

Cochrane Consumer Network Structure and Function Review



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Executive Summary

Strategy to 2020

Strategy to 2020 is Cochrane's response to the challenges of maintaining its position as a leading provider of evidence-based health information in a more competitive, complex and demanding environment. As part of its Goal 4 'Building an effective and sustainable organisation', we have said 'We will review and adjust the structure and business processes of the organisation to ensure that they are optimally configured to enable us to achieve our goals'.

Purpose of the Review

The purpose of this review is to evaluate how well the current functions and structures of the Consumer Network support the strategic goals of Cochrane, as outlined in *Strategy to 2020*, and to consider what changes are needed to ensure the organisation has the right structures in place to achieve its mission.

How the information gathering element of the review was undertaken

A working group drawn from the Consumer Network oversaw the process. The main elements of the review were:

- A survey of the organisation's 53 Review Groups, about the nature and extent of consumer involvement in their work
- A survey of the 1338 members of the Cochrane Consumer Network, about their experience of volunteering for Cochrane and future aspirations and needs
- An analysis of the information held by the organisation about its consumer volunteers
- A literature review of published papers about consumer involvement in Cochrane and in systematic reviews more broadly
- A survey of the views of external partners
- Internal consultation with Centres

What the information gathering found

Review Groups Survey

- Review Groups overwhelmingly value the involvement of consumers and there are examples of good practice in involvement to be found throughout the network though practice is inconsistent
- Review Groups would value support with targeted recruitment and training in involvement

- There needs to be an effort better to engage with Review Groups in order to facilitate improved involvement across a range of issues including recruitment, training, communication, resources and innovation in involvement

Consumer Survey

- Consumer Network members are a disparate group, with complex and multiple ways of identifying themselves in their interactions with Cochrane.
- They are motivated and united by an interest in evidence-based medicine and a desire to contribute to the production and dissemination of Cochrane evidence (including knowledge translation and knowledge mobilisation).
- Their contributions are largely made by commenting on abstracts, reviews and Plain Language Summaries
- There is an unmet demand to do more, including contributing to the whole research cycle, attending meetings and undertaking training to achieve this. Communication with consumers could be improved
- Amongst consumers who were asked, overall satisfaction levels with the Consumer Network are lower than for the organisation as a whole

Consumer Membership Analysis

- There are high levels of uncertainty about the levels of consumer involvement in Cochrane and there is a clear need to know more
- Consumers are largely found in the developed and English speaking world
- Social media offers interesting ways of communicating with a wider range of existing and potential consumers
- The new "Cochrane Membership" offers exciting opportunities (and some challenges) if CCNet membership is subsumed in to the new Scheme

Literature Review

- A semi-systematic scoping review found 36 papers dating from 1999 that deal with consumer involvement in Cochrane and other systematic review organisations
- Reviews identify significant Cochrane consumer involvement in the production and dissemination of systematic review evidence
- Consumer involvement has historically been inconsistently practised across the network
- Consumers are principally identified in the literature as being located in English-speaking and high-income countries, and their role is largely limited to commenting on abstracts, reviews and Plain Language Summaries
- Barriers to, and benefits of consumer involvement have been identified in studies, though these have not been demonstrated by research
- There has been little change over time

External Partners' Survey

- The views of external partners are key given the complexity of the environment in which Cochrane functions
- Many organisations have an expectation about the level and nature of consumer involvement in the work of Cochrane
- The survey of external partners reinforces many of the key messages identified elsewhere
- In particular there are expectations that consumers will be involved in the prioritisation of future important reviews, the identification of outcomes important to patients, and dissemination

Centres Consultation

- The Centres Executive supports the principle of an increased role in the involvement of consumers and the establishment of a network of "Consumer Champions" based at Centres

Overall the review concludes that Cochrane pioneered the involvement of consumers in research and presently there are over 1330 *Archie* registered consumers, with an active core of between 300 and 500 regularly involved in the production of health evidence. This is something to celebrate; however practice across Cochrane varies and, with some notable exceptions, it has not kept pace with the world outside Cochrane. Review Groups and consumers are looking for support to develop practice in involvement. The present organisational structures do not facilitate effective consumer involvement and changes to enhance involvement are suggested in the review.

Future priorities

The review identifies seven areas for work to take the organisation forward to 2020:

- 1 Develop a Cochrane statement of principle.
- 2 Integrate consumer involvement throughout Cochrane structures.
- 3 Support consumer involvement throughout the research cycle.
- 4 Engage with Cochrane Membership for the full benefit of consumer involvement.
- 5 Build on and develop programmes of support for Cochrane consumers.
- 6 Improve communication with consumers and about consumer involvement.
- 7 Build effective external partnerships.

1. Background to the Consumer Network Structure and Function Review

'We will review and adjust the structure and business processes of the organisation to ensure that they...enable us to achieve our goals'.

In 2013, Cochrane undertook an extensive consultation process to develop a new strategic plan and define the organisation's direction over the next six years. *Strategy to 2020* is Cochrane's response to the challenges of maintaining its position as a leading provider of evidence-based health information in a more competitive, complex and demanding environment. In addition to our core mission of producing high-quality synthesised research evidence, *Strategy to 2020* emphasises access to and utility of that evidence, and establishes our aspiration to make Cochrane the 'home of evidence' by building greater recognition of our work, demonstrating impact and becoming the leading advocate for evidence-informed health care.

A key question is how Cochrane should meet these aspirations, and specifically, how its current structures and ways of operating should be reformed to better enable it to achieve its goals. As part of Goal 4 'Building an effective and sustainable organisation', we have said 'We will review and adjust the structure and business processes of the organisation to ensure that they are optimally configured to enable us to achieve our goals'.

This Consumer Network Structure and Function Review sits alongside the ongoing review of structure and functions of Review Groups, and will complement the planned review of Fields, Centres and Branches and the and the organisation-wide Governance Review. The review will be conducted in an open, consultative way that provides opportunities for consumers, external partners and staff to contribute to shaping the future of the Consumer Network.

Purpose

The purpose of this review is to evaluate how well the current functions and structures of the Consumer Network support the strategic goals of Cochrane, as outlined in Strategy to 2020, and to consider what changes are needed to ensure the organisation has the right structures in place to achieve its mission. The review will pay particular attention to those goals in *Strategy to 2020* in which the Consumer Network plays a central role: supporting the involvement of consumers in the production and dissemination (including knowledge translation and knowledge mobilisation) of systematic reviews.

The current key aims of the Consumer Network are:

1. To support Cochrane entities in the inclusion of consumers
2. To support consumers' participation in the Collaboration
3. To increase consumer membership in low income countries and non-English speaking countries
4. To increase awareness of Cochrane reviews among consumers globally
5. To develop and disseminate information for consumers

The review looks at key aspects of the Consumer Network. It considers:

- The extent and nature of consumer involvement in the production and dissemination (including knowledge translation and knowledge mobilisation) of Cochrane systematic reviews

- Strengths and weaknesses of the different models of consumer participation in the production of reviews within the different Review Groups
- The consumer role in the dissemination of reviews
- Pathways for involvement in the Consumer Network
- Support and training that are available to consumers
- Priorities for the future development and support of increased consumer involvement in Cochrane systematic reviews

The review secondly:

- Identifies the existing roles, functions and structures of the Consumer Network
- Examines its strengths and weaknesses
- Brings forward proposals for reform of the Network including resource, training and personnel implications of different approaches.

Terms of reference

The Review Terms of Reference are: to examine the extent and nature of consumer involvement in the prioritisation, production, dissemination and use of Cochrane systematic reviews; ways in which consumers become involved and are supported (for example how they are recruited, welcomed, supported, trained and developed); examine the strengths and weaknesses of different roles that consumers play in the prioritisation, production, dissemination and use of Cochrane systematic reviews; and to review the current structure, functions and membership of the Consumer Network and make recommendations concerning the organisation and functioning of CCNet to achieve Cochrane's strategic goals, including issues related to the proposed new Cochrane Membership.

These recommendations will be provided to the Steering Group by the end of September 2015 at the latest, for consideration by the Steering Group at the Cochrane Colloquium in Vienna in early October; with the subsequent development of an implementation plan by December 2015.

The recommendations will be developed in a collaborative process led by the Consumer Executive and the Structure and Function Review Working Group, with shared ownership of the methods and approaches taken and will be based on widespread consultation with Cochrane members, funders and other key stakeholders.

