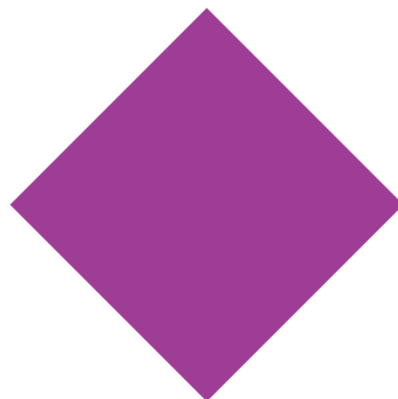


Report on the Cochrane Consumer Survey

Prepared for: Cochrane Consumer Executive

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Informed decisions.
Better health.**



Background

The Cochrane Centres, Branches and Network Structure and Function Review makes it explicit that Centres, Associates and Affiliates (the Groups) are encouraged to support the work of the Cochrane Consumer Network. To help these Groups achieve this recommendation, the Cochrane Consumer Network Executive (CE) thought it was important to find out how best to encourage and support consumer-related activities. To this end, and as a first step, the CE conducted a survey with the Groups. The survey aimed to identify:

- What consumer activities are currently being undertaken;
- What consumer activities groups wish to undertake;
- What support is needed by the Groups to assist them in undertaking these activities.

Methods

We obtained the list of the Groups to email the survey from Archie, Cochrane's contact database. A total of 44 Groups were emailed. A reminder was sent to those Groups who did not respond by the first deadline.

Entity	No. of entities	No. of responses received	Response rate (%)
Cochrane Centres	19	10	52.6%
Associates	23	13	56.5%
Affiliates	2	1	50.0%
Total entities	44	24	54.5%

The survey was first emailed on 30 May 2018 and a reminder was sent on 6 August 2018 to those Groups who did not respond to the initial email. A copy of the survey was attached with each email sent. The survey consisted of three questions:

1. Please list the consumer activities your Centre, Associate Centre or Affiliate is currently involved in
2. Please list the consumer activities you would like to undertake
3. Do you need any support to undertake consumer activities?

Results

Question 1: Please list the consumer activities your Centre, Associate Centre or Affiliate is currently involved in?

Five respondents indicated that currently their group is not undertaking any consumer-related activities. Of those respondents who indicated that they are involved in consumer-related activities, four main kinds of activities were highlighted:

1. Translation of consumer-targeted materials

The most common consumer-related activity respondents indicated they are currently involved with is the translation of consumer-targeted materials into local languages. Specific materials identified as being

translated included: plain language summaries, Cochrane Reviews and/or abstracts, “Testing Treatments”, and “Sense about Science booklets”. Only two respondents indicated that their group has developed specific locally-targeted consumer-related materials.

2. Dissemination and communication of Cochrane evidence

Many respondents indicated that they are involved in various kinds of activities aimed at disseminating and communicating Cochrane Reviews and evidence. Specific activities mentioned included: making translated consumer-targeted materials available on local Cochrane websites and Facebook pages; featuring the content of Cochrane Reviews in local newspapers, radio talk shows and on Cochrane staff and consumer group twitter accounts and blogs; and promoting the work of Cochrane in national newspapers. One respondent indicated that their Group has a specific work stream devoted to dissemination and communication of evidence to the broader public, which includes regularly engaging with journalists and the media to highlight new Cochrane reviews.

3. Building capacity to use evidence amongst consumers

Various respondents indicated that they have run a number of workshops and training sessions to highlight the work of Cochrane and the Cochrane Consumer Network, explain Cochrane Reviews and/or build capacity in evidence-based medicine and shared decision-making in health care. One respondent indicated that their institution runs an annual EBHC workshops, which includes a dedicated stream for consumers. Another respondent said his institution has supported (through sponsorship) four workshops on conflicts of interest for consumer advocates and representatives of consumer organizations.

4. Co-production of evidence

A few respondents mentioned that they are involved with developing and/or implementing activities to facilitate involvement of consumers in the co-production of Cochrane evidence. Examples highlighted included inviting consumers/patients to collaborate on a Cochrane Review; engaging consumers in priority setting for systematic reviews; involving consumer organizations in the translation of Cochrane evidence into local languages; and obtaining input from consumers in the planning and conducting of Cochrane-related research projects. One respondent indicated that they have recently employed consumers as staff members in the unit.

In addition to these four main categories of activities, other consumer-related activities respondents mentioned currently undertaking included:

- Networking/engaging with consumer groups on an informal basis;
- Advocacy work with consumer/patient organizations;
- Promoting and supporting the work of local patient groups;
- Encouraging registration in the consumer network;
- Engagement with media practitioners through media roundtables/workshops;
- Inviting and covering the costs (e.g. through stipends) for consumer/patient organizations to attend national, regional and/or global Cochrane Symposia;
- Establishing a committee of consumer champions to guide the group’s consumer-focused initiatives, including developing digital platforms to improve the overall user experience and increase engagement.

Question 2: Please list the consumer activities you would like to undertake?

