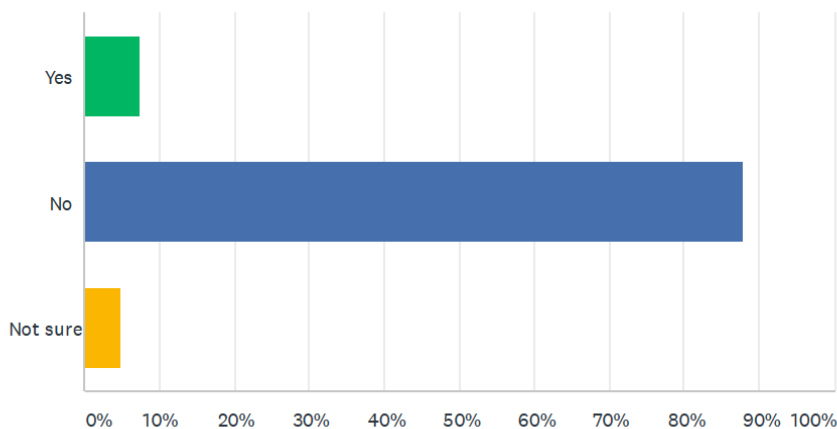
Answered: 75 Skipped: 0



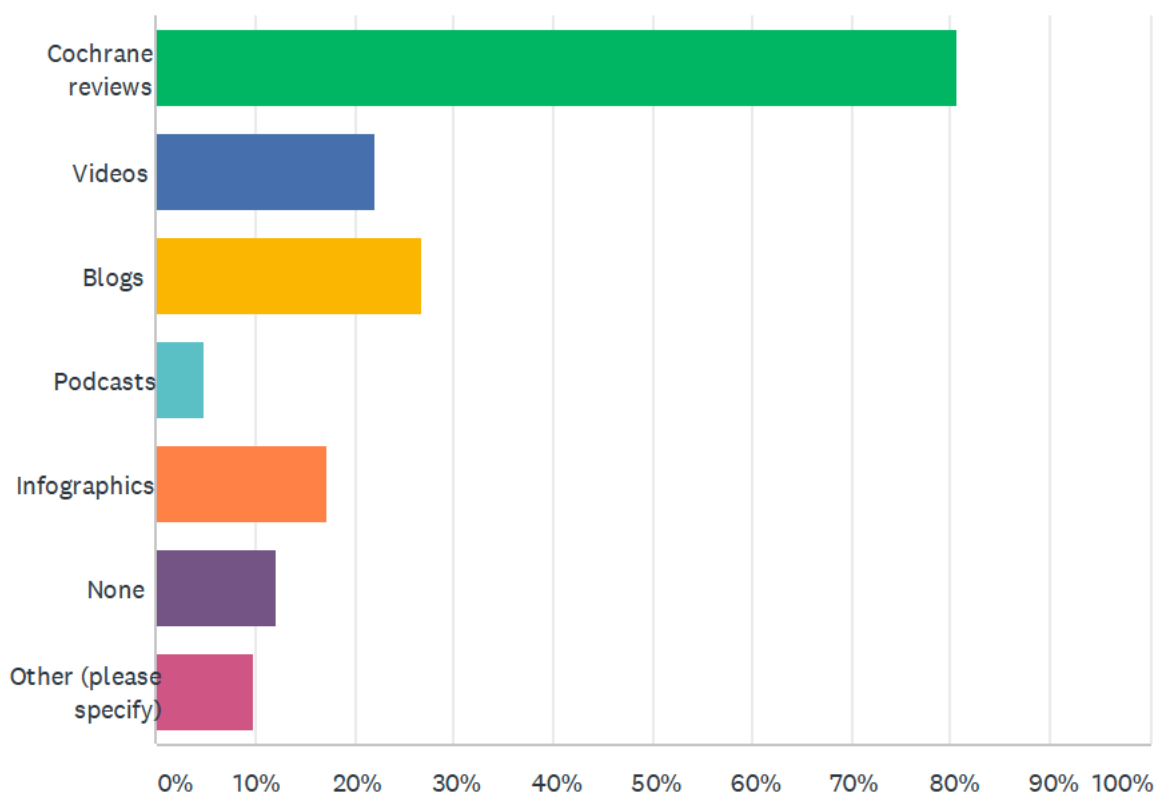
ANSWER CHOICES	RESPONSES	
Yes	62.67%	47
No	37.33%	28
TOTAL		75