	Review Objectives
1	Identify the extent and nature of consumer involvement in the prioritisation, production, dissemination and use of Cochrane systematic reviews through questionnaires, literature review and analysis of existing data.
2	Identify the ways in which consumers become involved and are supported (for example how are they recruited, welcomed, supported, trained and developed).
3	Examine the strengths and weaknesses of the different roles that consumers play in the prioritisation, production, dissemination and use of Cochrane systematic reviews.
4	Identify the existing functions, structures and membership of CCNet and examine their strengths and weaknesses.
6	Develop proposals and rank their priority to support increased consumer involvement in prioritisation, production, dissemination and use of Cochrane systematic reviews.
7	Identify proposals for reform of the CCNet including the way that it is organised and supports the increased involvement of consumers in the work of Cochrane, including issues related to the proposed new Cochrane Membership.

8	Make recommendations, with costed options as appropriate, for consideration by the Steering Group.
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Core principles

1. The review will be conducted in a way that is consistent with Cochrane core principles and makes people feel valued; the approach will be inclusive, respectful and consultative, and will pay particular attention to ensure that geographic, language and gender diversity within Cochrane are enhanced as a result of potential reforms.
2. The review will be inwards and outwards facing; we will consult internally with Cochrane groups and members, Central Executive Team and Cochrane Innovations, plus we will seek external perspectives to ensure the needs of funders and other key stakeholders are addressed.
3. The review will prioritise reforms to structures and processes that align with strategic goals, strengthen accountability, and enhance the sustainability of the organisation.
4. The review will make optimal use of existing data and documents in considering options for change.
5. The outcomes of the review will be consistent with *Strategy to 2020*, and complement the other organisational reviews, including the Governance Review.

Governance

The review will be overseen by the Cochrane Consumer Network Co-ordinator supported by a Structure and Function Review Working Group. The review will be inclusive in terms of consultation and communication,

both internally and externally. We will ensure our approach complements the other organisational reviews that are either ongoing or planned. The Working Group will ensure we have access to a broad range of views and can 'road-test' the suitability and feasibility of various proposals. The Advisory Group will comprise:

- (i) members drawn from Consumer Network Executive
- (ii) a member of Cochrane staff who can link the process with other structure and function reviews
- (iii) a member from a Cochrane Centre and
- (iv) a member with a more external perspective who can advocate for consumer involvement

Membership

1. Chris Champion (CET)
2. Anne Lyddiatt (CE Co chair)
3. Nancy Fitton (CE)
4. Sara Yaron (CE member elect)
5. Joy Oliver (Cochrane SA Centre)
6. Sally Crowe (Consumer Network member)
7. Richard Morley (Consumer Network Coordinator)

Communication and consultation

Information about the review, its progress and how to contribute to it, was communicated regularly. Where we could we used alternatives to written reports and documents to encourage people to get involved (e.g. surveys, interviews, Facebook, Twitter, etc.). The findings of the review are to be submitted to the Steering Group in September 2015 with consultation following that and before the development of an implementation plan.

Key stakeholders and informants

Key stakeholders are groups and individuals who need to be consulted as part of the development and conduct of the review, but who will not be part

of the day-to-day project group. Engagement with external partners may be a matter of some sensitivity due to a range of factors: cultural differences across the globe; political sensitivities; and delicate funding arrangements. Priority will be given to internal stakeholders at the initial stages, which may inform the way that engagement with external partners is conducted later.

The detailed Action Plan can be found at Appendix 1.

2. Cochrane Review Group Survey

“The involvement of consumers is essential in ensuring our reviews – and plain language summaries in particular – are accessible to the lay reader.”

“Consumers help to inform decisions made around identification and prioritization of patient-important topics and outcomes.”

“Involving and engaging consumers takes valuable time away from editorial tasks. We need to find a way to involve consumers more fully in our activities.”

The Review Group survey was conceived and initiated by the Consumer Executive in 2014 prior to the Structure and Function Review in order to gain an understanding from Managing Editors of the extent and nature of consumer involvement in the work of Cochrane Review Groups.

A survey and interviews were conducted between October 2014 and January 2015. The Consumer Executive wishes to thank all of those who took part in the survey and interviews. The full report will be published in due course. The key findings are set out below.

Response rate

42 Cochrane Review Groups out of a possible 53 took part, making a response rate of 79%.

Extent of consumer involvement

Of those CRGs that responded to this question (n=40), there was a wide variation in the numbers of consumers identified as being involved with their groups. Numbers varied from none (n=5) to 150 and when totalled, this amounted to 1057.

When asked how many consumers are regularly involved the numbers ranged from none to 129 and the total fell to 528. The average involved fell to 14.3.

Nature of consumer involvement

Of those CRGs who responded to this question (n=37) 78% groups (n=29) reported that consumers were involved in commenting on Plain Language Summaries (PLS). This was the most common form of involvement. 27% (n=10) involved consumers in writing the PLS. 35% (n=13) had involved consumers in prioritising review topics and 24% (n=9) in dissemination activities.

Importance of consumer involvement

83% of respondents to this question (n=35) said they believed consumers are important to the success of their group. 41% of respondents (n=17) were satisfied with the current level of involvement and only 12% did not wish to change their present involvement with consumers. If making changes to the way that they worked with consumers 76% of respondents (n=33) said that they would like help from CCNet to make changes.

How consumers are recruited

CRGs reported that they recruit their consumers in a wide variety of ways, from professional networks, from third-sector and consumer organisations, from the CCNet membership, via word of mouth, colloquia and symposia, clinicians, and via Managing Editors.

68% of respondents to this question (n=28) answered "yes" to the question "Would your group like help recruiting consumers?" However in discussion with CRGs, it was made clear that recruitment needed to be (i) targeted on patients with experience of specific conditions and interventions (ii) in close cooperation with individual CRGs to allow recruitment to be managed successfully, and (iii) appropriately resourced.

Registering consumers

75 % (n=30) of respondents to this question reported that they register their consumers on *Archie*. 37.5% (n=15) reported they recommend that their consumers join CCNet. Reasons for not recommending CCNet membership varied, including an assumption that they are already members, a lack of awareness that this is a possibility, a desire to protect consumers from being overwhelmed, and to keep the relationship direct and specific.

Consumer training and support

Of the CRG's that responded to this question (n=40) 30% (n=12) reported that they provide training and/or preparation for consumers.

Of those that do, this is in a wide range of ways including appraisal skills, customised training materials, checklists, workshops, guides and telephone support.

29% of those who responded to this question (n=12) recommend Cochrane Training to consumers. Reasons for not doing so include a lack of awareness of its existence (n=4), that it is too technical in nature, that it is not relevant, that consumers were appointed some time ago and do not need training, and that other guidance is sufficient.

Of those who recommend Cochrane Training, when asked "Did you find it useful?" 37.5% (n=6) responded in the affirmative. 56% (n=9) answered "other". Reasons cited included a lack of feedback from consumers (n=4) and the need for resources to be in multiple languages (n=1).

Providing feedback to consumers

32% of respondents (n=13) reported that they gave feedback to consumer referees. 49% (n=20) gave no feedback. Where it is given, feedback varies in method from emails, notification that a review has been published, use of a feedback template and collation of all the responses, to direct feedback from the Managing Editor in the form of an email or telephone call.

Other comments

A range of comments was received from Managing Editors including expressing a desire for more information about the work of CCNet and the support that is available, the need for the network to "raise its profile", a lack of appropriate information for consumers on joining, more information for Managing Editors on how to involve consumers, the importance of resources being available in order to support the involvement of consumers, the need for better and new training resources, the importance of support with recruitment, and a desire to be involved in innovative forms of engagement.

Conclusions

It is clear that Review Groups overwhelmingly value the involvement of consumers and particularly from people with direct experience of conditions and interventions and there are good practice examples of involvement to be found throughout the network. Review Groups would value support with targeted recruitment. There needs to be an effort better to engage with Review Groups in order to facilitate improved involvement across a range of issues including recruitment, training, communication, resources, and innovation in involvement.

Recommendations

- 2.1 Work with Review Groups and Centres in a phased and targeted programme of recruitment, especially in low-income and non-English speaking countries.
- 2.2 Develop training resources for consumers and Review Groups to promote involvement throughout the research cycle (and in particular priority setting, outcome identification and dissemination (including knowledge translation and knowledge mobilisation)).
- 2.3 Develop improved communication with Review Groups in order to meet the needs of Review Groups and promote the support that is available.
- 2.4 Build a programme of mentoring support for new consumers.

3. Cochrane Consumer Survey

“I really enjoy being part of Cochrane and doing reviews and protocols etc. It's challenging and I really feel that I'm making a difference in patient outcomes.”

