Minutes of teleconference of the Cochrane Collaboration Steering Group (CCSG) on 30 July 2013

(Minutes approved on 06 September 2013)

Present: Jonathan Craig (Co-Chair), Jeremy Grimshaw (Co-Chair and meeting Chair), Sally Bell-Syer, Rachel Churchill, Michelle Fiander, Julian Higgins, Steve McDonald, Mona Nasser, Mary Ellen Schaafsma, Liz Whamond (items 1-4) and Mingming Zhang.

Mark Wilson (Chief Executive Officer), David Tovey (Editor in Chief), Jini Hetherington (Company Secretary), Claire Allen (Deputy Administrator), Lorna McAlley (PA to the CEO, minutes) and Chris Mavergames (Item 5 only).

1. Welcomes, apologies, declarations of interest, and approval of the agenda

Jeremy welcomed everyone to the teleconference. Apologies were received from Marina and Denise. Jeremy proposed that Item 4 (*Cochrane Strategy to 2020*) would be covered in brief as there would be many opportunities to provide feedback on the document before a final Special CCSG teleconference, on 27 August 2013, to provide sign off. Jeremy explained that Item 5 (Linked Data Project) would be a preliminary discussion and that this item would be covered in more depth during the CCSG meeting, at the Quebec Colloquium. No declarations of interest were identified and the agenda was approved.

2. Approval of minutes of CCSG teleconference on 11 June 2013

Sally asked for clarification on the process to ensure that action items, arising in the minutes of CCSG meetings, were undertaken and completed. Mark explained that, depending on the specific items, in general all action items should be completed by the following CCSG meeting and any remaining should be completed by the CCSG meeting after that. Mark clarified that it is the Central Executive team's responsibility to ensure that all action items are completed, by taking on items where possible or following up with individuals and offering assistance, if required. Mark reported that all action items arising from the CCSG teleconference of 11 June had been completed, with the exception of the Discretionary Fund and Game Changers papers, as these are due to be redrafted and circulated to the CCSG in time for the Colloquium in Quebec. David reported that advertising for the new 12-month full time Editor contract had been intentionally delayed until September 2013, to co-ordinate the position's start date with the end of a current 12-month contract, to ensure no overlap occurs.

A minor correction to the minutes was requested, from Steve, in relation to Item 6 (Cochrane Training). Lorna will amend the minutes accordingly. The minutes were then approved, subject to this correction being made.

Actions: Lorna to circulate the amended and approved minutes to all entities, archive them in Archie and make them available on Cochrane.org. Lorna to include the item: 'Matters arising from (previous date) CCSG meeting' on future CCSG agendas, to ensure action items have been addressed.

3. Approval of minutes of Special CCSG teleconference on 25 June 2013, to discuss *Cochrane Strategy to 2020*

A minor correction was requested, from Julian, in relation to his feedback. Lorna will amend the minutes accordingly. The minutes were then approved, subject to this correction being made.

4. Cochrane Strategy to 2020

Mark gave a brief overview of the current status of the strategy development, explaining that he and Lucie had integrated the feedback received from the CCSG and the Consultation Group on the first *Cochrane Strategy to 2020* (short draft) into the fuller document, which had been distributed to all entities for their consideration on 12 July. Feedback continues to be received, which has been overwhelmingly supportive in content. The proposal for a shortened 'Cochrane' re-brand has been particularly well received. Mark also noted the wide range of individuals offering their feedback, which has been encouraging. The latest draft of the *Cochrane Strategy to 2020* has integrated some questions put forward either by the CCSG or arising from Mark and Lucie's reworking, or from comments provided by the Consultation Group. The main area requiring further feedback is in providing examples or proposals for SMART Targets for the first 1-2 years of the strategy.

Mark encouraged further input from the CCSG in this area. He outlined the intense process of continuing consultation: resulting in the production of a final document which the CCSG will receive ahead of the Special CCSG teleconference on 27 August. Any necessary amendments arising from this final teleconference will be made in time to be included in the final draft which will be sent out to the Collaboration as part of the AGM document pack at the end of August, for the Annual General Meeting, on 21 September in Quebec.

Mark explained he intends to send the strategy document to a small group of external stakeholders and major donors for their feedback and welcomed any suggestions from the CCSG of individuals or organisations they think should be included in this group.

Mark answered a several queries, clarifying the best ways of conveying feedback on the strategy. Jeremy congratulated Mark and Lucie on the huge amount of work carried out to date in developing the *Cochrane Strategy to 2020*.

Actions: CCSG members to send any additional feedback to Mark and Lucie before 12 August. CCSG members to inform Mark and Lucie of any individuals they recommend to join the small external consultation group.

5. Linked Data Project

Liz left the teleconference from this item onwards (due to connection problems).

Chris Mavergames joined the teleconference, for this item only. Jeremy welcomed Chris and invited him to provide an introduction to the concept of Linked Data, describe in broad terms where the strategy is going and outline the key issues for the next steps of the project. Jeremy clarified that no decision from the CCSG would be required on this item during the teleconference.

Chris outlined the background for the project, which began with discussions on Linked Data between Wiley and The Collaboration in May 2011. These discussions were motivated by needs identified through user

research, namely that users of Cochrane Reviews wish to view content and data in ways that were not being offered. Over the following two years it became apparent that there was potential to improve both the review production and the dissemination systems. A project board was formed which held meetings from January to May 2013 and produced the *Cochrane Tech to 2020* paper (Item 5.2).

In describing Linked Data, Chris reminded the CCSG of a statement made by Ben Goldacre, at the mid-year meetings, in Oxford 2013: "Cochrane needs to get better at talking to machines" so that both its output, and its data could be much more useful to researchers and other users – explaining that this is the core of the project. Chris summarised the project and the approach he envisaged, making the following key points:

1) The Linked Data Project involves creating new technical architecture to connect up our databases and systems, to make them more inter-operable with other systems, and have the potential to drive production and dissemination in better ways, including enabling creation of derivative products.

2) We would move towards an agile and innovative development paradigm for all of our informatics and knowledge management projects, including Archie and Revman, which will be user-centered in its approach to design.

3) The project is as much about content as it is about technology, which is why the Project Board has been working so closely with the Editorial Unit. The Project Board is made up largely of individuals who have a non-technological background, and the paper (*#Cochrane Tech to 2020*) was written in a way that attempts to be understandable to all.

4) Essentially, the current way of creating and disseminating the Collaboration's content is simply not sustainable for many reasons: such as issues of Open Access, being too labour intensive, not leveraging technology enough, and that the one-size-fits-all dissemination method currently in operation does not meet user needs. Therefore, the aim is to investigate using these new linked data technologies to make ourselves more sustainable and to use them as enabling technologies which build on what we have – rather than replacing it.

5) The project should be considered as a fundamental game-changing concept on the road to 2020. Chris hopes for a robust, honest and ongoing dialogue, with mapped business goals and priorities, in which the CCSG will be supportive not just in terms of financial backing but in facilitating change management and communication to respective entities.

Chris invited questions from the CCSG. Clarification was sought on Wiley's role within the Linked Data Project. Chris explained that Wiley were initially heavily involved, until December 2012, and that Wiley had funded the initial consultation work. However, Wiley's own systems are adopting the Linked Data approach and the Collaboration needs to avoid any form of vendor lock-in, particularly in consideration of Open Access, to enable control over how our content is structured and tagged. Therefore, Wiley must be decoupled from any downstream consumers, which will ensure a 'future-proof' structure for the Collaboration. However, the Project Board still regularly communicates with Wiley to make sure our Linked Data will be compatible with theirs.

Jeremy suggested that the CCSG needed to have a clearer understanding of exactly what Linked Data is, how it will affect the way members of the Collaboration work together, and why it is so important for the Collaboration in terms of the strategic value of moving forward with the project. This would require a further, more accessible explanation for those who have a less technological background.

David added that he sees Linked Data as a motif for utilizing technology to its greatest impact; to improve review production and downstream product development, how to get the product out, improve the search and provide content. David encouraged the CCSG to think of these aspects when considering the project.

The importance of having strategies in place to receive continuous feedback from users was acknowledged. It was asked whether the Collaboration would be leading developers or late adopters of linked data approaches. Chris explained that we would be leading in the sense of introducing systematic reviews into the synthesized evidence space – but very much following in terms of the amount of medical linked data which is already in the field. There is no systematic review ontology (or schema) at present, therefore we would be leaders in this area.

In terms of review production, it was asked how Linked Data would benefit CRGs. Chris responded that although it is not entirely clear yet, there is huge potential which will be driven by what urgent user needs arise. Jeremy requested that Chris should prepare a broad presentation for Quebec to encompass:

- a broad vision of what Linked Data will enable us to do in the future which cannot presently be done;
- some examples and case studies demonstrating this;
- the road map ahead over years 2 and 3 (recognising that this will be speculative);
- benefits and risks;
- the potential for working with partners and how people might engage in the process.