If yes to Q5:

Q6 - Are you part of the Cochrane Consumer Network? (n=41)



Q7 – What Cochrane products have you used? (n=41)

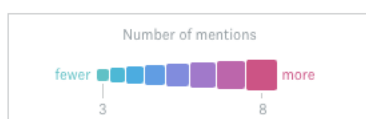


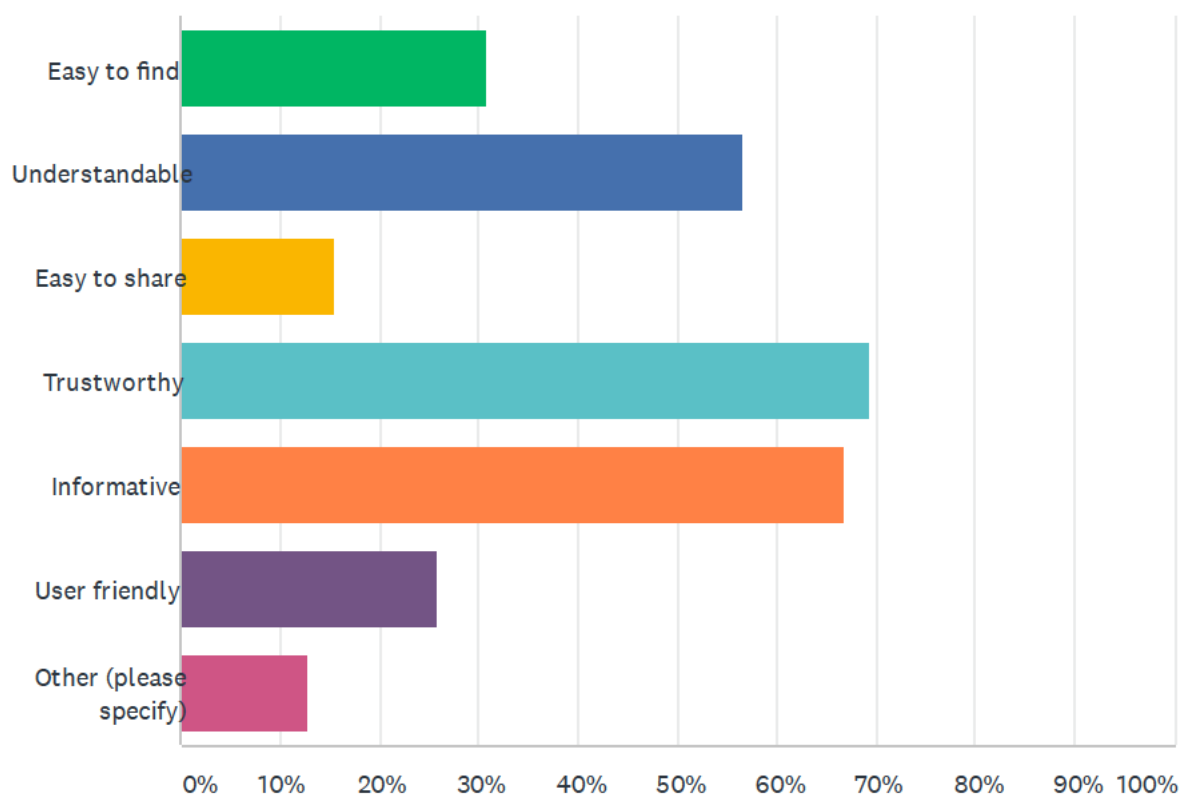
Other:

- Cochrane reviews meta analysis tools
- Social media feeds (Twitter)
- Online Cochrane Handbook for Systematic Reviews of Interventions
- Meta-analysis tool