“I am deeply committed to Cochrane, but feel quite disconnected at the moment... I am not sure how to get back involved and to ensure I am up to date etc.”

“I have enjoyed the little I have done so far for Cochrane but it would be good to feel less isolated as a member of CCNet.”

“I feel underutilized.”

There are approximately 1338 registered consumers on *Archie* although the number of active consumers is significantly fewer and may be in the region of 500 (see Review Group survey). Consumers can include patients; carers and family members; people who work paid or unpaid for an organisation that supports the aims of Cochrane (for example a not for profit organisation, patient-led or patient advocacy group); and less often, healthcare professionals; researchers and the public.

An online survey was created in order to capture information about our consumers, to understand how and why they joined, what they do for the organisation, how well they are supported, what their aspirations are and their views about CCNet. The survey ran from 24th April 2015 to 22nd May 2015.

Response rate

The survey was visited 117 times though response rates varied for individual questions. This is a historically large number of responses to a CCNet survey. It represents 9% of *Archie* registered users or perhaps around 23% of active consumers. Inevitably there will be an element of self-selection in those who have responded, with the most active likely to have participated and it is important to bear this bias in mind when considering the responses.

Geographical distribution of respondents

The geographical distribution of responses broadly reflects the distribution of consumers as recorded in *Archie*. Out of a total of 102 responses 31% (n=32) were from the UK, 13% (n=13) Canada, 12% (n=12) Australia, 11% (n=11) the USA, India 6% (n=6), Spain 6% (n=6), and Egypt 4% (n = 4).

Gender of respondents

72% of respondents (n=81 out of 113) identified themselves as female.

How consumers defined themselves in relation to their involvement with Cochrane

The way that people think of themselves in relation to their involvement with Cochrane is clearly complex. When asked to choose the main ways in which they thought about themselves 115 people responded. With 257 choices recorded overall, this indicates that people see themselves in multiple roles. The most popular response was "Patient/someone with a personal experience of a health condition" (65%, n=75), followed by member of the public (35%, n=40), working for an organisation that supports the aims of Cochrane (23%, n=26), healthcare professional (23%, n=27), researcher (22%, n=25), family member (18%, n=21), and carer (17%, n=19).

How consumers found out about Cochrane

Consumers reported that they found out about Cochrane in a variety of ways, the most common being when looking for health care evidence (33%, n=35), followed by "An organization I belong to informed me about Cochrane" (23%, n=25). "Other" responses (23%, n=25) included being recommended by their healthcare professional, friends or relatives informing them, and working for Cochrane.

Why consumers became involved in the work of Cochrane

Consumers reported that they became involved for a range of reasons. The most common response was "I wanted to contribute the consumer viewpoint to the work of Cochrane" (70%, n=73), followed by "I was interested in finding out about health care evidence" (61%, n=63) and "I was interested in engaging with or educating people about evidence based healthcare (for example, trials, systematic reviews etc.)" (57%, n=59).

Length of involvement

Amongst the 107 respondents, a full range of lengths of involvement is represented, as follows:

Respondents' length of involvement with Cochrane

Less than 1 year	17%, n=18
More than 1 year	26%, n=28
More than 5 years	28%, n=30
More than 10 years	29%, n=31

78% of respondents (n=85) indicated that they are registered on *Archie*, with 13% (n=14) replying "Don't know".

Involvement with Centres

42% of respondents (n=44) report that they have no involvement with Centres, and 32% (n=33) that they answer requests for consumer involvement that come from their Centre or Branch. A number of respondents (n=6) expressed uncertainty about the existence of Centres. Of those who identified some involvement with Centres, the most popular were: UK (35%, n=18), Canada (21%, n=11), US (17%, n=9), and Australasia (13%, n=7).

Involvement with Review Groups

Consumers were asked when they last had any involvement with a Review Group. 62% (n=63) reported they had involvement less than a year ago. 15% (n=15) reported never having any involvement.

When asked what activities they had been involved in, the three most common responses were commenting on a protocol (n=48), commenting on a Plain Language Summary (n=48) and commenting on a systematic review (n=51). This contrasts strongly with more active forms of involvement such as helping identify important reviews ("prioritisation") (n=12), or identifying important patient outcomes (n=12).

When asked what activities consumers would be interested in doing, the picture is strikingly reversed, with fewer people wishing to comment on systematic reviews or protocols. The most popular activities are: attending the Colloquium (n=49); commenting on Plain Language Summaries (n=46); identifying outcomes important to patients (n=45), and attending any kind of Cochrane event (n=42). Overall there would seem to be a significant unmet desire to contribute to the work of Cochrane, to be engaged more actively, and throughout the research cycle.

Overall communication with Review Groups amongst respondents is thought to be good (strongly agree 34%, n=31; slightly agree 21%, n=19). 28% (n=25) strongly agree that they always receive feedback, and 19% (n=17) slightly agree. 6% (n=5) slightly disagree and 7% strongly disagree. When feedback is received respondents generally think it good quality (strongly agree: 26%, n=23; slightly agree 24%, n=21).

Training

When asked if consumers felt properly trained to undertake the things they are asked to do, 42% (n=38) responded that they strongly agreed. 26% (n=24) slightly agreed. No one strongly disagreed. This is an encouraging response. 53% (n=47) indicated that they had received informal support, 39% (n=35) had accessed online training, and 28% (n=25) had received formal training. Respondents having had no training amounted to 28% (n=25).

When asked what subjects respondents would like to be trained in there was a demand for a wide range of training across many subjects, the most popular topics being identifying important outcomes for patients (n=44); commenting on protocols and systematic reviews (n=42); and writing a Plain Language Summary (n=39).

With regard to their preferred method of training, respondents indicated a general interest in a wide range of formats, with no clear preference emerging.

Cochrane Consumer Network

With regard to communication with CCNet, when asked if they would know whom to contact in CCNet, 46% of respondents (n=41) replied no, whilst 40% (n=36) said yes. 41% (n=38) always read the CCNet newsletter; 49% (n=45) sometimes read it. 86% (n=78) have visited the CCNet website in the last year. 24% (n=22) follow the Consumer Network on Twitter and 28% (n=26) have visited CCNet Facebook pages in the last year. 4% of respondents reported some difficulty with language.

When consumers were asked about their satisfaction with CCNet and Cochrane, respondents generally reported a higher level of satisfaction with Cochrane than they do with the Consumer Network (see table below).

	Consumer Satisfaction	
	CCNet	Cochrane
Very satisfied	11% (n=10)	25% (n=3)
Quite satisfied	38% (n=34)	46% (n=42)
Neither	33% (n=30)	18% (n=16)
Quite dissatisfied	4% (n=4)	7% (n=6)
Very dissatisfied	2% (n=2)	1% (n=1)
Not applicable or no comment	11% (n=10)	3% (n=3)

Conclusions

Consumer members of CCNet are a disparate group, with complex and multiple ways of identifying themselves in their interactions with Cochrane. They are motivated and united by an interest in evidence-based medicine and a desire to contribute to the production and dissemination of Cochrane evidence. Their contributions are largely made by commenting on abstracts and Plain Language Summaries. Some presently feel under-used and there is an unmet demand to do more, including contributing to the whole research cycle, and attending meetings and undertaking the training to achieve this. Communication with consumers could be improved and overall satisfaction levels with CCNet are concerning.

Recommendations

3.1 Engage with consumers, Review Groups and the forthcoming *Project transform* in order to facilitate new and effective ways for consumer involvement throughout the research cycle.

3.2 Review the effectiveness of the Consumer Stipend in order to meet the strategic need to improve the involvement of consumers in the research process.

3.3 Develop a programme of new training resources for consumers and Review Groups to facilitate consumer involvement.

3.4 Work with consumers, Review Groups, Centres, Fields and others in order to spread good practice and encourage involvement

throughout the research cycle and in particular in the areas of prioritisation, outcome identification and dissemination (including knowledge translation and knowledge mobilisation).

3.5 Work with consumers, Review Groups and Centres to develop effective processes of support for consumers, including recruitment, induction, mentoring and communication.