Respondents identified a number of consumer activities that they would like to undertake. We organised these activities into five main categories:

1. Better identify key consumer advocates and their needs

Various respondents felt it is important to have a better understanding of who the main consumer advocates are, and what their needs may be. It was suggested that it could be useful to conduct a mapping exercise to identify the range of relevant stakeholders and stakeholder groups. It was also proposed that surveys should be conducted with local consumers to identify the specific support needs of consumers and patient organizations.

2. Build relationships with and between consumer advocates

Many respondents indicated that there is a need to develop and strengthen relationships with consumer groups, and also amongst consumer groups, including voluntary and health organizations. A number of strategies were proposed for how this might be achieved. These included: recruitment of more members (e.g. through advocacy visits to stakeholders); establishment of more formal Cochrane consumer networks nationally, regionally and globally; facilitating communication between consumers and related organizations nationally, regionally and globally; and inviting more consumers to attend Cochrane Colloquia. It was, however, mentioned that participation of consumers at Cochrane Colloquia will be limited potentially by language and cultural barriers, issues which require further consideration.

3. Enhance co-production of evidence

It was mentioned by a number of respondents that there is a need to explore ways in which consumers/patient groups can be more actively involved in the conducting of systematic reviews and other related Cochrane projects. It was suggested that one way of achieving this could be to identify 'consumer champions', who could advocate for and facilitate consumer involvement in Cochrane research and other activities.

4. Build capacity to use evidence amongst consumers

Building capacity amongst consumers in the use of evidence was emphasised by nearly all respondents. Capacity-building activities proposed included conducting workshops for consumers on Cochrane Reviews and the use of health evidence, and other training activities aimed at patient-centred medicine, decision-making for consumers and tools for the physician-patient interface.

5. Increase dissemination and promotion of Cochrane and evidence to consumers

Many respondents indicated that a number of activities to disseminate and promote Cochrane and evidence to consumers are being undertaken. However, they emphasised that these activities need to be increased, a greater variety of formats need to be employed (e.g. text, audio and video), and the scope of consumers targeted needs to be broadened (i.e. patients, public and not just health professionals). Respondents suggested a range of communication channels that should be utilised to promote the work of Cochrane and evidence. These included mainstream media (e.g. newspapers, radio, television, talk shows); social media (e.g. Facebook, Twitter); podcasts; webinars; leaflets and flyers. It was suggested that harnessing these channels requires building tighter relationships with the media. Other promotional activities suggested included: the printing and translation of more plain language summaries and other relevant information for dissemination to consumer groups; and identifying and using health days (e.g. World AIDS day) and disease specific conferences to host consumer specific events.

When highlighting the consumer activities that they would like to undertake, a number of respondents identified limited resources, including a lack of awareness of local funding sources outside of industry that would support work like this, as a major barrier to undertaking desired activities. Other barriers mentioned included limited in-house skills and expertise to develop and implement consumer activities; the difficulty of translating Cochrane evidence into simple content that can be understood by consumers; and the uncoordinated nature of many local consumer and patient organizations which makes engagement difficult.

Question 3: Do you need any support to undertake consumer activities?

Respondents identified various forms of support they felt they needed in order to undertake the consumer activities they currently do and would like to do. We organised these support needs into seven main categories:

1. Increased consumer materials

Many respondents indicated that they would like more knowledge translation products targeted specifically at consumers. Specific products mentioned included: information kits on what consumers can do; webinars; and update-to-date, user friendly brochures and leaflets on the work of Cochrane, the Cochrane Consumer Network and how consumers can get involved in Cochrane. It was indicated that if these products were developed centrally, they could be translated into other languages by regional or country-specific groups.

2. Capacity building and training on knowledge translation

Almost all respondents emphasised that they require more advice, training and technical support on how to develop and disseminate evidence for consumers. It was also highlighted that they need guidance on how to identify key consumers and how (and which channels) they could apply for funding for consumer-related activities.

3. Learning from others (i.e. shared learning experiences)

The issue of 'learning from others' on how to effectively involve and engage consumers in Cochrane activities was mentioned by numerous respondents. Various strategies for promoting shared learning were identified, including sharing case studies or real-life examples of Cochrane consumer activities; publishing success stories of consumer involvement that different Cochrane Groups/Centre have effectively undertaken; and exchange visits with other countries to help obtain ideas for implementing consumer promotion plans.

4. More financial and human resources to conduct consumer activities

Funding support from the Consumer Network and other potential bodies/organizations to assist with consumer activities was requested by most respondents.

5. Network building and streamlining of consumer activities

Some respondents suggested that the CE should help build networks and co-operations for, and streamlining of, consumer activities across the entities.

6. Involving consumers in the design and execution of consumer activities

Like the co-production of Cochrane evidence and research, a number of respondents felt that consumers should be involved in the planning and implementation of consumer activities. It was felt that this would help to ensure that the content and medium of activities are more acceptable, relevant and understandable to consumers. It was suggested that this could be achieved by inviting consumers to attend Cochrane Colloquia; better respecting and listening to the views of experienced consumers (and thinking of innovative ways to do this); and clarifying the role of local consumer champions.

7. Raise awareness of the importance of consumer involvement

One respondent emphasised that the success of consumer activities and involvement depends on the formal support of Cochrane leadership. In particular, it was highlighted that Cochrane leadership needs to understand and raise-awareness of the importance of consumer involvement in clinical decision making and research.