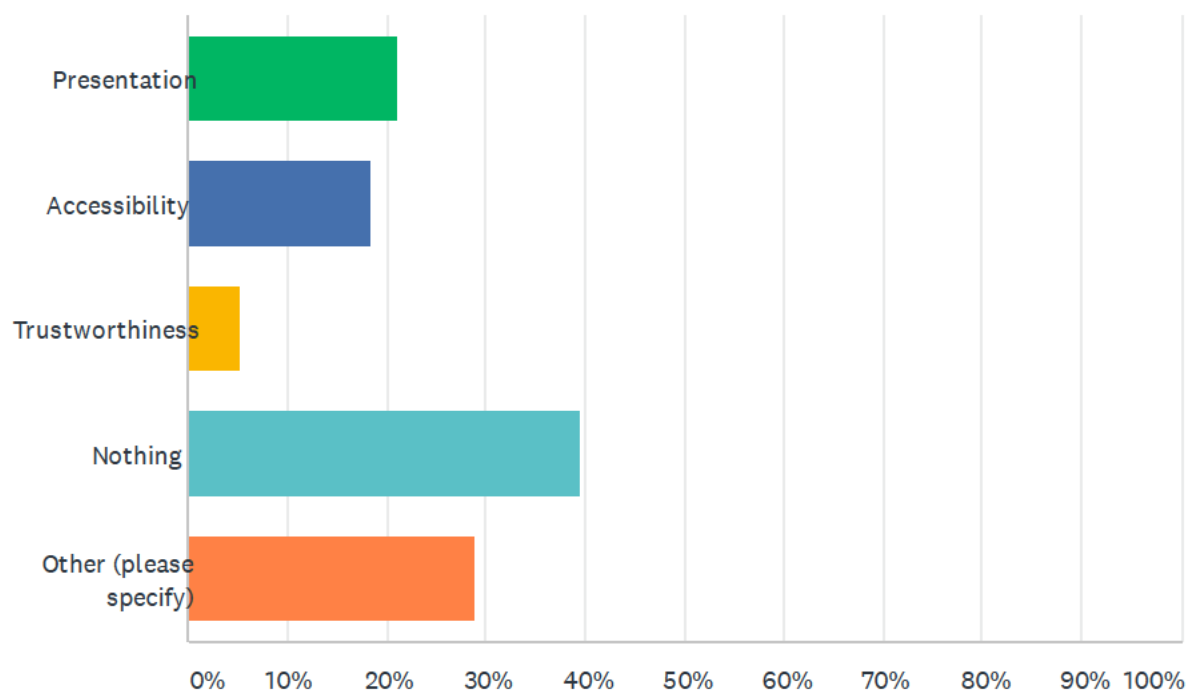
Q8 - What did you use Cochrane products for (e.g. to inform decision making, for general interest, ...)? (n=35)

systematic reviews interest **Research** Decision making
 General interest Inform