3.6 Undertake an annual survey of consumer satisfaction in order to improve practice.

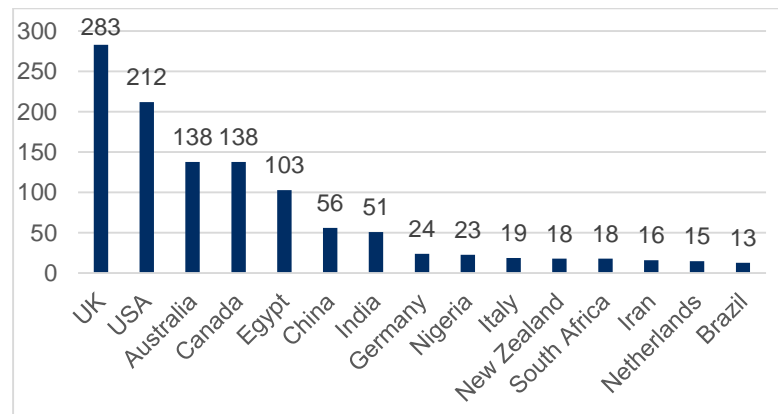
3.7 Work towards ensuring consumers are as representative as possible of the population as a whole in respect of gender, age, ethnicity, disability, sexual orientation, socio-economic group, spoken language, and the developed/developing world.

3.8 Work towards embedding consumer involvement of consumers in governance at all levels and in all Cochrane entities.

3.9 Reaffirm Cochrane's commitment to consumer involvement by developing a statement of principles which the organisation can commit to.

4. Analysis of Cochrane Consumer Network Membership

Table 1 Top 15 most popular countries for consumer involvement (*Archie*)



It is important to have an understanding of the levels and nature of consumer involvement in Cochrane and the principle source of this data is *Archie*.

New consumers are usually registered to *Archie*, the internet based repository for the Cochrane Collaboration's documents and contact details. It contains data about all the persons involved in Cochrane and all the documents and reviews produced. An analysis of the present membership is an important part (but not the whole story) of understanding the extent of consumer involvement in Cochrane

In the future a new form of membership is planned ("Cochrane Membership"). The objective is to 'establish a membership structure to improve our organisational cohesiveness and to reduce barriers to participation by creating a clear and open route into the organisation for people who want to get involved'. This has major implications and offers significant opportunities to rethink and enhance the nature of consumer involvement in Cochrane evidence.

Current Consumer Network membership

1338 consumers are registered to *Archie* (February 2015). (See Appendix 2) Little is recorded on *Archie* to enable a detailed analysis because the data held on consumers is so limited.

In addition, CCNet manages Facebook pages (<https://www.facebook.com/groups/188375461224285/>) and a Twitter account (@cochraneconsumr) and these are popular and growing ways of interacting with the network.

Members are represented in 79 countries across the world. The most popular countries are the UK, USA, Australia and Canada, which

together account for over half of the membership (n=771). These are from the developed and English speaking world. Egypt, China and India are the most popular countries from the developing world.

CCNet identifies its core consumers as patients, carers and family members, health advocates, members of patient groups, and citizens seeking "high quality, unbiased information about a health condition or treatment". It also welcomes others as non-voting members, namely staff of organizations, journalists or professionals such as healthcare practitioners and health researchers who share the ethos of Cochrane and are interested in building patient empowerment and autonomy.

27% (n=358) members are registered with no affiliation. 73% are recorded as being affiliated to an institution and overwhelmingly universities. 33 for example are employed at Ain Shams University or Medical School, Cairo, Egypt. This would suggest an imbalance in CCNet membership

There is anecdotal evidence of an unknown number of consumers working with Review Groups who are not registered as members of CCNet.

There is a clear need to know more about the consumers who are involved with Cochrane.

Social Media

CCNet manages two Facebook accounts and a Twitter account (@cochraneconsumr). 446 people are registered as members on Facebook. 1,549 are recorded as Followers on Twitter. We know little about them however. It is likely that there is considerable overlap

between memberships. Both of these represent a powerful tool for involvement and engagement, including the recruitment of consumers, and the dissemination of results (including knowledge translation and knowledge mobilisation).

Cochrane Membership

The idea for a Cochrane Membership scheme was first raised and approved in the strategic review of 2008-09. In 2013, after further consultation, it was reaffirmed as one of the key objectives of Cochrane's Strategy to 2020. Contributing to the goal of building an effective and sustainable organization by becoming more inclusive and open, the objective is to 'establish a membership structure to improve our organisational cohesiveness and to reduce barriers to participation by creating a clear and open route into the organisation for people who want to get involved'.

At the time of writing this report, plans for Cochrane Membership are about to go out to the wider partnership for consultation. There will be opportunities for consumers to contribute to its development. Core elements are largely established however.

Purpose

Through the establishment of a membership scheme it is hoped to open Cochrane up to the world by allowing anyone to support and become involved in its work. The guiding principle will be inclusivity and the outcome Cochrane wants to achieve is a vibrant worldwide community of members who feel part of Cochrane and who have clear, easy and varied ways to contribute to its mission if they wish to.

The opportunity

As identified in the review of consumer membership and the Consumer Survey there are a range of issues that affect consumer involvement in the work of Cochrane. From consumers' perspectives these include uncertainty about how they can be involved in ways that meet their individual needs; having sufficient opportunities for involvement such that people feel they are making a valued contribution; effective communication; and training to support their involvement.

From the organisation's perspective there is clearly a need to recruit more consumers, especially from low-income and non-English-speaking parts of the world; with experience of specific conditions and interventions to meet the needs of the production of research; and to understand about our consumer volunteers in order to support them and the research process, more effectively.

How will it be different from the present?

Cochrane Membership will build on and formalise work already in existence but it will create more opportunities to get involved or be part of Cochrane and make it clearer how to find these opportunities.

- Existing contributors will automatically have membership
- New members will be able to register on the Cochrane website without establishing a personal relationship with a specific Cochrane Group. Signing up will be free, but members will have to provide some basic personal information.
- There will be a single 'Cochrane account' system encompassing existing *Archie* accounts and new members. (New members will not have access to any *Archie* roles or permissions that they would not otherwise have).

- There will be a single online home for members where they can maintain a profile, access opportunities, contribute to its work and find information.
- Members will be supported to get involved in a variety of ways, with clear avenues to participate as appropriate to interests, levels of skill and time available.
- Through the scheme Cochrane will seek to acknowledge their support/contribution.

***Project Transform* and Cochrane Membership**

In addition to improving pathways to existing ways to get involved, *Project Transform* will allow people to contribute in innovative new ways to the Cochrane review process. These will include crowdsourcing of tasks, and a task exchange allowing Groups and author teams to find individuals with skills and availability to contribute to specific projects, such as a review in progress, a translation project, etc. Whilst the membership scheme is broader than this, the new opportunities for engagement will be the core of the new opportunities being offered to potential members and so we will be working closely with *Project Transform* to integrate these new opportunities

Implications for the Cochrane Consumer Network (CCNet)

At present new consumers sign up via the Cochrane Consumer website for "membership" of the Consumer Network (CCNet) which places them on a mailing list. They are also registered on *Archie* as "consumers". "Membership" also confers some features, for example invitations to take part in reviews that Review Groups regularly issue, a newsletter, the ability to vote to choose members of the CCNet Executive (for patient, carer, and patient advocate members of CCNet only) and potential access to Consumer Stipends for meetings.

As noted earlier there are issues with the membership of CCNet in that there are registered consumers who are students, health professionals, medical journalists and researchers and who are possibly not patients, carers or patient advocates (“core consumers”); consumers working with Review Groups who are unregistered; and difficulties of definition as people often identify themselves in multiple ways (as patients/health professionals, or carers/researchers, or patient advocates/carers, for example) in their interactions with Cochrane. Cochrane Membership will go a long way to addressing some of these issues.

In the final analysis the important principles are that consumers are involved in the production and dissemination (including knowledge translation and knowledge mobilisation) of Cochrane evidence throughout; that consumers are effectively supported in their role; and that the consumer perspective is integrated throughout the organisation.