Jeremy thanked Chris for his introduction to the project and for attending the teleconference for this item. Chris welcomed contact from anyone wishing to discuss the project in more detail. It was agreed that CCSG members could email Mark with any questions in the first instance, copying in all members to the discussion.

Actions: Lorna to add Linked Data as an item on the CCSG meeting agenda in Quebec. Chris to produce a further presentation on Linked Data, as detailed in the above minute, for the CCSG meeting, in Quebec.

6. Proposal to re-evaluate the structure and functions of Cochrane Review Groups

David explained that this paper had been redrafted taking into consideration the feedback received since the previous iteration was discussed during the CCSG teleconference on 11 June. David emphasized that the paper had been made 'Open Access' to ensure transparency from the outset of the project, which will look at the structure and function of CRGs currently and assess how well adapted they are to meet the challenges of the future. This will require a fairly broad view of the challenges and opportunities the Collaboration faces – such as the interaction with stakeholders, building capacity and expertise, building professional career development and addressing the challenges of the author experience. David stressed that there are no preordained end points. The current structure and function will be evaluated, as will other plausible structures and functions, to see the extent to which they make us more or less able to achieve our strategic goals, as set out in *Cochrane Strategy to 2020*. It's crucial there is no prior assumption that CRGs will change in any specific way.

This project will have both an internal focus - recognizing the diversity of the CRGS, and an external focus - as funders of Cochrane infrastructure need to be involved in these conversations. David proposes to start the review project at the CEU and build outwards. A Project Board, for governance, would be chaired by Mark.

Internal and external advisory groups would be formed. Funds would be made available to co opt internal stakeholders to support the project. Funds would be used for external consultancies to support the project.

This would be a 12-14 month project, with a project plan offering further scope and detail to be provided for the CCSG meeting in Quebec, followed by an interim report at the 2014 mid-year meeting in Panama and aiming to provide conclusions and recommendations for the CCSG to consider at the 2014 Colloquium in Hyderabad.

David invited comments from the CCSG. Rachel explained that this project arose from the Co-ordinating Editors' Board meeting (in Oxford) and commented that although CRG Co-Eds are very much in support of this initiative some CRG staff will find this review threatening and destabilizing, emphasizing the importance of keeping people involved in the process. As this review is in response to the new *Cochrane Strategy to 2020* we need a model across the Collaboration which is fit for purpose to meet the strategic goals. We need to maintain peoples' involvement in creating this model, so that it is helpful in allowing us to make these changes in time.

Sally echoed the importance of ensuring the review does not appear to be threatening and suggested that engaging a cross section of CRGs for involvement in the consultation process would help. It was confirmed that, as an Open Access document, the paper could be circulated to members of all entities.

Michelle requested that David consider involving two TSCs on the consultation board for this project, given that TSC work is fundamental to review groups and the production of systematic reviews. David clarified that the Project Board is to make sure the project on track – and *not* to steer recommendations in any direction. The big content input will come from the advisory group and the external consultants. The involvement of external consultants was recognized as extremely important. Advice was given by CCSG members on the process of recruiting an external consultant to assist with the review.

Thanks were expressed for David's work in fleshing out the proposal for this review. There was a general consensus that it is essential for the review to be undertaken. It was also noted that this initiative overlaps with both the formation of the *Cochrane Strategy to 2020* and the Linked Data project. The CCSG approved the recommendation for funding the review of the structure and function of Cochrane Review Groups (CRGs), with a budget of GBP 49,000.

Action: David to begin implementation of the project, including the formation of the Cochrane Review Group Project Board and the recruitment of an external consultant.

7. Managing Editor Support funding proposal

Sally provided the background for this paper, prepared by Harriet MacLehose (ME Support Manager), which requested funding for the next three years for the ME Support Team. Sally explained that the ME Support model, established a year ago, is working very well but that there are currently three support roles in place and that these individuals are operating to full capacity and often overstretched. The original funding was for the five support posts but only three candidates were recruited at the start of the programme. As the first years' funding will run out in September, further funding is required to advertise to fill these 2 additional posts to achieve the planned compliment of staff. David stated that, given the success of the programme to date, he believes the workload clearly merits the employment of these additional two posts. Sally added that

this funding request had been submitted once the team were sure that the newly established ME Support model was established and working effectively.

Clarification was sought by CCSG members over the nature of the assistance the ME Support Team provides and how the success of the model would be measured. Sally described ME support as providing support to Managing Editors who have training needs, and helping with queries on their editorial process. It replaces support previously provided by the IMS Support Team. It also provides assistance and mentoring for less experienced Managing Editors. In terms of evaluation, Sally expressed that it had been premature to hold a formal review at this stage but agreed that the service should be evaluated. David agreed with this approach. It was suggested that the ME Support broadens out to think about how to support managerial as well as editorial and technical skills.

General support was given and the recommendation for funding the ME Support Team, at its originally conceived capacity, for a further three years was approved with the caveat that a review would be conducted after two years and the findings presented to the CCSG, to inform decisions on any future funding requests if required.

Actions:Sally to communicate the decision to the Managing Editors Executive.A review of the Managing Editor Support Project to be held in 2015.Mark to include the additional income in the 2013-14 and future budgets.

8. Endorsement of the Declaration of Istanbul on Organ Trafficking and Transplantation Tourism

Jonathan explained that the CCSG has been as asked to endorse this declaration (paper attached) which was brought to the CCSG's attention by Angela Webster, Deputy Co-ordinating Editor of the Renal Group, at the Coeds Board meeting in Auckland, 2012. The CCSG members agreed that a decision would be deferred to the CCSG meeting in Quebec where it could be considered with more time.

Action: Lorna to add Endorsement of the Declaration of Istanbul on Organ Trafficking and Transplantation Tourism as an item on the agenda for the CCSG meeting in Quebec.

Rachel left the teleconference.

9. Any other business

Mark reported on the progress of several matters: staffing at the COU; recruitment; contacting the Charity Commission; and the Funding Arbiter position.

Staffing at the COU

Mark explained that the restructuring of roles within the COU was progressing, with all existing staff in the process of finalising their revised job descriptions. The new structure will formally come into effect on 1 September 2013. The integration of the IMS and Web Development Teams was progressing very well. Agreement had been reached in principle, with a date agreed with Gerd Antes for the handover of the Web Team in Freiburg; and practical details still being worked out with Peter Gøtzsche and the Rigshospitalet in Copenhagen.

Recruitment

Mark thanked Mary Ellen, Sally, Michelle and Lorne Becker for giving their time to assist as members of the panel in the recent Heads of Department interviews, in Oxford and London. Mark reported that individuals had been successfully appointed to two of the roles (Helen Morton – Head of Communications and External Affairs, and Chris Mavergames – Head of Informatics and Knowledge Management). Both Helen and Chris will be at the Colloquium in Quebec. Chris will start in his new post on 1 September. Helen will begin in early October. Mark explained that the final position, the Head of Finance and Core Operations, had yet to be filled and further interviews would be held in early September.

Charity Commission

Mark explained that, although – despite numerous attempts - he had not managed to speak with our interlocutor at the UK Charity Commission by telephone, he had drafted a paper setting out the reasons for the Collaboration's need to amend its M&A which he would send to the CCSG after this meeting. Mark requested that any comments or questions from the CCSG be sent to him as soon as possible, and that the paper would be sent to the Charity Commission and the wider Collaboration in the following days.

Funding Arbiter

Mark reported that Cindy Farquhar has agreed to take on the Funding Arbiter position with effect from October 2013. The CCSG expressed their thanks to Cindy for taking on this role.

Teleconference of the Cochrane Collaboration Steering Group Tuesday 30th July 2013 Agenda

Toll-free dial-in numbers:

Australia: 1 800 256 758 (10pm) Canada (Alberta): 1 866 220 6419 (6am) Canada (New Brunswick): 1 866 220 6419 (9am) Canada (Ontario): 1 866 220 6419 (8am) China: 4001 200 559 (8pm) Germany: 0800 101 2079 (2pm) Italy: 800 124 795 (2pm) UK: 0808 109 5832 (1pm)

Participant access code: 2953709, followed by #

- 1. Welcomes, apologies, declarations of interest, and approval of the agenda.
- 2. Approval of minutes of CCSG teleconference on 11 June 2013 [RESTRICTED ACCESS].
- Approval of minutes of Special CCSG teleconference, on 25 June 2013, to discuss *Cochrane* Strategy to 2020 [RESTRICTED ACCESS].
- 4. Cochrane Strategy to 2020 [OPEN ACCESS].
- 5. Linked Data Project [RESTRICTED ACCESS]:
 - 5.1 Funding request: #CochraneTech to 2020 start up package.
 - 5.2 #Cochrane Tech to 2020.
 - 5.3 Background paper: Cochrane Linked Data Project: From "Star Trek" to the present.
 - 5.4 Linked Data at the Cochrane Collaboration: A Technical Strategy.
- 6. Proposal to re-evaluate the structure and functions of Cochrane Review Groups [OPEN ACCESS].
- 7. Managing Editor Support funding proposal [OPEN ACCESS]:
 - 7.1 Appendix 4 [RESTRICTED ACCESS].
- Endorsement of the Declaration of Istanbul on Organ Trafficking and Transplantation Tourism [OPEN ACCESS].
- 9. Any other business.