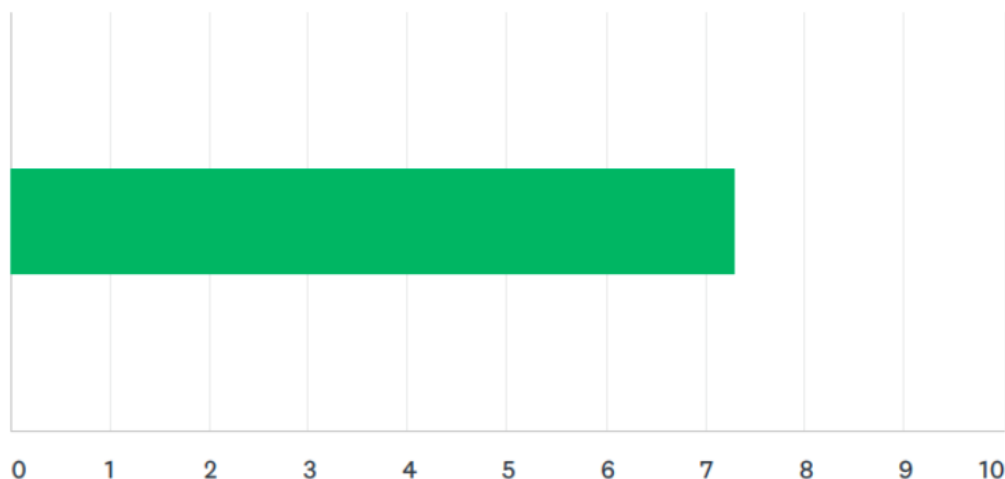


Q9 - What did you like about the Cochrane products you used? (n=39)**Other:**

- Blogs were understandable and informative. Cochrane Reviews were more difficult to navigate and find the exact topics that I was looking for. More complicated to decide what to look at that would be useful for me.
- Authoritative
- Have only heard of yourselves never used your products

Q10 - What could be improved on the Cochrane products you used? (n=38)**Other:**

- “I worry about the diligence of some reviews in their searches for studies”
- “I found it difficult to find the exact topics I was looking for. Possibly I wasn't using the right wording. Doesn't come up on google searches I don't think?”
- “I never realised until today that the reviews were free to access”
- “It would be good to have key definitions of words when you hover your cursor over them.”
- “Speed of updating reviews eg Exercise for ME/cfs, patients could be harmed in the meantime.”
- “I can't think of anything, but there are always ways to improve things!”
- “How to section for lay people to interpret information”
- “Don't know”
- “I find them rather expensive.”
- “Put plain English summary before technical report”

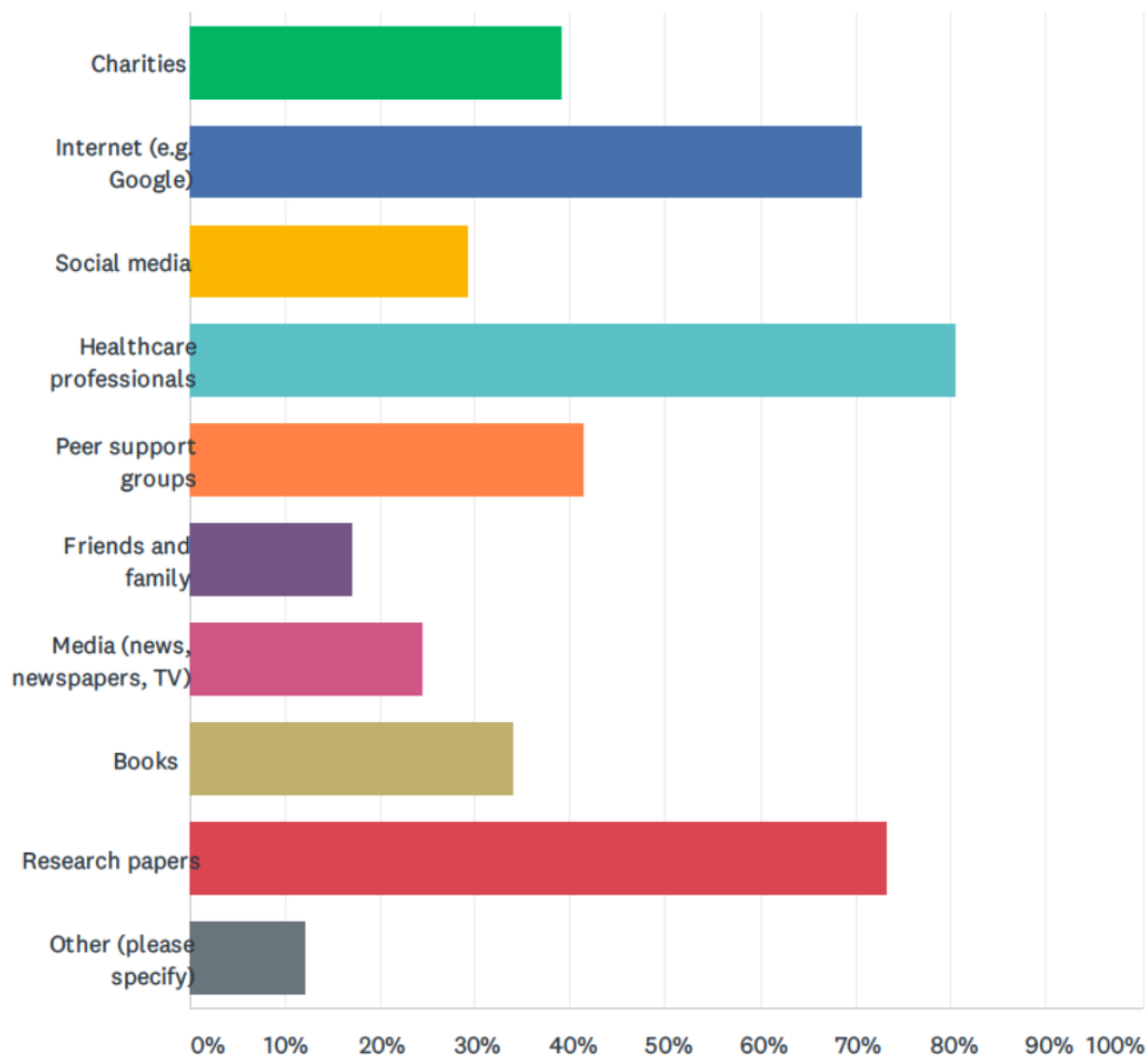
Q11 - How confident were you using the Cochrane products? (n=39)**Q12 - Please help us understand why you selected the answer above: (n=30)****Responses:**