Conclusions

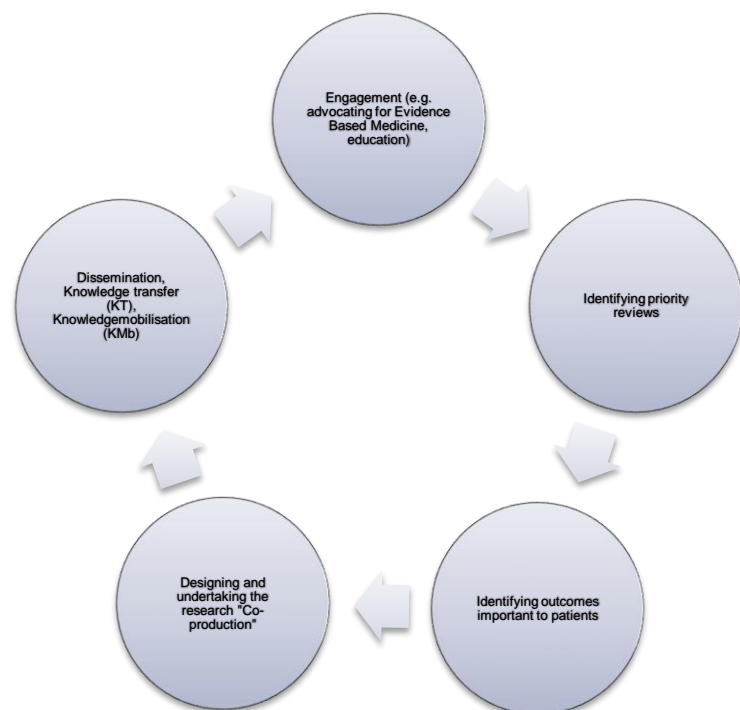
There are high levels of uncertainty about the levels of consumer involvement in Cochrane including an incomplete understanding of the total numbers involved (probably somewhere between 300 and 500 people) and how they contribute. There is a clear need to know more. From what we do know, consumers are largely found in the developed and English speaking world. There is an urgent need to recruit new consumers from the developing and non-English speaking world. This will need to be undertaken in a phased and considered manner, working closely with Review groups and Centres. Social

media offers interesting ways of communicating with a wider range of existing and potential consumers. The new Cochrane Membership offers exciting opportunities to address a range of issues identified in this review.

Recommendations

- 4.1 Engage with the new Cochrane Membership in a way that facilitates new and effective ways of consumer involvement and includes ways of capturing accurate data about levels of involvement.
- 4.2 Work with Review Groups and Centres in a phased and targeted programme of recruitment, especially in low-income and non-English speaking countries.
- 4.3 Develop an improved communication strategy incorporating the effective use of social media.

5. Literature Review



There is a body of research that is represented in literature about consumer involvement in the work of Cochrane and in systematic reviews more broadly. It is important to undertake a literature review to capture the learning from this evidence and to include it as part of the information gathering process for the Structure and Function Review.

Researchers at the UK Universities of York and Manchester, and the Consumer Network Coordinator, have undertaken a semi-systematic scoping exercise: a search of the literature which while extensive would not seek to be fully comprehensive.

The general findings are summarised in this report, however the authors are intending to publish their findings in an appropriate peer-reviewed journal.

Methods

Objective

To conduct a systematic scoping exercise to evaluate the evidence base on consumer involvement in organisations which commission, undertake or support systematic reviews, with an emphasis on the Cochrane Collaboration.

Inclusion and exclusion criteria

We included any study which evaluated or reported on consumer involvement in an organisation which commissions, undertakes or otherwise supports systematic reviews, or which reported on consumer involvement in an individual systematic review process. We excluded studies which reported on consumer involvement in research which did not explicitly include systematic reviews. This

included studies of priority setting exercises where this was not related to the undertaking of systematic reviews.

Search Strategy

We searched the following databases and other electronic sources in June 2015:

- CINAHL Plus
- MEDLINE In-Process & Other Non-Indexed Citations and MEDLINE
- Embase
- Cochrane Methodology Register (CMR)
- HMIC Health Management Information Consortium
- ProQuest Dissertations & Theses: UK & Ireland

The searches were date-limited to records from 1990 onwards and were designed by an information specialist.

Data extraction and Synthesis

One researcher extracted data into structured tables. Studies were grouped by the level at which the evaluation was performed (organisational, individual Cochrane Review Group (CRG), or individual systematic review(s)). Organisational studies were further grouped by whether the evaluation was focused on the Cochrane Collaboration, another organisation or on multiple organisations. Studies of individual CRGs were grouped by the CRG evaluated. Syntheses of studies were not extracted as individual studies but were used to ensure that all individual studies were identified and included. A narrative synthesis, structured by the study groupings identified, was produced. Themes of types of involvement and impacts were identified, as were perceived barriers to involvement. Emphasis was

given to those studies which evaluated the impacts of consumer involvement. Consumer perceptions of their involvement were also highlighted.

Results

We identified four types of reports (Table 1):

- 1) Surveys and other evaluations of consumer involvement at an organisational level in the Cochrane collaboration or other organisation.
- 2) Case reports, surveys or other evaluations of consumer involvement in a single CRG
- 3) Case examples of consumer involvement in individual systematic reviews (10 Cochrane and 2 non-Cochrane)
- 4) Syntheses or summaries of consumer involvement in individual systematic reviews

Table 2: summary of identified studies

Number of studies	Organisational level evaluations	CRG case reports	Individual reviews	Syntheses/ summaries
Total	11	10	12	3
Cochrane	7	NA	2	NA
Non-Cochrane	4	NA	10	NA

Discussion

Clear themes emerged from the analysis which are consistent with findings elsewhere in this report.

Studies as far back as 1999 have identified significant consumer involvement in the production and dissemination of Cochrane evidence and a recognition by most Cochrane Review Groups that the

involvement of consumers is an important part of the research process. The literature consistently reports that consumer involvement is largely focused in the English-speaking and developed world.

Consumers are identified as contributing throughout the research cycle: from priority setting; outcomes identification; commenting on protocols reviews and plain language summaries; helping to disseminate knowledge and playing important roles within Review Group teams. It is also clear from the literature that consumer involvement historically has been focused on commenting on reviews and plain language summaries. Consumers have not been consistently involved in areas like prioritisation and outcomes identification. These findings have not changed significantly over time. In general there is evidence of inconsistency across the Cochrane network, in terms of commitment to involvement, resources directed at involvement, and the variety of different approaches taken.

Some individual Review Groups are well-represented in the literature, revealing a commitment both to involving consumers and to publishing the results of their work (for example the Cochrane Muscular-Skeletal Group, Skin Group, Haematological Malignancies Group and the Cochrane Pregnancy and Childbirth Group) however in general there is a scarcity of information about the extent and nature of consumer involvement in Review Groups and a rarity of audit of involvement processes such that the impact of activity is unrecorded in published literature. The 10 case studies identified related to only 4 CRGs.

The literature identifies a range of perceived barriers to effective involvement across the network (including lack of resources, guidance, language and the recruitment of suitable consumers) but also a clear range of benefits from the involvement process (the use of consumer-oriented/ more relevant outcomes, changes in language, informing of methodology and adding “depth” to the review).

Whilst these perceived barriers and benefits are subjectively identified there is a shortage of objective evidence about what works.

Recommendations

5.1 Reaffirm Cochrane’s commitment to consumer involvement by developing a statement of principles to which the organisation as a whole can commit.

5.2 Work towards ensuring consumers are as representative as possible of the population as a whole in respect of gender, age, ethnicity, disability, sexual orientation, socio-economic group, spoken language, and the developed/developing world.

5.3 Work with Review Groups and Centres in a phased and targeted programme of recruitment, especially in low-income and non-English speaking countries.

5.4 Work with consumers, Review Groups, the forthcoming *Project Transform* and others in order to facilitate new and effective ways of involving consumers throughout the research cycle.

5.5 Work with consumers, Review Groups, Centres, Fields and others in order to spread good practice and encourage involvement throughout the research cycle and in particular in the areas of prioritisation, outcome identification and dissemination (including knowledge translation and knowledge mobilisation).

5.6 Engage with the new Cochrane Membership in a way that facilitates new and effective ways of consumer involvement and includes ways of capturing accurate data about levels of involvement.

5.7 Encourage Review Groups to record their experience, to capture the impact of consumer involvement and to publish where possible.

5.8 Consider conducting a trial in order to understand what makes effective consumer involvement in the production and dissemination of Cochrane evidence (including knowledge translation and knowledge mobilisation).

6. External consultation

Consumer involvement “rated as ‘important’ on average, with ‘setting priorities for research’ seen as the most important and ‘co-production of research’ the least important.”

“Engagement of... lay people [in priority setting] from local and national settings was considered important as that can serve as the beginning of a longer stakeholder engagement journey.”

Cochrane exists in a complex web of networks and organisations, and healthcare systems that harness the goodwill of researchers, clinicians, patients and family members, and third-sector organisations, in a wide range of economic, cultural and political environments.

Cochrane commissioned the consultancy firm, Technopolis, <http://www.technopolis-group.com> to undertake a wide-ranging process of engagement with external organisations in a process of surveys and structured interviews in order to produce evidence for a number of Cochrane Structure and Function Reviews, including the Consumer S&FR. The full report will be available in due course. The key relevant elements are set out below.