Cochrane Strategy to 2020

CONSULTATION DOCUMENT

[12 July 2013]

Cochrane Strategy to 2020 is Cochrane's new strategic plan. It defines the organisation's direction for the next six years and provides the framework for strategic decision-making. It relies on all Cochrane contributors- volunteers and staff – to ensure its success.

1. Introduction to this Draft

DEVELOPMENT

This *Consultation Document* has been prepared by Mark Wilson, Chief Executive Officer; and Lucie Binder, Senior Advisor; with input from David Tovey, Editor in Chief of *The Cochrane Library*.

The *Cochrane Strategy to 2020* has been developed from the recommendations of the participants at the 2013 strategic session in Oxford, UK, in March, which was attended by more than 100 leaders from Cochrane's global network of groups and members of Cochrane's management committees. These participants were responding to an analysis of the organisation's current strategic framework; a series of policy and strategy documents developed by Cochrane contributors from the 2008-9 Strategic Review onwards; and wide consultation over the past year with contributors and staff.

It has then been drafted in discussion with staff from the Central Executive¹; and been reviewed and approved by Cochrane's Steering Group (the Board of Trustees). It has also received input from a Consultation Group established to provide in-depth feedback to Mark and his team (please refer to page 6 for more information on the Consultation Group).





Images: 2013 strategic session, Oxford, UK

PURPOSE AND PROCESS

This *Consultation Document* presents the proposed new *Strategy to 2020* to all Cochrane contributors and selected external stakeholders for their input and to inform further development.

Its release marks the start of a month-long consultation process during which the *Strategy to 2020* will be refined on the basis of the feedback received; and SMART (Specific, Measurable, Attainable, Relevant & Time-Bound) targets for achieving the new strategic objectives developed for 2014-15. A final version of the *Strategy to 2020* will be prepared for the Steering Group's sign-off in late August and then submitted

¹ 'Central Executive' is the working title of the amalgamated central support units (Operations Unit, Editorial Unit, Web Team, IMS Team).

for official approval from Cochrane's members at the Annual General Meeting, in Québec City, on 21st September 2013.



A shorter specially-formulated document designed for external communication and use will be released following approval of the *Strategy to 2020* and will be translated into a variety of languages, including at least the five other official languages of the World Health Organization (Spanish, French, Russian, Chinese and Arabic).

Cochrane Strategy to 2020 development process: 2013

1	Analysis of the organisation's current strategic framework by the Chief Executive Officer (CEO) and team. Delivered to all Cochrane contributors.	February – March
2	Strategic session examining the conclusions of the strategic analysis and beginning revision of the strategic plan. Attended by entity leaders and members of Cochrane's management groups.	March
3	Development of <i>Cochrane Strategy to 2020</i> by the CEO and team.	April – July
4	Release of the first draft of the <i>Strategy to 2020</i> to all Cochrane contributors and selected external stakeholders.	July
5	 Consultation process with contributors and external stakeholders: 1. Refinement of the <i>Strategy to 2020</i> 2. Development of SMART targets for 2014-15 	July - August
6	Finalisation of the <i>Strategy to 2020</i> by the CEO and team, with advice from the Consultation Group and Central Executive, and the oversight of the Steering Group.	August
7	Sign-off of the <i>Strategy to 2020</i> by the Steering Group.	August
8	Request for Cochrane members' approval of the finalised <i>Strategy to 2020</i> at the Annual General Meeting in Québec City.	September
9	 Provisional on the <i>Strategy's</i> approval: 1. General public release of the <i>Strategy to 2020</i> in different versions and languages 2. Follow-up consultation with funders 	October onwards
10	Central Executive staff develops workplans for achieving the 2014-15 targets in consultation with the global network of Cochrane groups.	November

YOUR FEEDBACK

Tell us what you think

- Are you supportive of the broad direction of the Strategy to 2020 as presented to you here?
- Is there anything you would change? Is there anything you would add? If so, why?

Using the example targets specified in this document as a guide, what targets should be set for 2014-15 onwards? Remember that each target should be SMART:

Specific	What should be accomplished? Who should be involved? What are the requirements?	
Measurable	How can we tell when it has been accomplished?	
Attainable	Can it be accomplished?	
Relevant	Does it contribute to achieving the objectives? How?	
\mathbf{T} ime-Bound	By when can it be achieved?	

There are a number of ways for you to provide your feedback:

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Online at <u>cochrane.org</u>

By email to strategy@cochrane.org

Via a telephone appointment with Mark Wilson or Lucie Binder Contact Lorna McAlley <u>lmcalley@cochrane.org</u> if you'd like to arrange an appointment

During one of the online webinars to be hosted by Mark Wilson Details to follow soon

If you are a member of a Cochrane group, via your Entity Executive

2. The Strategy: structure and content

STRUCTURE OF COCHRANE STRATEGY TO 2020

There are various ways in which strategic plans can be structured; and planning structures and terminology are used differently by different organisations.

Cochrane Strategy to 2020 has been developed with the following structure: Vision > Mission > Goals > Objectives > Targets > Workplans:

- **Vision:** Outlines what the organisation wants the world in which it operates to be.
- **Mission:** Defines the fundamental purpose of the organisation, describing why it exists and what it does to achieve its vision.
- **Goals:** Establish the desired endpoints for achieving the mission.
- **Objectives**: Describe the ways in which goals will be operationalised and achieved.
- **Targets**: Represent the tangible stepping stones on the path towards the achievement of an objective. An objective may have one or many targets that must be fulfilled to achieve it.
- **Workplans**: Set out how the targets will be achieved.

In the *Strategy to 2020,* the objectives have been developed as overarching aims to 2020. SMART (Specific, Measurable, Attainable, Relevant & Time-Bound) targets and accompanying workplans will be developed and reviewed on an annual basis to achieve these objectives. Some of the targets will be annual, some will be for a two-year period and a few may be for longer. All targets will be approved by the Steering Group and will establish the priority tasks the organisation is setting itself for a given time period. Progress against the targets and the wider objectives and goals will be reported on regularly to the Steering Group and annually to the membership at the Annual General Meeting.

VISION, MISSION AND GOALS

The majority conclusion from the participants at the 2013 strategic session was not to adjust the current Vision statement. However in drafting the agreed individual goals and objectives of *Strategy 2020*, it became apparent that the current wording of the Vision does not fully capture Cochrane's aspirations. This document therefore suggests changes both to the Vision and Mission in order to capture better what kinds of change the organisation hopes to achieve over the six years to 2020.

A further change is that the Goals have been kept to four by introducing a new Goal 3 (but amalgamating the old Goals 4 & 5 as presented in Oxford). This is because of significant overlap of the objectives under Goals 4 & 5 and to keep the primary focus on Cochrane content and externally-focused activities and not our internal organisation.

AN EXPLANATION OF SOME OF THE TERMS USED IN THIS DOCUMENT

Central Executive	Is the working title of the amalgamated central support units (Operations Unit, Editorial Unit, Web Team, IMS Team).
Cochrane content and Cochrane evidence	We have used both of these terms throughout this document to refer to Cochrane Systematic Reviews and all other forms of information that Cochrane produces to inform healthcare decision-making.
Consultation Group	The role of the Consultation Group is to act as a sounding board for ideas and provide rapid feedback to Mark Wilson and his team. It does not compete with the strategic function of the Steering Group or replace wide consultation with contributors and external stakeholders. It is not meant to be representative of the organisation's structure or roles, although it does represent a range of views and interests. Members currently on the Group are: Xavier Bonfill, Director of the Iberoamerican Cochrane Centre, Spain; Amanda Burls, Cochrane Systematic Review author, UK; Sally Green, Co-Director of the Australasian Cochrane Centre, Australia; Rintaro Mori, Director of the Japanese Satellite of the Pregnancy and Childbirth Group, Japan; Sreekumaran Nair, Director of the Indian Satellite of the Public Health Group, India; Alan Pearson, Co-ordinator of the Nursing Care Field, Australia; Ian Shemilt, Convenor of the Campbell and Cochrane Economics Methods Group, UK; Jasvinder Singh, Director of the US Satellite of the Public Health Group, JuSA; Elizabeth Waters, Co-ordinating Editor of the Public Health Group, Australia; Taryn Young, Deputy Director of the South African Cochrane Centre, South Africa. All members of the group are registered Cochrane Systematic Review authors.
Cochrane groups	We know that many people find the use of the term 'Cochrane entity' confusing, so in this document we have simply referred to 'Cochrane groups' and by this we mean all Cochrane Review Groups, Methods Groups, Fields, Centres, satellites and branches. <i>Do you agree with this approach?</i>
'Linked data'	Refers to a new method of structuring data and content. You can read more about it on Wikipedia, here. The technology teams of the Central Executive have been working in collaboration with a number of contributors and external advisors to introduce a linked data approach to the management of Cochrane content, which they will present to the Steering Group in July.
Staff	Refers to staff of Cochrane groups and the Central Executive.