- “It was effective”
- “Feel it is a good system”
- “Methodology is super clear and consistent between reviews. I do worry about the diligence in finding studies, and possible bias in inclusion/exclusion criteria.”
- “Not confident I am finding the right information on the Library for health conditions, or searching in the right place. Lots of information - quite overwhelming. Blogs help though to put that into one place, but don't always cover the topic you are looking at.”
- “When reading Cochrane reviews, I have found the results and discussion parts to be in accessible for taking information away from. I will read articles that will reference a Cochrane review to say "this review showed that Therapy A was effective" but when I read through the review myself I find the information was never presented to be so clearly read/understood.”
- “I'm not a clinician so my understanding isn't perfect but I still have pretty high confidence”
- “Review structure isn't overly intuitive”
- “Independent”
- “Sometimes I feel I don't have the background knowledge required to understand the info Cochrane provides”
- “Clear information”
- “Have used Cochrane reviews in research”
- “I am fairly familiar with Cochrane products, but can always learn more!”
- “Felt a little out of depth while reading some systematic reviews.”
- “Plain language summaries helped.”
- “Easy to use and I'm very familiar with them”
- “I know enough about stats to benefit from it”
- “Relatively easy to read and when I looked Cochrane up it was well regarded”
- “I have not used it for several years”
- “I knew that they were reliably used to look at health topics previously”
- “Evidence syntheses are done using strict methodological guidelines”

- “I have a generally good level of comprehension of scientific discussions”
- “Excellent but no data set is perfect.”
- “As stated above never used your products only ever heard of yourselves in passing.”
- “User friendly”
- “Considered, ethical and professional”
- “So much qualitative information missed and many areas where as there is little quantitative information just end up with “more research needed””
- “Not sure”
- “I understood it was peer reviewed research”
- “Everything is clearly labelled.”
- “I have no doubt whatsoever in the trustworthiness of Cochrane’s materials”

