

## Cochrane Consumer Network

### Delivery Plan

2016 to 2020





# Background to the Delivery Plan 2016 to 2020

## Purpose

The purpose of this Delivery Plan is to set out a framework for implementing the key priorities identified by the recent Cochrane Consumer Network Structure and Function Review. The network of consumer contributors is a fundamental part of Cochrane, and contributes at every level to the goals identified in Cochrane's Strategy to 2020:

### **GOAL 1: Producing evidence**

To produce high-quality, relevant, up-to-date systematic reviews and other synthesised research evidence to inform health decision making.

### **GOAL 2: Making our evidence accessible**

To make Cochrane evidence accessible and useful to everybody, everywhere in the world.

### **GOAL 3: Advocating for evidence**

To make Cochrane the 'home of evidence' to inform health decision making, build greater recognition of our work, and become the leading advocate for evidence-informed health care.

### **GOAL 4: Building an effective & sustainable organisation**

To be a diverse, inclusive and transparent international organisation that effectively harnesses the enthusiasm and skills of our contributors, is guided by our principles, governed accountably, managed efficiently and makes optimal use of its resources.

## The Cochrane Consumer Network (CCNet)

The Consumer Network is a body of patients, carers, family members, and others, who work to support consumer engagement and involvement in the production of and dissemination of Cochrane evidence. Consumer involvement in research can be defined as “research being carried out ‘with’ or ‘by’ members of the public” (<http://www.invo.org.uk/>). Cochrane consumers are also actively engaged in knowledge transfer ensuring that information and knowledge about research and the results is provided and disseminated to the broader public.

The current key aims of the Consumer Network are:

1. To support Cochrane groups in the inclusion of consumers
2. To support consumer participation in all areas of Cochrane
3. To increase consumer membership in low and middle-income countries and non-English speaking countries
4. To increase consumer awareness of Cochrane reviews worldwide
5. To develop and disseminate Cochrane evidence for consumers

More information about the Consumer Network can be found at <http://consumers.cochrane.org/>

## Cochrane Consumers Structure and Function Review's (SFR)

The Cochrane Consumers Structure and Function Review's (SFR) was undertaken in 2015 to evaluate how well the network functions and structures supported the strategic goals of Cochrane, as outlined in Strategy to 2020. The review looked at key aspects of the Consumer Network, in particular:

- 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 different models of consumer participation in the production of reviews
- The consumer roles in the dissemination of reviews
- Pathways for involvement in the Consumer Network
- Support and training available to consumers
- Priorities for the future development and support of increased consumer involvement in Cochrane reviews

Secondly, the review:

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

Completed in time for the Cochrane Steering Group meetings in Vienna, October 2015, the SFR concludes that Cochrane was one of the pioneers in the involvement of consumers in research. Currently there are over 1400 Archie registered consumers, with an active core of between 300 to 500 regularly involved in the production and dissemination of Cochrane health evidence. This is something to celebrate, however practice across Cochrane varies and, with some notable exceptions, Cochrane has not kept pace with the rest of the research world. Authors, review groups, and consumers themselves are looking for support to develop good practice in involvement. The present organisational structures do not always facilitate effective consumer involvement so changes to enhance involvement are suggested in the Review.

The key priorities identified in the SFR form the heart of this Delivery Plan. In addition to the priorities from the SFR, the Delivery Plan takes in to account other key issues and opportunities facing Cochrane. The Delivery Plan sets out its priorities rationale, resources required, planned outcomes with time frames for a comprehensive and ambitious programme of activity from 2016 to 2020. The implementation of the Delivery Plan will be overseen by the Cochrane Consumer Network Executive.

# Delivery Plan 2016 to 2020 Priorities

The SFR identified seven priorities in the Delivery Plan, with the inclusion of an eighth, which was added in the process of developing the Plan.