Methodology

A global online survey was followed by in-depth telephone interviews with a cross-section of stakeholders before all data were fully analysed and synthesised for final reporting.

Key themes for consideration were:

- Priority setting practices, and relevance/ timeliness of the evidence Cochrane produces
- Development and application of Cochrane’s methods to support the production of evidence
- Accessibility/ usability of Cochrane’s evidence and ways to improve those
- Cochrane’s communication of its goals and principles to external partners and stakeholders through its local/ regional network, and across specialised fields
- Cochrane’s organisational structure

The survey ran between 20 April and 31 May 2015. A total of 452 individuals responded to the survey (English: 364, French: 33, Spanish: 44: German: 11). Of these, 379 respondents provided answers beyond the profiling section; only these were included in the survey analysis

Most respondents lived in Europe (71%) and North America. Within Europe, and overall, the country with the largest number of respondents was the UK (38% overall and 54% of respondents from Europe), followed by the United States (9%). The predominant native language was English (52%), followed by Spanish (11%) and French (10%).

The largest number of respondents indicated that they worked for a university (44%), a hospital or healthcare facility (17%) or a research institute (10%). 10% of respondents described their employer as 'other'; of this group, 32% (13) work for industry (pharma, CRO, trade association, private healthcare provider). Most respondents identified as 'Researcher (non-clinical)' (28%), followed by 'Clinician' (20%). Many respondents chose 'other' to describe their role (18%); of these, 40% (32) indicated that they were students or student nurses.

Priority setting practices

External stakeholders, including those that work closely with Cochrane, conveyed that very little is visible about Cochrane's priority setting practices. Survey responses to questions indicated that knowledge of, and engagement in, priority setting processes is low. 71% of respondents could not comment if Cochrane was receptive to external views, and 84% had never been involved in priority setting. For example, neither respondents from Germany nor Spain had been involved in priority setting for Cochrane. 14% of respondents from the UK had been involved. Canada, with 28% of respondents, had the highest participation of any country. Despite the

current low level of engagement, there was significant interest to be engaged in the future, as signalled by 51% of respondents.

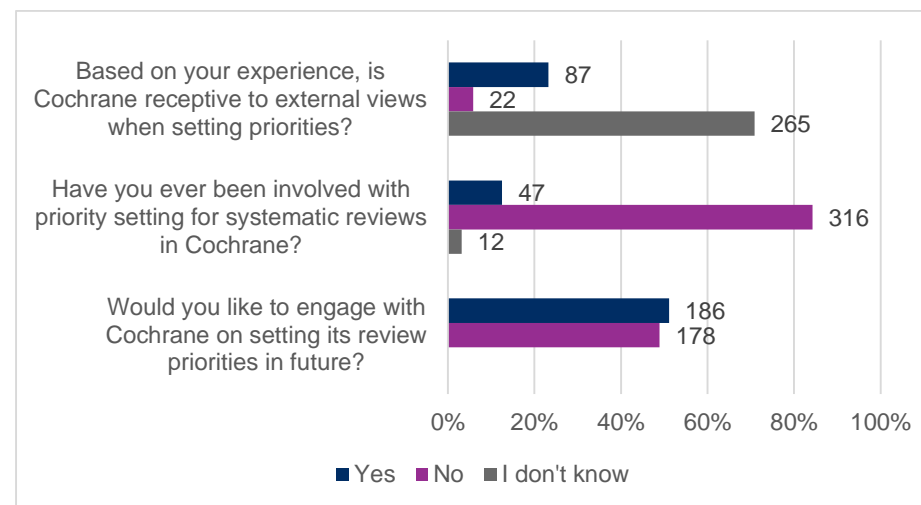


Table 3 Priority setting and external consultation (n = 364 – 375)

Most people consulted in this exercise assumed that Cochrane's priorities are strongly influenced by their own researchers and found that those priorities are more relevant to academics than healthcare practitioners. External stakeholders indicated that they hear about new systematic reviews when the protocol is published by the study team. This however may be too late for them to effectively provide input to the research questions. There has been no mention during the external stakeholder consultation of the various topic lists that are discussed and published online by editorial review groups. Importantly, the recent publication of the Cochrane-wide Priority Review List for 2015/161 was also not known to external stakeholders consulted. When discussed during interviews of such new initiatives, respondents were all in favour but asked why this information never reached them. This valid question points to the need for a

better dissemination strategy for Cochrane utilising existing networks to cascade the information down to relevant individuals. The transition to a membership organisation (discussed below) may create the broader community needed to implement efficient communication strategies.

It was discussed that emphasis should be on full transparency about how priority lists are drawn up and how people external to Cochrane may contribute to it. There was a sense of enthusiasm that Cochrane's priority setting process may become more open as experience showed that the processes and response from various editorial review groups were highly varied. It was suggested that beyond consulting objective administrative data on disease burden, medical journal editors could be requested to feed into Cochrane's priority setting processes as they have a good overall view of the existing research landscape and available published data. Guideline developers, major funders and international organisations could also be consulted to obtain a list of the topics they are preparing to address in the future. Specifically mentioned was the potential for collaboration with a number of existing initiatives, such as the Guidelines International Network (G-I-N), the Haute Autorité de Sante (HAS) in France, the Health Search database in Italy, and the Canadian Agency for Drugs and Technology in Health (CADTH).

In addition, engagement of professionals and lay people from local and national settings were considered important as that can serve as the beginning of a longer stakeholder engagement journey. It was suggested that taking on researchers from local settings (even if not at the suitable level to carry out systematic reviews independently) and also in the research phase may help uncover new data sources, help with language difficulties, increase the understanding of contextual issues, and not only help future dissemination activities but, by the end of the journey, build vital research capacity often lacking in resource poor settings.

In terms of engagement practices of priority setting with Cochrane, respondents would prefer to participate via workshops and consultation on

topic lists (preferably using online consultation). Additional suggestions were Delphi rounds, including Cochrane representatives in meetings at other organisations, provision of feedback at the end of every guideline update cycle, and adopting the James Lind Alliance or the TREKK method.

Role of the consumer

When asked about patient, patient advocate and healthcare consumer involvement in the production of Cochrane evidence and in Cochrane activities, the various dimensions were all rated as 'important' on average, with 'Setting priorities for research' seen as the most important and 'Co-production of research' the least important.

This result is somewhat at odds with interviews where it was advised to involve patients and patient groups in the priority setting exercise with caution in order for Cochrane to remain free from potential conflict of interest or being influenced by specific and predictable agendas. Interviewees emphasised both the role for patients to be involved in setting relevant outcome measures in the research questions and also their crucial role in disseminating the results of the research as widely as possible. 'Co-production in research' being poorly rated in the survey may be explained by the large respondent cohort of non-clinical researchers who consider conducting research requires highly specialised training.

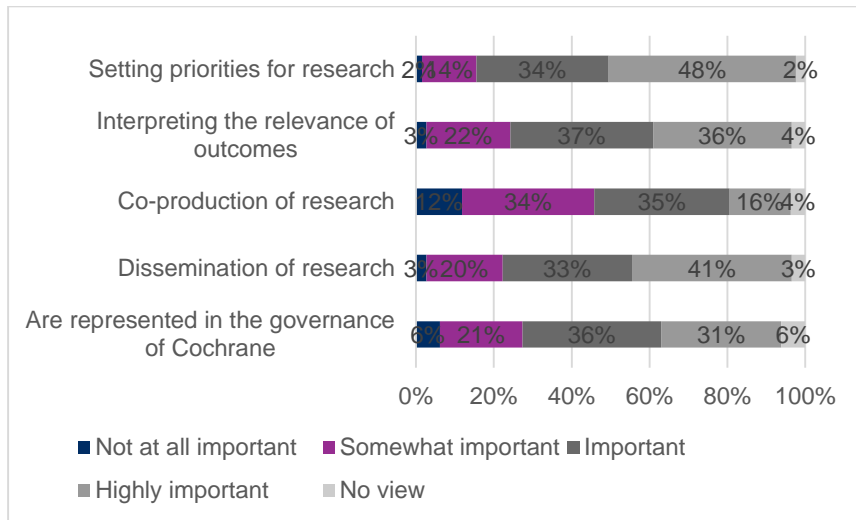


Table 4 Involvement of patients, patient advocates and healthcare consumers in the production of Cochrane evidence and in Cochrane activities (n = 371 – 374)

Organisational structure

Cochrane is a global network with representatives across 41 countries. It has a complex organisational structure with Centres and Branches, Fields and Networks, and Methods and Review Groups. Almost no interviewee could explain the functioning of Cochrane as an organisation. Despite this fact, about 40% of survey respondents were aware of and/or interacted with Cochrane groups globally, and 70% were aware of the local presence of Cochrane in their region or country. In terms of partnership between Cochrane and the external stakeholders' organisations: one third had a partnership and about one third did not have a partnership, and surprisingly about one thirds of the respondents did not know if there was a partnership with Cochrane.