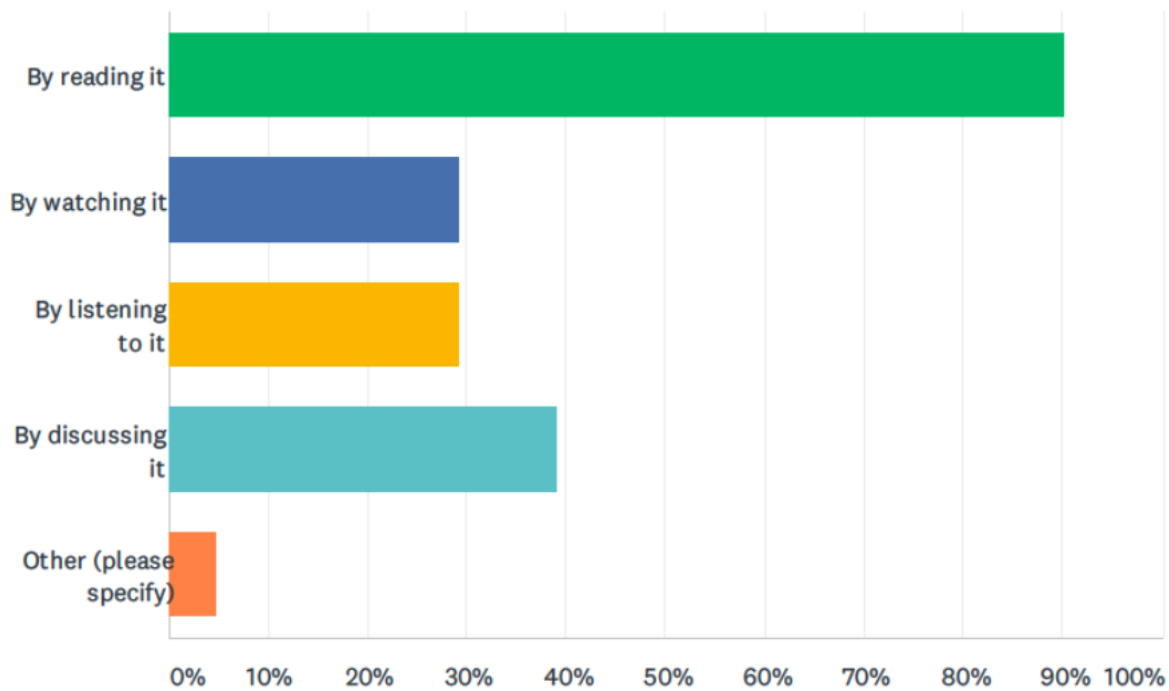
If no to Q5:

Q13 - Where do you get your general health information/ advice from? (n=41)