Our thinking: Use of the term 'Cochrane'

Throughout the *Strategy to 2020* we have introduced the concept of 'Cochrane', which encompasses all aspects of the organisation and its content, including *The Cochrane Library*. As you will see, it is one of the targets under Goal 3 to remove the artificial distinction between organisation and content by introducing an overarching 'Cochrane' brand.

Most users and many volunteers don't recognise the internally-focussed divisions between 'the *Library*' and 'the Collaboration', but they do want to know how they can find Cochrane evidence or "get involved with Cochrane". Additionally, 'Cochrane' is a universal name that does not require translation into different languages, whereas '*Library*' and 'Collaboration' do.

The proposal is to take better advantage of the brand power that already exists in the Cochrane name. We recognise that introducing the Cochrane concept may be pre-emptive but felt that the *Strategy* consultation process would be a useful opportunity to test it out, with the understanding that the final version of the *Strategy to 2020* may revert back to existing terminology.

3. The Strategy: Draft for consultation

Cochrane Strategy to 2020

A note on this version of the Strategy to 2020

This version of the *Strategy to 2020* is a draft for consultation with Cochrane contributors and external stakeholders, and will be developed, refined and re-ordered over the coming months on the basis of feedback received. You will see that some of the sections of the *Strategy* will require completion following the consultation period. This includes *Introduction* sections that will introduce Cochrane, it structure and its funding model; and the concepts of the *Strategy*, to a general audience.

Please note that in the '*Our thinking*' boxes, the comments are presented by Mark Wilson and his team for your input. In the remainder of the *Strategy*, "we" and "our" refers to the organisation as a whole, and therefore all contributors and staff.

A NEW TAGLINE:

Existing:	The Cochrane Collaboration:	Working together to provide the best evidence for health care
	The Cochrane Library.	Independent, high-quality evidence for health care decision making

Proposed: Cochrane: *Trusted evidence. Informed decisions. Better health.*

Our thinking: A single Cochrane tagline

We propose a single tagline for Cochrane as a logical follow-through of a single Cochrane brand. This tagline was previously used on the 2010/11 Annual Report and was well received by contributors. It also flows nicely from the proposed new vision and mission statements. During the consultation process we will test people's reactions to this single tagline and use the feedback to inform the review of marketing and brand, which will take place following the appointment of the new Head of Communications & External Affairs. As part of that review, the tagline(s) may be subject to further change.

- **Existing**: Our vision is that healthcare decision-making throughout the world will be informed by high-quality, timely research evidence. The Cochrane Collaboration will play a pivotal role in the production and dissemination of this evidence across all areas of health care.
- Proposed: Cochrane's vision is a world of better health for everyone where every decision about health care is informed by synthesized research evidence that is high-quality, relevant and up-to-date.

Our thinking: a new vision statement

The aim of this proposed new vision statement is to capture Cochrane's aspirations better. We have heard from many of you that you believe a world of better health is possible through evidence-informed decision-making about health care: that is why you are committed to Cochrane's work and why so many of you volunteer your time to conduct it.

Although it is possible to amend a vision statement with a new strategic plan, it is unusual. If Cochrane commits to a new vision statement we anticipate that it will serve us well beyond 2020.

OUR PRINCIPLES

Cochrane's current principles have been left unchanged. They have guided the development of the *Strategy* and will continue to guide the organisation to 2020.

Cochrane's work to fulfil our mission is guided by ten key principles:		
1	Collaboration	by internally and externally fostering good communications, open decision-making and teamwork
2	Building on the enthusiasm of individuals	by involving and supporting people of different skills and backgrounds
3	Avoiding duplication	by good management and co-ordination to maximise economy of effort
4	Minimising bias	through a variety of approaches such as scientific rigour, ensuring broad participation, and avoiding conflicts of interest
5	Keeping up-to-date	by a commitment to ensure that Cochrane Systematic Reviews are maintained through identification and incorporation of new evidence

6	Striving for relevance	by promoting the assessment of healthcare interventions using outcomes that matter to people making choices in health care
7	Promoting access	by wide dissemination of our outputs, taking advantage of strategic alliances, and by promoting appropriate prices, content and media to meet the needs of users worldwide
8	Ensuring quality	by being open and responsive to criticism, applying advances in methodology, and developing systems for quality improvement
9	Continuity	by ensuring that responsibility for reviews, editorial processes and key functions is maintained and renewed
10	Enabling wide participation	in our work by reducing barriers to contributing and by encouraging diversity

RESPONDING TO OUR STRATEGIC CHALLENGES & OPPORTUNITIES

A note on this section

This section summarises the rationale for the goals and objectives presented in the *Strategy to 2020*. In the final iteration of the *Strategy* it may be expanded, re-ordered or reproduced in other sections of the document.

When Cochrane was established twenty years ago, the concept of evidence-based health care was confined to the academic discussion of a handful of pioneers. Today it is regarded as a scientific milestone of the last century² and one in which Cochrane and its contributors can rightly claim to have played a pivotal role in developing. But as it becomes more mainstream and the evidence provision arena more crowded, Cochrane's position as a leading producer and voice in evidence-based health care is no longer so secure. In order to ensure long-term sustainability, we must respond to our strategic challenges and opportunities in a timely and effective way:

We must be nimble

Our credibility is based on our commitment to high-quality evidence and independence from commercial funding, but there are tensions between quality and speed of production; and our pool of potential funding sources is restricted in ways that it is not for our competitors. We have traditionally been very good at using information and web technologies to support our production and distribution processes - the *Cochrane Database of Systematic Reviews* was available on the web by 1996³. We now need to re-focus on taking maximum advantage of new technologies to bring efficiencies to these processes, allowing us to deliver our evidence to our users more quickly and effectively without compromising on quality.

² Medical Milestones: Celebrating Key Advances since 1840. ISSN 0959-8138, BMJ January 2007; 334 (suppl):s1-22.

Available from: http://www.bmj.com/highwire/filestream/438857/field_highwire_adjunct_files/0

³ The Cochrane Collaboration Chronology. Available from: http://www.cochrane.org/about-us/history

We must continue to produce relevant evidence

Cochrane's origins lie with a small group of clinical researchers seeking to improve the quality of care provided to women and infants during pregnancy and childbirth⁴. The target users for the evidence they produced were well-defined, the relevance of the questions asked to those users was clear, and the uptake of the evidence into practice potentially immediate. Since those early days the number of contributors has grown dramatically, as has the number, remit and use of Cochrane Systematic Reviews. In 2001 there were 1,700 registered Cochrane contributors; today there are more than 31,000⁵. In May 2012 the number of published Cochrane Systematic Reviews passed 5,000⁶, addressing a broad range of healthcare topics and questions; full-text review downloads by users of *The Cochrane Library* exceeded 5,400,000⁷ in that year alone.

Reviews should address outcomes that are meaningful to people making decisions about health care.

Higgins JPT, Green S (editors). Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org. Our challenge is to continue to ensure that the priorities of our contributors in expanding the breadth and depth of Cochrane evidence match those of our growing number of end users. In other words, the relevance and applicability of Cochrane evidence for informing people's healthcare decision-making must remain at the heart of its design. We already know, for example, that the Cochrane Systematic Reviews that users are accessing most correspond clearly to trends in global health⁸; we have the both the opportunity and responsibility to expand the evidence we produce in these key areas.

We must improve the accessibility of our evidence

Cochrane Systematic Reviews are widely regarded as the highest standard of healthcare evidence, credibility that is both based in, and reflected by, their format and structure; they are the process record and written culmination of a comprehensive scientific investigation. However, user feedback shows that they are not the most accessible or usable way of presenting evidence to people to inform their healthcare decision-making. In April 2012 we published the recommendations of a comprehensive review of Cochrane content that established plans to improve accessibility and usability of all content; these recommendations are reflected here in the *Strategy to 2020's* objectives. The challenge now is to implement the plans for which we have well-defined requirements in a timely manner and to think creatively about further developments. We have already caught a glimpse of what improved accessibility can do: since French-language plain language summaries have been made available on the *Cochrane Summaries* website they have overtaken English as the most accessed content on this site.