There was substantial variation between countries about the awareness of a local presence and whether that made engagement easier.

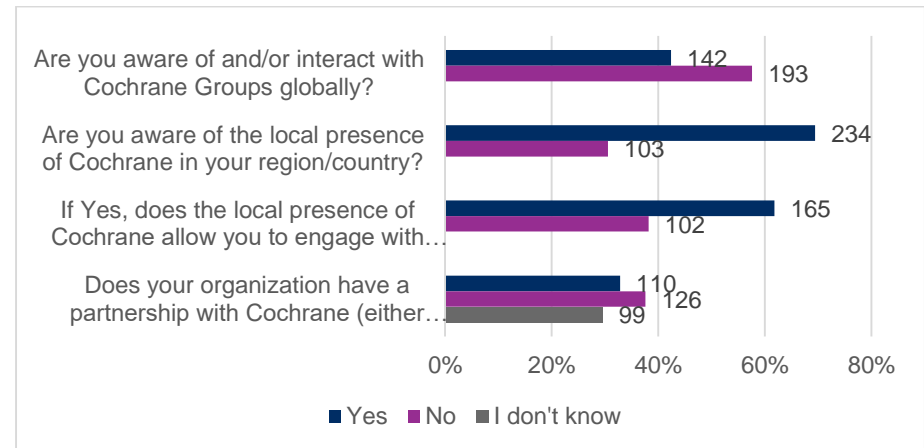


Table 5 Awareness and views on Cochrane's local presence (n = 335 – 337)

Very few respondents answered the question of how their local Centre could better meet their needs. Suggestions included enhanced local dissemination of information, interaction with public and patients, offering courses/meetings, and appointment of an in-country Cochrane representative.

Conclusions

The views of external partners are key given the complexity of the globalised world in which Cochrane functions, increasing partnership working, and the way that funding for its work is generated. Many organisations rightly have an expectation about the level and nature of consumer involvement in the work of Cochrane. The survey of external partners reinforces many of the

key messages identified elsewhere. In particular there are implications for the prioritisation of future important reviews (an area where consumers can play a vital role), the identification of outcomes important to patients and the dissemination of research (including knowledge translation and knowledge mobilisation). All these areas were regarded by external partners as important and yet these are the least common areas for consumers to be involved in (with some notable exceptions).

Recommendations

6.1 Work with consumers, Review Groups and others in order to facilitate new and effective ways of involving consumers throughout the research cycle. In particular, key areas for development include prioritisation, the identification of outcomes important to patients and dissemination (including knowledge translation and knowledge mobilisation).

6.2 Work with consumers, Review Groups, Centres, Fields and others in order to spread good practice in involvement throughout the research cycle and in particular in the areas of prioritisation, outcome identification and dissemination (including knowledge translation and knowledge mobilisation).

6.3 Work with Centres to develop strong partnership arrangements with a range of organisations that can support consumer involvement in research, taking in to account local variations.

7. Internal Consultation - Centres

“Cochrane’s global network of Centres offers an opportunity for an alternative model for supporting consumer involvement that would benefit both consumers (by giving them a recognisable physical locus) and Centres (by enhancing their existing engagement and dissemination role).”

Cochrane pioneered the involvement of consumers in its global process of production of health evidence. The network of consumers is spread across 79 countries of the world. Cochrane’s network of Centres has a potentially key role to play in supporting consumer involvement. Consultation with the Centres Executive took place in writing and at the Centres Executive meeting on 8th July 2015 based on the following analysis and proposals.

Background

There are presently over 1330 registered consumers spread across 79 countries globally, according to *Archie*. Of these, between 300 and 500 are regularly active in the production of Cochrane evidence, according to a recent survey of Review Groups. Consumers are presently mostly recruited from the English speaking and developed world.

Voting members of the Consumer Network presently choose the Consumer Executive (CE) of 5 consumers (currently from USA, Canada, China, UK and Israel) who are supported by the Consumer Network Coordinator. The key objectives of the CE are:

1. To support Cochrane entities in the inclusion of consumers.
2. To support consumers’ participation in Cochrane.
3. To increase consumer membership in low income countries and non-English speaking countries.
4. To increase awareness of Cochrane reviews among consumers globally.
5. To develop and disseminate information for consumers.

A geographical approach to consumer involvement

The existing Consumer Executive faces an overwhelming challenge in supporting consumer involvement within the work of Cochrane across the globe.

The challenges to effective support for consumer involvement across the network include:

- Language
- Cultural differences
- Variations in health systems
- Different local partnerships landscapes
- Variations in health and research priorities
- Reach and capacity of the existing CE

Through Cochrane's global network of Centres there is an opportunity to consider an alternative model for supporting consumer involvement that would benefit both consumers (by giving them a recognisable physical locus) and Centres (by enhancing their existing engagement and dissemination role, (including knowledge translation and knowledge mobilisation).

Synergies from Establishing the New Consumer Network

Enhancing the role of Centres is in line with other changes to the functions of Centres and Fields currently being considered. Synergies will grow over time from Centre involvement but key benefits will include:

- Developing partnerships to create the environment in which consumers involvement can thrive
- Recruitment, support, training and networking for consumers
- Involvement of consumers in knowledge mobilisation/transfer
- Increased engagement in priority low income and non-English speaking parts of the world

- Creating for consumers a sense of identity and community, regionally

These roles complement the existing Centre engagement functions in education, advocating for evidence informed medicine, partnership building, translation, training and knowledge mobilisation/transfer.

Challenges for the New Consumer Network

There are a number of challenges in making this a reality including:

- Resourcing additional functions
- Acknowledging that Centres have different capacities across the network
- Integrating this work with existing Centre functions
- Implementing these changes over time
- Communicating these changes to consumers and the wider network at a time of anxiety about widespread change

Bearing these challenges in mind, any reform in consumer support would need to be:

- Evolutionary
- Managed sensitively
- Respectful of existing Centre capacities

How a geographic network might work

A network of "Consumer Champions" would be identified in Centres (probably a voluntary role at least initially) to lead on these issues at Centre level. This would mean that Centres would need to integrate and support that person, but the resourcing impact should be minimal.

A Consumer Executive, as at present, would coordinate, link and support the network of Consumer Champions. Existing CE members could easily be Consumer Champions in their regions, ensuring continuity and reassurance

about the pace of change. This group could be supplemented by a small number of new Champions from elsewhere to form a representative group.

An early role for the new Consumer Executive and Consumer Network Co-ordinator would be to work together to develop an understanding of current capacity and activity within regions and develop an action plan based on the results of the Structure and Function Review and *Strategy to 2020* and support for the building of Consumer involvement, with systems for monitoring progress against objectives.

Resources and support would continue to be provided by Cochrane centrally and in future there may well be opportunities to seek additional regional funding to enhance Centre capacity, should Centres wish.

Conclusions

If Cochrane is to develop its consumer involvement a radical re-shaping of the Consumer Network is required, that builds on the good work of the past but facilitates engagement at the right global scale. The establishment of a network of “Consumer Champions” based within Centres and giving Centres a core role of promoting consumer involvement can be part of the re-focusing of this area of work.

Recommendations

7.1 Work closely with Centres and Branches, via the Centres Executive in order to establish a new Consumer Network and to develop their core role in supporting consumer involvement ensuring that it is evolutionary, managed sensitively and respectful of existing Centre capacities.

7.2 Establish a network of “Consumer Champions” to promote consumer involvement through Centres and Branches

7.3 Develop a reformed Consumer Network Executive building on the work of the CCNet Executive and ensuring a smooth transition from the existing network.

7.4 As a priority develop an understanding of current capacity and activity within regions and develop an action plan based on the results of the Structure and Function Review and *Strategy to 2020*, and support for the building of consumer involvement, with systems for monitoring progress against objectives.

8. Priorities to 2020

1 Develop a Cochrane statement of principles

3.9 5.1 Reaffirm Cochrane's commitment to consumer involvement by developing a statement of principles to which the organisation as a whole can commit.

2 Integrate consumer involvement throughout Cochrane structures

3.8 Work towards embedding consumer involvement in governance at all levels and in all Cochrane groups.

7.1 Work closely with Centres and Branches, via the Centres Executive in order to establish a new Consumer Network and to develop their core role in supporting consumer involvement ensuring that it is evolutionary, managed sensitively and respectful of existing Centre capacities.