**Other:**

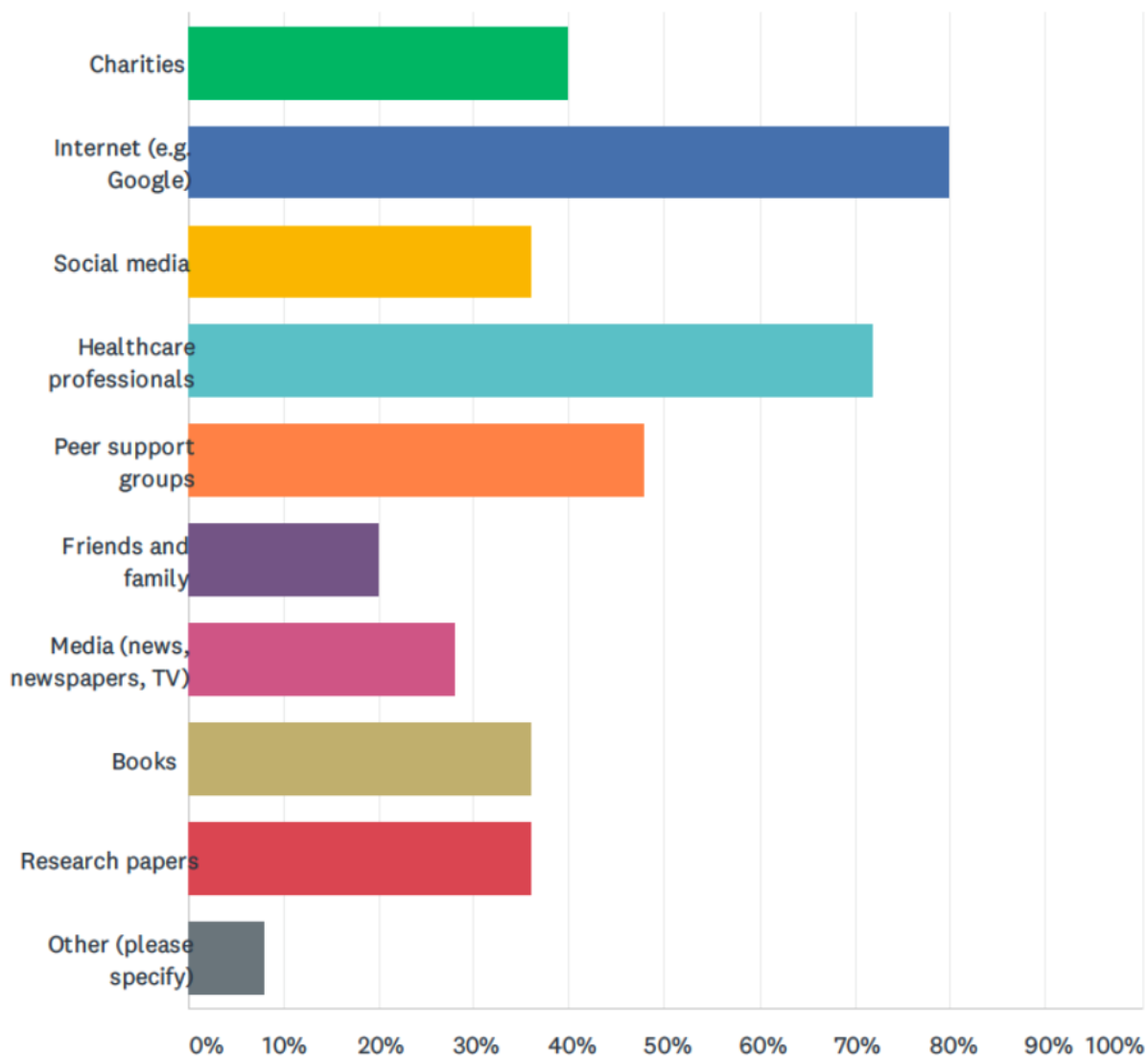
- “Cochrane!”
- “Patients”
- “Textbooks”
- “Medical Textbooks”
- “Research conferences, general update conferences”

Q14 - How do you prefer to consume/ access this information? (n=41)

**Other:**

- “It depends on what I’m using it for; I use all modes!”
- “Lectures”

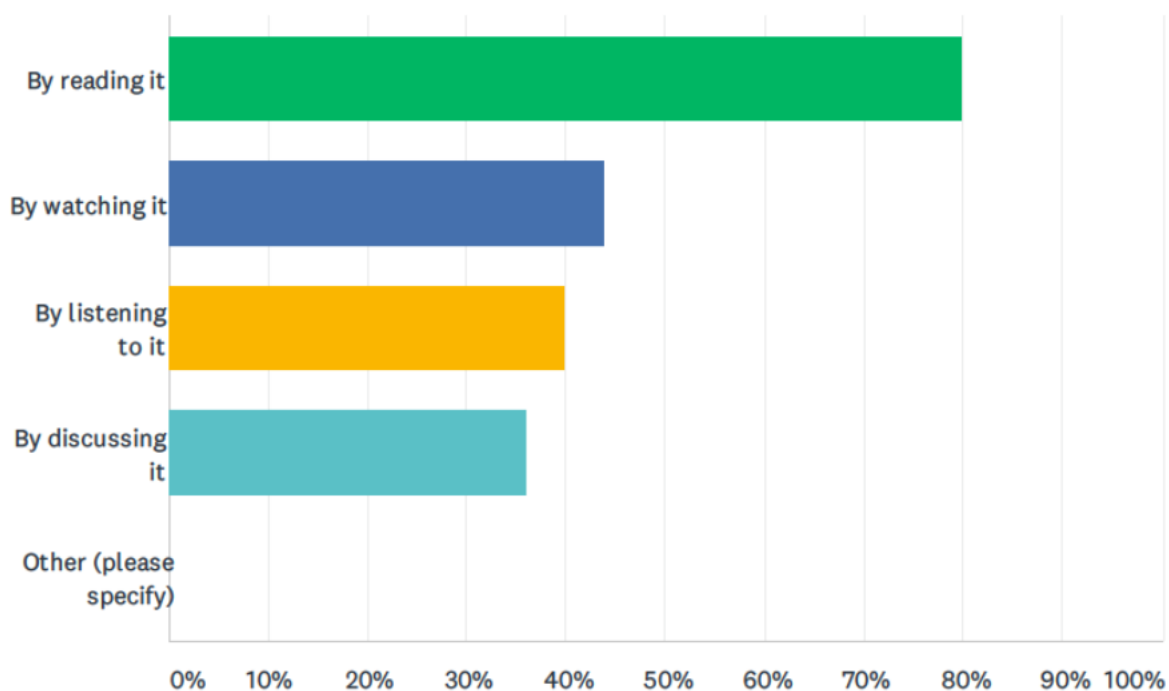
Q15 - Where do you get your general health information/ advice from? (n=25)