We must respond to the challenge and opportunity of open access

We are now living in a world of increasing open access to scholarly research via the internet. Cochrane is feeling the impact of this: the funders of our global network of groups are increasingly specifying that

http://www.cochrane.org/community/organisation-administration/minutes-reports/full-meetings-ccsg

⁴ M.J. Friedrich. The Cochrane Collaboration Turns 20. Available from: JAMA, May 8, 2013–Vol 309, No. 18 1881

⁵ Data sourced from Archie. Available from: http://archie.cochrane.org/

⁶ Data sourced from *The Cochrane Library*. Available from: http://www.thecochranelibrary.com/view/0/AboutTheCochraneLibrary.html ⁷ Data sourced from John Wiley & Sons, Ltd. Available from Oxford 2013 Steering Group agenda:

⁸ The top 10 most accessed Cochrane Systematic Reviews in 2012 address topics in smoking cessation, care of older people, obesity and mental health. Data sourced from John Wiley & Sons, Ltd. Available from Oxford 2013 Steering Group agenda:

http://www.cochrane.org/community/organisation-administration/minutes-reports/full-meetings-ccsg and compared to The Top 10 Causes of Death. World Health Organization. Available from: http://who.int/mediacentre/factsheets/fs310/en/

the research they fund be made available open access. Already more than half the world's population has one-click access to Cochrane content on *The Cochrane Library* through licenses or free access through the low- and middle-income countries programme. In collaboration with our publishing partner, John Wiley & Sons, Ltd, we have made all Cochrane Systematic Reviews and updates published from February 2013 available on an open access basis twelve months after publication in the *Cochrane Database of Systematic Reviews*, and in PubMed Central or various country-specific PubMed databases. Additionally, authors and funders have the option to fund individual articles, or groups of articles, to be open access immediately upon publication.

However, we are aware that users are looking for information right now, free of charge or other access barriers, and if they can't access it through Cochrane they will seek it elsewhere – even if that means compromising on quality. We also know that the funding security of our network of groups is dependent on an open access future. Our challenge – and our opportunity – is to continue to move proactively towards global open access for all Cochrane Systematic Reviews whilst securing replacements for our licensing income. This is the income that we will use to secure the organisation's long-term sustainability by resourcing the objectives and targets set out in this *Strategy to 2020*.

We must demonstrate impact

It is not enough to make our evidence available, we must also ensure that it is used to inform decisionmaking. Cochrane has always been a strong voice in evidence-based health care, but we know that we can do more to improve its consistency and impact. As global research funding budgets are being squeezed and both our global network of groups and volunteers are under increasing pressure to show the value of their work to their funders, this is becoming ever more important to our financial sustainability.

We must ensure that our organisation can support our plans

Cochrane is a collaborative network of more than 31,000 people from over 100 countries whose ongoing commitment to the organisation will be the deciding factor in its long-term success. Feedback from these contributors shows that there are a series of pressure points in their 'Cochrane experience', particularly related to the experience of producing Cochrane Systematic Reviews. This feedback also tells us that people find it difficult to know how to get involved with Cochrane. Our challenge now is to improve the effectiveness and cohesiveness of the organisation, and invest back into the volunteers that support it, in order to ensure its long-term sustainability.

Cochrane Strategy to 2020 captures our aspirations and priorities to enable us to respond to these strategic challenges and opportunities. It articulates our goals over the next six years, and sets out how we plan to achieve our vision.

Our mission:

- **Existing:** The Cochrane Collaboration is an international organisation that aims to help people make well-informed decisions about health care by preparing, maintaining and promoting the accessibility of systematic reviews of the effects of health care interventions.
- **Proposed**: Cochrane is a global, independent organisation whose mission is to promote evidence-based health care around the world by producing high-quality, relevant systematic reviews and other forms of evidence; making them accessible to people everywhere; and ensuring they inform healthcare decision-making.

A question for you: add a "Who we are" section?

Something that makes Cochrane different from many organisations is that *who* we are and *how* we conduct our business is as important as *what* we do. Our independence, global network of collaborators and volunteer-base are at the heart of our identity. However, this presents problems for a short and succinct mission statement! We have debated whether we should increase the length of the tagline and mission statement to add additional wording about who we are, or remove this wording entirely and create a new "who we are" section between the vision and mission. What do you think?

Possible increases to the tagline and mission:

Tagline: Cochrane: *Global Collaboration. Trusted evidence. Informed decisions. Better health.*

Mission: Cochrane is a global, independent, volunteer-based organisation whose mission is to promote evidence-based health care around the world by producing high-quality, relevant systematic reviews and other forms of evidence; making them accessible to people everywhere; and ensuring they inform healthcare decision-making.

Possible reduction to the wording in the mission statement (the wording would instead be added and expanded in a new "who we are" section):

Cochrane's mission is to promote evidence-based health care around the world by producing high-quality, relevant systematic reviews and other forms of evidence; making them accessible to people everywhere; and ensuring they inform healthcare decision-making.

Our goals and objectives:

GOA1 1: PRODUCING EVIDENCE

Existing: To ensure high quality Cochrane systematic reviews are available across a broad range of healthcare topics.

Proposed: PRODUCING EVIDENCE

To produce high-quality, relevant, up-to-date synthesized research evidence to inform healthcare decision-making. Cochrane Systematic Reviews will be the best evidence on all health care issues.

Objectives to 2020:

HIGH-QUALITY:

1. We will continue to develop and implement comprehensive quality assurance mechanisms for editorial and methodological standards throughout the production and updating process for Cochrane Systematic Reviews and related content.

RELEVANT:

2. We will engage with healthcare consumers, health professionals, guidelines developers, policymakers and other key users to identify uncertainties and questions that are most relevant and important to them; and prioritise the production and updating of Cochrane Systematic Reviews and related content accordingly.

UP-TO-DATE:

3. We will ensure that Cochrane Systematic Reviews represent the best evidence currently available by establishing and managing performance against updating targets, particularly for high priority reviews.

WIDE COVERAGE:

4. We will continue to support the production of Cochrane Systematic Reviews across all areas of health care in order to develop the widest possible body of reliable knowledge about health.

PIONEERING METHODS:

5. We will continue to invest in innovative methods for designing and conducting research evidence synthesis that help us to deliver our mission and improve research conduct.

EFFICIENT PRODUCTION:

6. We will improve our technology and revise our processes to create a more timely, consistent and efficient editorial and production system.

Targets:

2014-15 Possible Targets:

Please note that these examples are for illustrative purposes only at this time and not all are SMART.

Through to the end of 2015 we will:

- I. Engage with healthcare consumers, health professionals, guidelines developers, policy-makers, other key users, and funders to develop **a list of high-priority Cochrane Systematic Reviews** that address uncertainties and questions of most importance and relevance to them; then produce them in an efficient and timely manner thereafter.
- II. Set, and establish mechanisms for meeting, mandatory updating targets for high-priority Cochrane Systematic Reviews.
- III. **Develop and deliver the first phase of the 'Linked Data' project,** fundamentally changing the way Cochrane's data and content are structured, stored and used in order to realise our ambitions for improving content production and distribution processes; diversifying and expanding content and products; and reducing 'vendor lock-in' to specific systems, software, or publishers or consumers of our content.

GOAL 2: MAKING OUR EVIDENCE ACCESSIBLE

Existing: To promote access to Cochrane reviews and other products of The Cochrane Collaboration.

Proposed: MAKING OUR EVIDENCE ACCESSIBLE

To make Cochrane evidence accessible and useful to everybody, everywhere in the world, at any time, through innovative products and services.

Objectives to 2020:

USER-CENTRED DESIGN AND DELIVERY:

1. We will put the needs of our users in their healthcare decision-making at the heart of our content design and delivery.

- 2. We will increase consultation with our users to develop creative and flexible formats and delivery solutions for content that make it more discoverable, accessible, useful and usable in diverse contexts and settings worldwide.
- **3.** We will inform people about how to interpret Cochrane evidence and use it in their decisionmaking.

OPEN ACCESS:

4. We will achieve universal open access to Cochrane Systematic Reviews immediately upon publication for both new and updated reviews, and the archive of existing published reviews.

ACCESSIBLE LANGUAGE:

5. We will simplify and standardise the language used across our content to improve readability and reduce ambiguity.

MULTI-LINGUAL:

6. We will translate Cochrane content into at least the five other official languages of the World Health Organization (Spanish, French, Russian, Chinese and Arabic) and make it accessible in the same way as English-language content.