1. Develop and adopt a statement of principles about consumer involvement in Cochrane
2. Integrate consumer involvement and representation in all levels of Cochrane decision-making groups
3. Support consumer involvement throughout the entire review production and evidence dissemination process
4. Contribute to the development of the Cochrane Membership plan to ensure the it offers maximum opportunities for consumer membership and involvement
5. Build on current and develop new, programmes of training and support for Cochrane consumers
6. Improve communication with Cochrane consumers
7. Build effective external partnerships
8. Increase awareness of evidence-based medicine and the use of Cochrane evidence when making health decisions among consumers worldwide

	Objective	Rationale	Resources	Outcome	Timescale
<b>Priority 1.0 Develop and adopt a statement of principles about consumer involvement in Cochrane</b>					
1.1	Reaffirm Cochrane’s commitment to consumer involvement by involving people inside and outside the organisation leading to a Cochrane statement of principle for consumer involvement, to which the entire Cochrane organisation can commit.	The Consumer Structure & Function Review identified variations in levels of understanding about, commitment to, and degree of consumer involvement across Cochrane. This year long process of consultation will examine, clarify and re-affirm the value of consumer involvement in Cochrane reviews. It will include issues such as: “Who are consumers?” “What is unique about the consumer experience?” “How do we best capture the impact of consumer involvement” “How can we make the consumer experience more satisfactory?” “How do we recruit a more representative range of consumers?” A range of methods will be used including: blogs, Twitter chats, face to face meetings etc. The consultation will culminate in a draft policy statement to be submitted to the Cochrane Steering Group for endorsement.	Task group drawn from Cochrane groups – Review Groups, Fields, Centres, CET	Policy statement to be launched and tabled at the Cochrane Steering Group meeting at the 2016 Colloquium.	Begins January 2016 Completed by October 2016

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<b>Priority 2.0 Integrate consumer involvement and representation in decision-making groups at all levels in Cochrane</b>					
2.1	Work towards embedding consumer involvement in governance at all levels and in all Cochrane groups.	Improvement of, and support for, consumer involvement has been seen as almost exclusively the realm of the Consumer Network Executive. The complexities of Cochrane (health topics, geography, scale, culture, language etc.) and the need to embed consumer involvement throughout the entire review process would benefit from consumer involvement being a consistent thread throughout all Cochrane structures. Part of the 2016 discussion on the future of consumer involvement will relate to how best this should happen and will be included in the paper to go to CSG in October 2016		Position paper to CSG October 2016. Implementation from 2017.	Begins January 2016, position paper to CSG October 2016, and implementation from 2017
2.2	Work closely with Centres and Branches, through the Centres Executive, to establish an enhanced and invigorated consumer network and to develop the role of Centres and Branches in supporting consumer involvement and growth ensuring that it is evolutionary in level of involvement, managed sensitively and takes into account Centre capacities, organisational and local	The Centres Structure and Function Review offers the opportunity for willing Centres and Branches to develop their role in supporting consumer involvement. Important roles for Centres could include linking their role in promoting evidence based medicine to developing partnerships for consumer involvement, recruitment, training, support, networking (at symposia and other events) and the involvement of consumers in dissemination activities. Not all Centres will be in a position to undertake this work. Involvement will need to be	A Task Group of key and interested stakeholders to be established  Financial resources, including a potential "Challenge Fund" to support building capacity for the enhanced Centre role.	Analysis of Centres' capacity. Pilot activity with one willing Centre in 2016 with roll out to three planned from 2017.	Task Group established January 2016 Analysis begins March 2016, completed June 2016 Pilot activity begins June 2016 Rolled out to three 2017 and more thereafter