7.2 Establish a network of "Consumer Champions" to promote consumer involvement through Centres and Branches

7.3 Develop a reformed Consumer Network Executive building on the work of the CCNet Executive and ensuring a smooth transition from the existing network.

7.4 As a priority, develop an understanding of current capacity and activity within regions and develop an action plan based on the results of the Structure and Function Review and *Strategy to 2020*, and support the building of consumer involvement, with systems for monitoring progress against objectives.

3 Support consumer involvement throughout the research cycle

2.3 Develop improved communication with Review Groups that supports exchanges about the needs of Review Groups and the support that is available.

3.7 and 5.2 Work towards ensuring consumers are as representative as possible of the population as a whole in respect of gender, age, ethnicity, disability, sexual orientation, socio-economic group, spoken language, and the developed/developing world.

2.1, 4.2 and 5.3 Work with Review Groups and Centres in a phased and targeted programme of recruitment, especially in low-income and non-English speaking countries.

3.1, 5.4 and 6.1 Work with consumers, Review Groups, the forthcoming *Project Transform* and others in order to facilitate new and effective ways of involving consumers throughout the research cycle.

3.4, 6.2 and 5.5 Work with consumers, Review Groups, Centres, Fields and others in order to spread good practice and encourage involvement throughout the research cycle and in particular in the areas of prioritisation, outcome identification and dissemination (including knowledge translation and knowledge mobilisation).

5.7 Encourage Review Groups to record their experience, to capture the impact of consumer involvement and to publish where possible.

5.8 Consider conducting a trial in order to understand what makes effective consumer involvement in the production and dissemination of Cochrane evidence (including knowledge translation and knowledge mobilisation).

4 Engage with Cochrane Membership for the full benefit of consumer involvement

4.1 and 5.5 Engage with the new Cochrane Membership in a way that facilitates new and effective ways of consumer involvement and includes ways of capturing accurate data about levels of involvement.

5 Build on and develop programmes of support for Cochrane consumers

2.4 Build a programme of mentoring support for new consumers.

3.2 Review the effectiveness of the Consumer Stipend in order to meet the strategic need to improve the involvement of consumers in the research process.

2.2 and 3.3 Develop training resources for consumers and Review Groups to promote involvement and in particular to promote innovation in involvement practices throughout the research cycle (e.g. priority setting, outcome identification and dissemination (including knowledge translation and knowledge mobilisation)).

3.5 Work with consumers, Review Groups and Centres to develop effective processes of support for consumers including recruitment, induction, mentoring and communication.

3.6 Undertake an annual survey of consumer satisfaction in order to improve practice.

6 Improve communication with consumers and about consumer involvement

4.3 Develop an improved communication strategy incorporating the effective use of social media.

7 Build effective external partnerships

6.2 Work with Centres to develop strong partnership arrangements with a range of organisations that can support consumer involvement in research, taking in to account local variations.

Appendix 1

Structure and Function Review Delivery Plan

Activity	Completed	Delivered
CE consultation	2015 Feb	<ul style="list-style-type: none">• Consultation with CE about plan for S&F• Identify additional members of project board to ensure integration• Gain approval from project board on S&F plan• Advance notification to CCNet via newsletter, social media
Consultation and data collection (CE & CCNet)	2015 April	<ul style="list-style-type: none">• Survey of CCNet members to complement Review Group Survey of Cochrane Review Groups (completed December 2014) including innovative use of Twitter and Facebook to gather views• Seek views of CE members
External partners	2015 April	<ul style="list-style-type: none">• Questions developed with CET and other SFR teams
Baseline data (CRGs)	2014 Dec	<ul style="list-style-type: none">• Utilize data collected in baseline data survey of CRGs during Dec 2014.
Baseline data (Fields)	2015 Feb	<ul style="list-style-type: none">• Questions developed with CET and other SFR teams
Baseline data (Centres)	2015 Mar	<ul style="list-style-type: none">• Questions developed with CET and other SFR teams
Cochrane staff	2015 Mar	<ul style="list-style-type: none">• Questions developed with CET and other SFR teams

Activity	Completed	Delivered
Data analysis	2015 Apr	<ul style="list-style-type: none">• Analyse data from each of the baseline surveys<ul style="list-style-type: none">○ CRGs○ Fields○ Centres and Branches• Analyse data from the Consultation process<ul style="list-style-type: none">○ CE○ CCNet○ External Partners• Literature review of consumer involvement in systematic reviews• Collect and analyse data from<ul style="list-style-type: none">○ <i>Archie</i>○ Facebook○ Twitter• Core data conclusions for S&F review:<ul style="list-style-type: none">○ Identify areas of opportunities for growth○ Identify problem areas where need is not met○ Identify areas of success for CCNet

Activity	Completed	Delivered
Data sharing (mid-year meeting)	2015 May	<ul style="list-style-type: none"> • Contact Fields Exec, ME Exec, Centre Directors Exec and offer to discuss initial conclusions with groups during their mid-year meetings. • Where invited, discuss initial findings with Execs at mid-year meeting to gain additional input for S&F review
Report on baseline data	2015 Apr	<ul style="list-style-type: none"> • S&F Options Consultation Paper <ul style="list-style-type: none"> ○ Prepare part 1 of the paper: a review of the core data conclusions (see activity 8) that resulted from the consultation process and baseline data surveys. • Paper can be modelled after the CEU's 'Options Exploration paper' from Feb 2014 (http://editorial-unit.cochrane.org/structure-function-project)
CCNet models	2015 May	<ul style="list-style-type: none"> • Develop a set of potential CCNet models based on the initial results of the baseline survey data and the consultations.
Consultation on options – CE/project board	2015 May	<ul style="list-style-type: none"> • Present "S&F Options Consultation Paper" to the CE /project board at the Mid-year meeting for extended discussion • Review options with CE
Consultation on options - CCNet, Cochrane and External Partners	2015 Jun	<ul style="list-style-type: none"> • Provide advance warning to stakeholders about the consultation process via newsletter, social media • Develop consultation process (online survey) to include with the "S&F Options Consultation paper"

Activity	Completed	Delivered
Report on Final Consultation	2015 Jul	<ul style="list-style-type: none">• Assess responses to consultation process• Provide a report for the project board• Report can be modelled after the CEU's "Summary of responses to the consultation" from Mar 2014 (http://editorial-unit.cochrane.org/structure-function-project)
Project board selection meeting	2015 Aug	<ul style="list-style-type: none">• Meet with project board to review responses to consultation on options• Determine selection from the options• Develop next steps for implementation
Report for CSG	2015 Sept	<ul style="list-style-type: none">• Prepare report for CSG with MW/CC on future directions for CCNet based on the results from the C&F review• Review report with CE for comments
Development of implementation plan	2015 Dec	<ul style="list-style-type: none">• Develop implementation plan with the project board

Appendix 2

Consumers registered to *Archie*, February 2015

UK	283	Costa Rica	7	Kenya	3	Ethiopia	1
USA	212	Greece	7	Norway	3	Finland	1
Australia	138	Mexico	6	Rwanda	3	Ghana	1
Canada	138	Bahrain	5	Saudi Arabia	3	Indonesia	1
Egypt	103	Bangladesh	5	Spain	3	Iraq	1
China	56	Chile	5	Swaziland	3	Kuwait	1
India	51	Denmark	5	Switzerland	3	Lebanon	1
Germany	24	Romania	5	Austria	2	Nepal	1
Nigeria	23	Russian Federation	5	Belgium	2	Oman	1
Italy	19	Sweden	5	Bolivia	2	Pakistan	1
New Zealand	18	France	4	Cameroon	2	Poland	1
South Africa	18	Israel	4	Guatemala	2	Saint Kitts and Nevis	1
Iran	16	Peru	4	Korea, South	2	Seychelles	1
Netherlands	15	Singapore	4	Philippines	2	Sri Lanka	1
Brazil	13	Syrian Arab Republic	4	Portugal	2	Sudan	1
Colombia	13	Taiwan	4	Tanzania	2	Uganda	1
Malaysia	11	United States Minor Outlying Islands	4	Turkey	2	Ukraine	1
Thailand	11	Croatia	3	Benin	1	United Arab Emirates	1
Ireland	9	Hong Kong	3	Cyprus	1	TOTAL	1338
Japan	8			Dominican Republic	1		
Argentina	7			Ecuador	1		

Appendix 3 Consumer involvement in the Cochrane research cycle