Targets:

2014-15 Possible Targets:

Please note that these examples are for illustrative purposes only at this time and not all are SMART.

Through to the end of 2015 we will:

- I. **Diversify our product range and delivery solutions**, prioritising online distribution and optimising our mobile, social and syndicated content.
- II. Introduce a series of improvements to the presentation and delivery of Cochrane Systematic Reviews.
- III. Build **dissemination strategies** into the editorial process of Cochrane Systematic Reviews to ensure that every review has its own dissemination plan tailored to target users. We will specifically seek to target practitioners and 'content repackagers', especially guidelines developers, online information platforms, patient and consumer groups, medical librarians and journalists.
- IV. Finalise and begin delivery of a comprehensive strategy to **translate content** into at least the five other official languages of the World Health Organization (Spanish, French, Russian, Chinese and Arabic).

GOAL 3: ADVOCATING FOR EVIDENCE

Existing: No existing goal exists on external organisational profile and content application.

Proposed: ADVOCATING FOR EVIDENCE

To make Cochrane the home of evidence to inform health and health care, build greater recognition of our work around the world, and become the leading advocate for evidence-based health care.

Objectives to 2020:

THE HOME OF EVIDENCE:

1. We will make Cochrane the 'go-to' place for evidence to inform healthcare decision-making by offering a comprehensive range of evidence-based products and resources.

GLOBAL PROFILE:

2. We will clarify, simplify and improve the way we communicate to the world by creating an overarching 'Cochrane' brand.

GLOBAL IMPACT:

3. We will improve how we demonstrate the value and impact of Cochrane evidence to funders, users and other beneficiaries of our work.

GLOBAL INFLUENCE:

- **4.** We will shape the agenda for primary research and promote methodologically high-quality research that is applicable to real-world health questions.
- 5. We will campaign for transparency and integrity in scientific conduct, including the registration and reporting of results from all clinical trials, to ensure that the totality of evidence is available to those making healthcare decisions.

GLOBAL ADVOCATE:

- 6. We will advocate for evidence-based health care and the uptake of synthesized research evidence in healthcare policy-making and budgeting.
- 7. We will bring the concepts and terminology of evidence-based health care into mainstream use beyond the research and medical communities, so that people know why evidence should be used to inform their healthcare decision-making.

GLOBAL PARTNER:

8. We will build international and local partnerships and alliances with organisations that help us to reach people making decisions in health care, particularly guidelines developers, policy-makers, associations of healthcare practitioners and patient organisations.

Targets:

2014-15 Possible Targets:

Please note that these examples are for illustrative purposes only at this time and not all are SMART.

Through to the end of 2015 we will:

- I. Introduce an **overarching 'Cochrane' brand**. We will take better advantage of the brand power that already exists in the Cochrane name to raise further awareness. We will ensure consistency of branding, language and terminology across all Cochrane content. We will introduce a single Cochrane web presence that provides a consistent, accessible user experience.
- II. Introduce a **series of online metrics** that demonstrate how and where Cochrane evidence has been cited and used, particularly in health care guidelines; and publish **users' stories and examples of how practice has been changed** by Cochrane evidence.
- **III. Maintain our support for the** *AllTrials* **initiative** until regulations are in place internationally to mandate that all clinical trials are registered, and the full methods and the results of trials are reported.
- IV. Establish ten new partnership relationships with major health and health care international organisations including regional health bodies, guidelines developers, patient and consumer groups, and professional associations.

GOAL 4: BUILDING AN EFFECTIVE & SUSTAINABLE ORGANISATION

Existing: Goal 3: To ensure an efficient, transparent organisational structure and management system for The Cochrane Collaboration. Goal 4: To achieve sustainability of The Cochrane Collaboration.

Proposed: BUILDING AN EFFECTIVE & SUSTAINABLE ORGANISATION

To be a diverse, cohesive and transparent international organisation that effectively harnesses the enthusiasm and skills of our volunteers, is guided by our principles, governed accountably, managed efficiently and makes optimal use of its resources to ensure long-term sustainability.

Objectives to 2020:

INCLUSIVE AND OPEN:

1. We will establish a formal membership structure to improve our organisational cohesiveness; and to reduce barriers to participation by creating a clear and open route into the organisation for volunteers who want to get involved.

GLOBAL AND DIVERSE:

2. We will become truly global organisation by establishing a Cochrane organisational presence in all regions, building volunteer capacity in low- and middle-income countries; and becoming more diverse and multi-lingual by promoting gender equity and generational change, and ensuring that we work in different languages.

EFFECTIVELY SUPPORTING OUR VOLUNTEERS:

3. We will improve the experience of 'Cochrane Systematic Review production teams' to encourage and retain our volunteer contributors and increase the efficiency and speed of producing Cochrane evidence.

EXPANDING OUR CAPACITY:

4. We will make major new investments in the training and leadership development of our volunteers and staff.

TRANSPARENTLY GOVERNED:

5. We will increase the transparency of the organisation's governance and improve the opportunities for any member of the organisation to participate in governing the organisation and/or to be appointed to a leadership position.

EFFICIENT:

6. We will review and adjust the structure and business processes of the organisation to ensure that it is optimally configured to enable us to achieve our goals.

KNOWLEDGE CREATOR:

7. Using leading-edge technology we will focus on knowledge as our key 'commodity', maximising its dynamism and potential in our content and products, and achieving maximum value from it.

FINANCIALLY STRONG:

8. We will strengthen Cochrane's financial position by diversifying and expanding our funding base, both at core and group network level.

ENVIRONMENTALLY RESPONSIBLE:

9. We will review and adjust our operations to reduce their environmental impact.

Targets:

2014-15 Possible Targets:

Please note that these examples are for illustrative purposes only at this time and not all are SMART.

Through to the end of 2015 we will:

- I. Introduce a formal Cochrane membership scheme, open to all those who can offer the organisation useful skills and experience.
- II. **Conduct a Governance Review** to ensure that the organisation's governance processes and bodies fully enfranchise all of the organisation's constituencies, encompass diverse perspectives, are adequately skilled and work effectively.
- III. Review and adjust the structure, number and functions of the global network of Cochrane groups that support our volunteers.
- IV. Begin the translation of organisational resources into different languages and increase the number of contributors from non English-speaking countries by 30%.
- V. Establish a programme to identify, mentor and train future leaders of the organisation, prioritizing socio-cultural, linguistic, and gender diversity. By 2020, at least 50% of the organisation's leaders will be women and more than 50% will be from non English-speaking countries.
- VI. Introduce formal contracts between Cochrane groups and the Central Executive, setting out mutual responsibilities and performance targets.

Making it happen:

This section will be completed following the feedback received during the consultation period. It will be split into three sections:

- 1. Targets for 2014-15 onwards
- 2. Measuring success
- 3. Resourcing the *Strategy*

Measurements for success will be established against the targets, reviewed annually and reported on regularly to the Steering Group and annually to the membership at the Annual General Meeting. We also propose that a mid-point, externally conducted progress review is undertaken.

As we finalise the goals, objectives and targets we will also begin to plan how we will raise, allocate and spend the resources required to deliver them. Cochrane's regular income accrued from the *Cochrane Library* licence income and other sources will be the primary source of funding; and we will also invest a portion of our strategic financial reserves in critical areas of our work to help us reach our goals. However, successful implementation of the *Strategy to 2020* will also require Cochrane to diversify its funding base.

Proposal to re-evaluate the structure and functions of Cochrane Review Groups

Prepared by: David Tovey, Rachel Churchill, Marina Davoli, Sophie Hill, Sally Bell-Syer, Harriet MacLehose and Jonathan Craig

Date: 22 July 2013

Purpose:

To seek approval and funding for a review of the structure and function of Cochrane Review Groups (CRGs).

Urgency:

High

Access:

Open

Background:

The Cochrane Collaboration has been a hugely successful organization over a relatively brief lifespan of 20 years. It has become the leading brand for evidence-based information and is recognized for the preparation of Cochrane Reviews, published in the *Cochrane Database of Systematic Reviews* (*CDSR*), and other content in *The Cochrane Library*. The task of working with authors, mainly unpaid volunteers, to prepare and maintain Cochrane Reviews has been the task of the 53 CRGs – and these groups deserve considerable credit for what they have achieved to date. The major challenge for the next 20 years is how to maintain and extend such growth and impact.