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	culture.	managed sensitively to reflect local culture, language, research environment, funding and health services priorities. A key element will be to engage collaboratively with each centre to assess capacity and develop appropriate ways of working collaboratively. Consideration will be given to establishing a “Challenge” fund to encourage capacity building within centres.			
2.3	Establish a network of “Consumer Champions” to promote consumer involvement through Centres and Branches	Essential to the development of consumer involvement within Centres and Branches will be the identification of “Consumer Champions”. Initial work will focus on establishing the task group described in 2.2., then defining the role, and desired consumer qualifications. A Champion will be identified in each Centre/Branch initially as an opportunity to establish lines of communication and subsequently to be involved in the implementation of enhanced Centre/Branch roles.	A Task Group to be established of key and interested stakeholders as above.	Role descriptor and specifications for Consumer Champion role. Network of Consumer Champions established.	Establish Task Group as in 2.1 January 2016 Begin work in developing role descriptor and person spec in March 2106. Recruit to roles from June 2016 and in place by October 2016.
2.4	Develop a reformed Consumer Network Executive and ensuring a smooth transition from the existing network structure.	The Consumer Executive is a small voluntary group and as such struggles to engage with the wider Cochrane network effectively. It has no formal links with the network of Centres or review groups. Improving and/or creating formal links between Centres and the C.E will help improve communication, understanding, and build better relationships. During 2016 the CE will examine options for CE		Proposals developed for a re-structured CE. Implementation from 2017. Consultation on proposals. New CE established from March 2017.	Begins March 2016 with implementation from March 2017.

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		re-structuring and will develop proposals, and consult upon them with a view to implementation from 2017.			
2.5	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. Support the increase of consumer involvement, with systems for monitoring progress against objectives.	Undertake an analysis of Cochrane Centres' capacity to support consumer involvement-related activity. The analysis will include resources, partnership arrangements, current activities (engagement, training etc.), and examples of good practice. Subsequently in partnership with Centres, Branches, Consumer Champions and CRGs, it is proposed to develop a targeted programme of work in priority regions to enhance consumer involvement. This will include as a priority, targeted recruitment, and increased support for consumers and Centre staff using the new training resources being developed at 5.1 to 5.5.	A Task Group to be established of key and interested stakeholders as above.	A completed analysis of the capacity of Centres to undertake consumer involvement activities. Good practice examples. A priority list of Centres willing to move forward with increased consumer involvement.	Begins March 2017.
<b>Priority 3.0 Support consumer involvement throughout the entire review production and evidence dissemination process</b>					
3.1	Develop improved communication with Review Groups about the needs of Review Groups and the consumer support that is	Improved communication with Review Groups is crucial if consumer involvement is to be better integrated into their work. Key issues include recruitment, support, training and crucially the development of		Improved communication with Review Groups. Agreed process put in place.	Ongoing

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	available.	consumer involvement throughout the review process. Ways to Improve communication with MEs Executive and individual groups will be explored			
3.2	Work towards ensuring consumers are as representative as possible with respect to gender, age, ethnicity, disability, sexual orientation, socio-economic status, spoken language, and geographic location.	Consumers are known to be overwhelmingly white, English-speaking, middle-aged females from developed countries and may not be representative of the wider populations. This is a barrier to effective consumer involvement in the production of research that is important to address Recruitment will be key (see 3.3) to ensuring representativeness but requires time. The issue needs to be explored and a strategy developed to identify best practice in recruitment. Processes must be in place to record and monitor progress. A more diverse and representative consumer network is the ultimate goal.		Recruitment Plan for recruiting and involving a more diverse range of consumers.	Begins March 2017. Strategy in place December 2017.
3.3	Work with Review Groups, authors and Centres in a phased and targeted programme of recruitment, especially in low-income and non-English speaking countries.	The 2015 SFR revealed the need for the recruitment of new consumers. In addition to the regular processes we have developed some limited, focused work can begin immediately where an urgent need is identified However more sustained work will depend on, and benefit hugely from, a new relationship with Centres (see 2.2) the development of new learning and support resources (5.3), the new Membership Scheme (see 4.1), and new ways for consumers to get involved (see 3.4). In the short term,		Recruitment Plan	Begin discussion with Review Groups for urgent recruitment March 2016  Begin development of Priority Recruitment Plan April 2017, completed by October 2017. Sustained