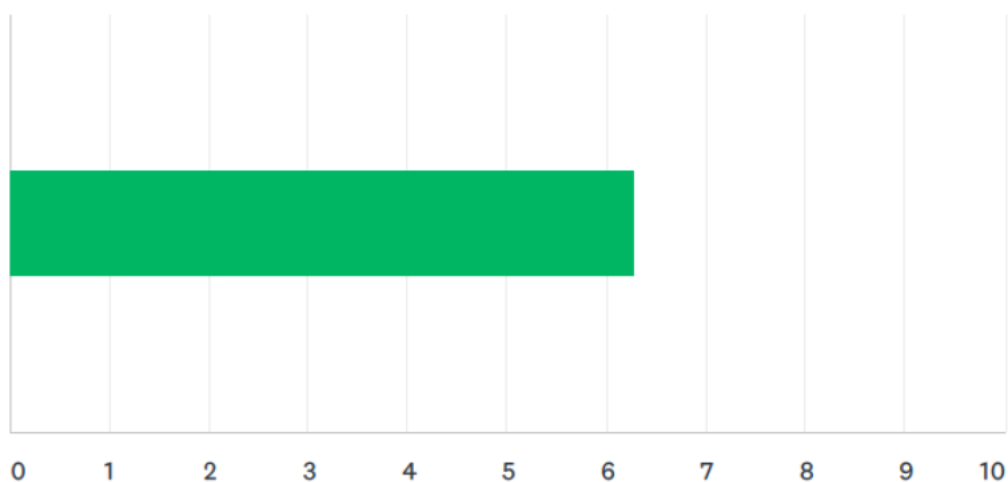
Other:

- “Info from school”
- “NHS”

Q16 - How do you prefer to consume/ access this information? (n=25)



Q17 - How much do you trust this information? (n=25)



Q18 - What would you do if you couldn't find the information you were looking for from the sources you normally use? (n=24)

- “Ask a doctor”
- “Continue researching it or ask asthma nurse”
- “Contact my medical team”
- “Google it”
- “Keep googling”
- “Ask the chemist or Dr”
- “Ask paediatrician”

- “Post a question on support Facebook group”
- “Ask clinical colleagues”
- “Parent support groups”
- “Ask in peer support groups or if I felt it was urgent contact GP”
- “Ask someone on a forum for advice”
- “Ask my Psych”
- “I would Google!”
- “Nothing”
- “Google it”
- “Ask around for other sources of information”
- “Our son has a BSc medical Genetics & Masters in Human and Molecular Genetics plus now a 2nd year medical student so I ask him and he usually can find what I’m looking for this I’m very lucky”
- “Ask my medical teams or in peer support groups for where other people find their information”
- “Google”
- “Contact pharmacy or GP”
- “👤 maybe ask friends/family”
- “Refer to that particular area of medical profession in writing”
- “Not sure. Look elsewhere is the obvious answer but would be concerned about content reliability”