Since the inception of The Cochrane Collaboration in 1993 the basic structure of CRGs has been unchanged. A core team of one or more Co-ordinating Editor, Managing Editor, and Trials Search Co-ordinator is supported by several editors, generally including a methodologist or statistician (similar to an editorial board). Peer reviewers also support the development of Cochrane Reviews. During this 20 year period, the overall infrastructure of the Collaboration has developed, providing a broader range of support for the activities of CRGs around review production, training and methods development. There has also been a growth in the number of CRGs, but this has been somewhat ad hoc and unplanned. CRGs are heterogeneous in scope and cannot easily be classified: some are based on a medical specialty or specific organ (e.g. musculoskeletal, heart, renal, skin, oral health); some focus on a group of conditions within a medical specialty (e.g. colorectal cancer, neuromuscular diseases, stroke); and others focus on complex interventions or service delivery (public health, effective practice and organization of care). This has led to challenges in ensuring comprehensive topic/question coverage and overlapping scope, and consistent processes and quality of outputs. Building a structure that is fit for the future will also require consideration of such diverse issues as engagement with stakeholders, building the capacity and expertise to develop new review types addressing different questions, professional and career development of team members, addressing the challenges of author experience and timeliness of review production, and also building the flexibility and nimbleness to respond to challenges that are yet to emerge.

Notwithstanding the considerable achievements of CRG teams, we believe that this is a timely moment for the Collaboration to take stock and evaluate how well the current structures support the functions¹ of CRGs now, and the extent to which they will support us in delivering the proposed Cochrane Strategy to 2020 and its ambitious goals.

We propose that this review should be led by the Cochrane Editorial Unit (CEU), working closely with representatives from the CRGs and other stakeholders. The review will be "holistic" – in that it will look at the whole system within which CRGs operate and will consider the needs and aspirations of CRG teams, alongside the Collaboration's strategic goals, and the needs of other stakeholders including review authors, methodologists, and users or funders of Cochrane content. Any recommendations will need to address the diverse nature of the CRGs and wider Collaboration – in terms of resources and funding, scope, geography and language. We recognise that achieving sustainability requires that the Collaboration is both inclusive and outwards facing in its approaches.

The review objectives are presented below:

No.	Objective
1	To understand the benefits and challenges of the current structure and functions of CRGs and the extent to which these influence the Collaboration's ability to meet the goals described in Cochrane Strategy to 2020
2	To understand the support needs of CRGs; how well they are delivered currently and how review groups might be supported more effectively in the future in order to meet strategic objectives
3	To complement the parallel project that is revising the quality assurance mechanisms for Cochrane Reviews
4	To identify a range of possible alternative models and structure for CRGs, and to evaluate the benefits and challenges associated with each of these in terms of delivering strategic goals
5	To explore and identify the change management issues associated with diversifying the current structure and solutions to address these issues
6	To employ a "whole system" approach that includes wide consultation with internal Cochrane stakeholders including CRG staff, review authors, methodologists and representatives from other entity types within the Collaboration
7	To consult widely with external stakeholders, including funders and users from diverse settings
8	To prepare a fully costed options appraisal document and recommendations for consideration by the CCSG

How the review will develop

The CEU will manage this as a project within its portfolio of work. As outlined in the draft project plan (Appendix), we will identify a Project Board to oversee and monitor the project and provide regular reports to the Collaboration and Steering Group. Convenorship of the Project Board will be determined at the first meeting, which will be chaired by the project sponsor, Mark Wilson, CEO, in order to ensure that there is a separation within the Project Board of those tasked with delivering the project (CEU, external consultant, and other internal and external stakeholders) and those responsible for monitoring it.

In order to ensure that the project benefits from the perspectives of individuals and groups inside and outside Cochrane, we will appoint two advisory groups (one internal, one external). The purpose of these groups will be to provide guidance and feedback on issues as they arise. We will also appoint an external consultant to support the core executive team (principally CEU) and also to provide facilitation where

¹ The core functions of CRGs have also recently been revised. The most recent version, used within the 2013 monitoring round, is presented in the <u>Appendix</u> of this document.

appropriate. We will also identify some key individuals within the Collaboration to provide more detailed guidance and leadership and will seek to provide either these individuals or their employers (e.g. a CRG for an ME) with funding to support their contribution to the project.

Consultation with stakeholders will include some teleconferences and webinars, email and discussion boards, and limited face to face conversations. We will also encourage written feedback as appropriate.

Timescale

We will produce a more detailed project plan plus an initial scoping document in time for consideration and consultation during the September 2013 Cochrane Colloquium, an interim report for the 2014 mid-year meetings and a final report for decision-making during the 2014 September/October Cochrane Colloquium.

Summary of recommendations:

We recommend that the CCSG approves and funds the proposed review of the structure and function of Cochrane Review Groups (CRGs).

Resource implications:

This review will be completed within 15 months at a cost of £49,000, as detailed below.

No.	Item	Detail	Amount (£)
1.	External consultancy: up to 30 days @ £800.00	External consultant's role will be to provide support and advice to the Project Board and CEU team to assist in delivering the project. The precise nature of work beyond this is yet to be determined but may include facilitated discussions with internal groups and stakeholders.	24,000
2.	Support for internal stakeholders	We will identify key stakeholders that can support the project and will aim to ensure that they or their CRGs are supported for their time on the project.	15,000
3.	Executive and project management support	Within CEU budget	0
4.	Meetings and communications: teleconferences plus some face-to- face meetings as required		10,000
		TOTAL	49,000

Impact statement:

We consider that this project can deliver intelligence that will help to ensure the sustainability of the Collaboration, and in particular its ability to achieve its strategic goals in respect of review production, training and author team support, advocacy and methods development as proposed in the Cochrane Strategy to 2020, currently undergoing consultation.

The project form (see <u>Appendix</u>) describes the potential positive and negative impacts that we have identified.

Decision required of the Steering Committee:

We hope that the CCSG will approve the recommendation.

Appendix. Project form: CRG structure and function

1. Project details

Workstream	CRG structure and function project
Project lead (name and team)	David Tovey, Editor in Chief (CEU)
Project members (name and team)	 Project Board: A Project Board will be tasked with providing governance and oversight, reporting to the CCSG. All members to be determined but to include Chief Executive Office, Editor in Chief, CEU team member, 3 Co-ordinating Editors, 2 Managing Editors, 1 Trials Search Co-ordinator, 1 review author, 1 Centres representative, and 1 methodologist. The Project Board will also consider additional members, including external involvement as appropriate.
	(2) CEU Project Team: Harriet MacLehose (Senior Editor) and John Hilton (Editor) supported by internal stakeholders and external consultant.
	(3) Internal and External Advisory Groups: to provide input, guidance, and feedback as requested. Membership to be determined
Project sponsor (name and team)	Mark Wilson, CEO
Sign-off: person and date project signed off	David Tovey, Editor in Chief

2. Project description

This project will evaluate how the current structure and function of Cochrane Review Groups support the strategic goals of the Collaboration as described in the Cochrane Strategy to 2020. We will explore the benefits and challenges created by the current and plausible alternative models, and will provide a costed-options appraisal for a range of different models and recommendations to be considered by the Collaboration leadership.

The project will consider all the functions of CRGs, not simply review production, but also training and author team support, advocacy and methods development. It will also consider how different communities within the Collaboration interact with CRGs and how this might be optimised.

The project will be overseen by a project board, but will be inclusive and diverse in its approach, with communication with internal and external stakeholders being a high priority. The project will be informed by individuals and groups representing all entity types within the Collaboration and in particular will consider the variation between CRGs in terms of scope, geography, language, funding and resources. Funders' and users' perspectives, along with concordance with the Cochrane Strategy to 2020 will also be crucial in determining the outcomes and any recommendations.

The operation of the project will be the responsibility of the CEU, supplemented by internal stakeholders (see funding below) and an external consultant.

3. Project objectives

No.	Objective
1	To understand the benefits and challenges of the current structure and functions of CRGs and the extent to which these influence the Collaboration's ability to meet the goals described in Cochrane Strategy to 2020
2	To understand the support needs of CRGs; how well they are delivered currently and how review groups might be supported more effectively in the future in order to meet strategic objectives
3	To complement the parallel project that is revising the quality assurance mechanisms for Cochrane Reviews

4	To identify a range of possible alternative models and structure for CRGs, and to evaluate the benefits and challenges associated with each of these in terms of delivering strategic goals
5	To explore and identify the change management issues associated with diversifying the current structure and solutions to address these issues
6	To employ a "whole system" approach that includes wide consultation with internal Cochrane stakeholders including CRG staff, review authors, methodologists and representatives from other entity types within the Collaboration
7	To consult widely with external stakeholders, including funders and users from diverse settings
8	To prepare a fully costed options appraisal document and recommendations for consideration by the CCSG

4. How will this project help us achieve the Cochrane Strategy to 2020?

The wordings shown below are those undergoing consultation as part of the Cochrane 2020 strategy.

Vision and mission

The project will identify whether changes to the structure and function of CRGs could help the Collaboration to achieve its vision, mission, and related goals.