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		managing expectations will be important. When appropriate the CE will engage in discussion with Review Groups and develop a Priority Recruitment Plan.			programme of recruitment begins 2018.
3.4	Work with authors, consumers, Review Groups, the Project Transform team and others to facilitate new ways of involving consumers throughout the review process.	<p>2016 will see discussion and re-affirmation of the importance of consumer involvement in the production and dissemination of Cochrane evidence. Central to this will be discussion about consumers' involvement earlier in the review process (i.e. in identifying priority reviews and relevant outcomes) as well as refining the existing ways in which consumers are involved (i.e. commenting on protocols, reviews and Plain Language Summaries).</p> <p>The 2016 Colloquium will see the launch of a Steering Group statement about its importance. The development of new resources will be essential to facilitate this extension of consumer involvement. Methods of spreading good practice, including at Cochrane meetings, through training, conversations with Review Groups and embedding consumers in the structures of Cochrane etc. is also essential. Project Transform offers exciting opportunities for the development of new ways to be involved. An annual survey of Review Groups and consumers will monitor progress in achieving this aim.</p>		Policy Statement agreed CSG. New training resources developed. Project Transform online.	Policy statement October 2016. Annual Surveys developed and undertaken in December annually.

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3.5	Work with consumers, Review Groups, Centres, Fields and external partners to spread good practice and encourage involvement throughout the research cycle. In particular in the areas of prioritisation, outcome identification and dissemination (including knowledge translation and knowledge mobilisation).	See above		Policy Statement agreed CSG. New training resources developed. Project Transform online.	Policy statement October 2016. Annual Surveys developed and undertaken in December annually.
3.6	Encourage Review Groups to record their experience, to capture the impact of consumer involvement and to publish where possible.	The literature review, undertaken as part of the 2015 SFR revealed that there is limited publication of consumer involvement activities. Review groups will be encouraged to record and report consumer involvement activities. This will be captured in the Annual Survey and a further literature review undertaken in 2020.		Reports on Review Groups' consumer involvement activities to be made available to the CE. Literature review.	Annual survey December. Literature review 2020.
3.7	Consider conducting research in order to understand what makes effective consumer involvement in the production and dissemination of Cochrane evidence (including knowledge translation and knowledge mobilisation).	One of the recommendations, arising from the 2015 SFR and literature review, was the potential to conduct further research (possibly a trial) into the impact of consumer involvement in the production of Cochrane evidence. This recommendation will be revisited in 2018 for discussion with potential interested parties, including the Consumer and Communication Review Group.		Research in to the impact of consumer involvement.	Research in to the impact of consumer involvement begins June 2018.

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<b>Priority 4.0 Contribute to the development of Cochrane Membership to ensure the scheme offers maximum opportunities for consumer engagement and involvement</b>					
4.1	Engage with the new Cochrane Membership in a way that facilitates new and effective ways of consumer involvement and includes means of capturing accurate data about levels of involvement.	The new Cochrane Membership Scheme offers significant opportunities to support the recruitment and engagement of Consumers in the production and dissemination of Cochrane evidence. The Consumer Executive will maintain its involvement in the design and roll out of the Scheme.		New Cochrane Membership.	Work with Membership development team from January 2016 to launch.
<b>Priority 5.0 Build on and develop new programmes of support for Cochrane consumers</b>					
5.1	Build a programme of mentoring support for new consumers.	The Consumer Executive has previously identified the need to establish a mentoring scheme to support new consumers. Some work has already been done to identify potential mentors. In order to take this forward it is proposed to establish a Mentoring Task Group to develop a scheme.	Mentoring Scheme Task Group.	Mentoring scheme established.	Task group established April 2017. Mentoring scheme commences October 2017.
5.2	Review the effectiveness of the Consumer Stipend process to meet the strategic need to improve the involvement of consumers in the research process.	The consumer stipend is an annual amount of £30,000 awarded to registered consumers to support their attendance at Cochrane colloquia. There is a need to review the effectiveness of the stipend application and award process to ensure that it is fit for purpose and meets the strategic needs of Cochrane.		Revised application process and criteria.	Begins January 2016. Ends March 2016.
5.3	Develop training resources	The Cochrane Training Group is	Cochrane Training	New online and group	Commenced 2015.

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	for consumers, Review Groups and centres to promote involvement and in particular to promote innovation in involvement throughout the review process (e.g. priority setting, outcome identification and dissemination)	developing new learning resources, with new online and group training materials to be produced in order to support consumer involvement. A programme of work has been devised and work has begun in partnership with the Consumer Executive.	Group. £5,000 grant available to fund consumer involvement in the production of resources.	training materials.	Completed by 2020.
5.4	Work with consumers, Review Groups and Centres to develop effective processes of support for consumers including recruitment, training, mentoring and ongoing communication.	Part of the process of ensuring that consumers are adequately inducted, recruited, trained and supported will involve working with Review Groups and Centres to ensure that the resources developed also meet the needs of Review Groups in particular, but also Centres. A range of methods will be used including surveys, workshops at symposia and colloquia and establishing a dialogue with the Managing Editors' Executive. This work has already begun with the Review Group survey as part of the 2015 SFR and attendance at the Managing Editors' meeting in Vienna 2015. There will be a need to maintain constant dialogue in the future.		Resources and support developed that meets the needs of consumers and Review Groups	Ongoing
5.5	Develop a range of measures to understand the consumers' experience including undertaking an annual survey of consumer	As part of the Consumer SFR, a survey of consumers was undertaken and produced a range of important information including satisfaction measures. Key to knowing the effectiveness of the range of		Develop measures that capture consumers' experience. Annual survey including a measure of consumer	December annually.

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	satisfaction in order to improve practice.	work that is being undertaken will be to understand the consumers' experience through an annual survey of consumer satisfaction.		satisfaction.	
<b>Priority 6.o Improve communication with Cochrane consumers</b>					
6.1	Develop an improved communication strategy incorporating the effective use of social media to improve the experience of being a Cochrane consumer.	The consumer survey completed in the SFR 2015 revealed concerns about the way in which the organisation communicates with consumes. Working with the Communications team, the Consumer Executive will review its communications strategy (e.g. newsletters, social media, web presence etc.)		Improved communications strategy.	Begins June 2016. Ends December 2016
<b>Priority 7.o Build effective external partnerships</b>					
7.1	Work to develop strong partnership arrangements with a range of organisations that can support consumer involvement in Cochrane, in line with the Cochrane Partnership Strategy	Cochrane works within a complex environment of partnership arrangements and funding bodies. Developing effective relationships with bodies outside Cochrane is the subject of the Cochrane Partnership Strategy, and is essential to the development of consumer involvement. This is important not only at a global strategic level but also at a regional level where such arrangement can help with recruitment, training, and collaboration. Work to develop closer relationships has already begun (for example meetings have already been held between UKCC and Involve and the James		Key partnerships developed at a regional and at a global level, including a new, strategic international consumer involvement network	Begins January 2016. Ends September 2017.

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		Lind Alliance). Cochrane is presently developing major strategic partnerships with global organisations. No suitable network exists for consumer involvement at this scale. It is proposed to work with others to assess the feasibility of building such a network with a potential launch in September 2017 at the global evidence conference in Cape Town.			
<b>Priority 8.o Increase awareness of evidence-based medicine and the use of Cochrane evidence among consumers worldwide</b>					
8.1	Contribute to the development of the Cochrane Knowledge Transfer/mobilisation strategy and work with authors, review groups and centres to identify and build on good practice in raising awareness of evidence based medicine and the use of Cochrane evidence amongst consumers and the public.	A key role for the Consumer Network is to identify ways of increasing the awareness of evidence based medicine and the use of Cochrane evidence. There are examples of good practice (e.g. Evidently Cochrane, Cochrane Mexico, and Making Sense of MS Research), and Cochrane will be developing a knowledge transfer/mobilisation strategy in 2017. The CE can play an important role in developing and implementing this strategy. Cochrane Membership (Priority 4) along with Cochrane Crowd and Task Exchange, offer the opportunity to engage with a significantly larger group of consumers.	Knowledge Transfer/mobilisation strategy; Cochrane Membership; Cochrane Crowd; Task Exchange.	Knowledge Transfer/mobilisation strategy	Commence 2017 Complete by October 2018.

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