Vision	"Cochrane's vision is a world of better health for everyone where every decision about health care is informed by synthesized research evidence that is high-quality, relevant and up-to-date."
Mission	"Cochrane is a global, independent organisation whose mission is to promote evidence-based health care around the world by producing high-quality, relevant systematic reviews and other forms of evidence; making them accessible to people everywhere; and ensuring they inform healthcare decision-making.

Goals

Goals	Relationship to review
Optimise efficient, timely, review production and topic coverage: best service for users and funders	We will identify whether changes to the structure and function of CRGs and the systems that support them could lead to more comprehensive topic coverage, improved engagement with users and funders, greater efficiency of editorial processes and timeliness of review production. We will also consider whether different structures and processes could optimise development of innovative review types and enhanced reviews based on the needs of users.
Minimise time to publication and efficient processes	We will explore whether different structures and models of working could increase the efficiency of the editorial processes and timelines of review production
Support Cochrane key principles	 While all the core principles are relevant to this project, those that have the most direct importance are as follows: 1. Internally and externally fostering good communications, open decision - making and teamwork. 2. Building on the enthusiasm of individuals, by involving and supporting people of different skills and backgrounds. 3. Avoiding duplication, by good management and co-ordination to maximise economy of effort. 5. Keeping up to date, by a commitment to ensure that Cochrane reviews are

	 maintained through identification and incorporation of new evidence. 6. Striving for relevance, by promoting the assessment of healthcare interventions using outcomes that matter to people making choices in health care. 8. Ensuring quality, by being open and responsive to feedback, applying advances in methodology, and developing systems for quality improvement. 10. Enabling wide participation in the work of The Cochrane Collaboration by reducing barriers to contributing and by encouraging diversity.
Share expertise across Collaboration	We will explore whether different structures and models of working could improve shared working across CRGs, and also improve interaction with other groups, such as methodologists, trainers, and staff from Fields and Centres.
Optimise consistency and quality of review author experience	We will explore whether different structure and models of working could improve the consistency and quality of author experience.
Optimise opportunities for professional development and support for CRG team	We will explore whether different structure and models of working could improve the opportunities for professional development and support for members of the CRG teams, and editors.
To promote greater inclusiveness across the Collaboration and to support greater geographical and other diversity	We will ensure that all proposed solutions and recommendations address the need to ensure greater geographical and language diversity of the Collaboration's activities and the relevance of its products.

5. What are the risks that could put the project in jeopardy?

Provide a list of the major internal and external risks that could put the project in jeopardy. Describe each risk, explain the impact if the risk is realized, and indicate the potential mitigation action.

No.	Risk	Potential mitigation action	
1	Under-estimate size of task in terms of time and resources needed to deliver the project	We will prepare interim reports to the project board and CCSG that will address the issues of capacity and performance against milestones	
2	Under or over estimate benefits of current structure and functions of CRGs	We will consult widely and will ensure that the benefits and challenges associated with current working arrangements are fully captured	
3	Under or over estimate benefits of alternative structures	We will consult widely and will ensure that the benefits and challenges associated with alternative working arrangements are fully captured	
4	Demotivate staff if increases concerns about job security or professional development opportunities	We will be open and transparent in our approaches. We will not have any pre-determined view on eventual outcomes. We will value everyone's contribution and expertise	
5	Implementation effort to introduce changes derails other strategic developments	We will take external and internal help in ensuring that any changes are implemented in ways consistent with best evidence on change management.	
6	Funders concerned that the Collaboration is disregarding their perspectives	We will develop and maintain an external advisory board for the project and ensure that communication with funders is frequent and regular.	

7	Recommendations are proposed that meet the needs of some stakeholders but at the expense of others	We will monitor all proposed recommendations and solutions to ensure their relevance and impact on a diverse range of stakeholders.
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6. Who are the key stakeholders?

Stakeholders are defined as those groups who will need to be consulted as part of the development and implementation of the project but who will not be part of the day-to-day project group.

Internal	External	Other (list)
 CRG and all editorial base staff (including Co-ordinating Editors, Managing Editors, Trials Search Co-ordinators, editors, methodologists, etc) Review authors Methodologists and methods community (includes methods groups) Other entity staff: Fields, Consumers and Centres Central support units 	 Current and potential funders of Cochrane infrastructure Current and potential funders of Cochrane licenses User groups (including, health professionals, consumers and guideline developers) 	

7. Who needs to be informed about the project?

We will use the CEU Bulletin to communicate about the project, but note here if other groups need to be communicated to separately.

All stakeholders above

8. Project activities and timeline

8.1. Details

No.	Activity	Person/team responsible	Time estimate	Time period	Dependencies
1.	Paper for CCSG				
2.	Develop project board	DT and authors of this paper	1-2 weeks		Approval of item #1
3.	Develop internal and external advisory groups	DT, Project Board			
4.	Develop detailed project plan and timelines	HM, JH		Sept 2013 (Colloquium)	External consultant to be appointed
5.	Develop consultation and communication plans	HM, JH		Sept 2013 (Colloquium)	
6.	Identify methodological approach	DT, Project Board		Sept 2013 (Colloquium)	

7.	Identify strengths and challenges of current structure and function	Tbd	
8.	Identify plausible alternative models for structure and function	Tbd	
9.	Identify benefits and challenges of alternative models and implementation effort for each	Tbd	
10.	Record and incorporate feedback from stakeholders	Tbd	
11.	Interim report	April 2014, mid year meetings	
12.	Write first draft paper	Tbd	
13.	Distribute first draft paper and invite feedback	Tbd	
14.	Compete final report and submit to CCSG	Sep/Oct 2014 Colloquium	

15. Budget needs

Can this work be included as part of the day-to-day work of each member of the project group?	Partially. CEU costs only.
Are additional resources needed? If so, specify.	External consultancy = £24,000 Internal project manager - with CEU budget Support for internal stakeholders = £15,000 Meetings and teleconferences = £10,000 TOTAL = £49,000

Provisional core functions of Cochrane Review Groups (CRGs)

1. To produce and maintain high quality relevant and accessible systematic reviews that inform decision making in healthcare and policy.

Essential activities in support of this function include:

1.1 Developing processes that identify and prioritise reviews which address issues and uncertainties that are of most relevance and importance to users, within the scope of the CRG.

1.2 Ensuring that reviews meet the conduct and reporting methodological standards that have been developed (MECIR) or that are developed in the future by the Collaboration .

1.3 Ensuring the readability of reviews to ensure that they are comprehensible to the identified user groups.

1.4 Ensuring appropriate input into the editorial process via peer review at the protocol and review stages by experts (including content experts, consumers, statisticians and methodologists).

1.5 Ensuring open and transparent editorial processes and decision making in respect of the registration, conduct and production of reviews.

1.6 Promoting geographical diversity and inclusiveness within the Collaboration by seeking to recruit authors and editors from low and middle income country settings and prioritising the publication of reviews that are relevant to these settings where possible.

1.7 Helping to monitor the impact of reviews produced by the CRG, and contributing as appropriate to activities organised centrally to identify and increase impact and knowledge translation.

1.8 Providing support for review authors within the context of available resources and the need to ensure that best possible product for users of the CDSR.

1.9 Maintaining timely and respectful communications with review authors and others involved in the review process.

2. To identify relevant studies within the scope of the review group and to contribute bibliographic material relevant to these within the CENTRAL register of controlled trials.

Essential activities in support of this function include:

2.1 Developing and maintaining a specialised register and publishing the studies within the register, as appropriate in CENTRAL, unless specific permissions have been approved by the Editor in Chief in consultation with the Co-ordinating Editors' and TSCs' Executives, and all included and excluded studies identified by the group's reviews are submitted to CENTRAL.

3. To address the requirements in relation to the Collaboration.

Essential activities in support of this function include:

3.1 Complying with reporting requirements, put in place by the Collaboration, necessary to ensure good governance.

3.2 Supporting the development and implementation of strategic plans and governance arrangements developed within the Collaboration.

3.3 Identifying and addressing the professional development needs of core staff at the editorial base.

3.4 Seeking to identify learning opportunities for peer reviewers, review authors and editors and providing advice about accessibility of such resources.

3.5 Maintaining a collegial, respectful relationship with all Cochrane entities and management groups.
Managing Editor (ME) Support funding proposal: 2013 to 2016

Document prepared by: Harriet MacLehose (ME Support Manager), with contributions from the ME Support team (Liz Dooley, Rebecca Gray, Anupa Shah) and Sally Bell-Syer (ME representative, Cochrane Collaboration Steering Group (CCSG))

Submitted for approval to: CCSG via David Tovey (Editor in Chief) on 16 July 2013

Purpose

To seek approval for an additional three years of funding (from 1 October 2013) for ME Support.

Urgency

High.

Access

Open, except for Appendix 4 (restricted access).

Background

2012 proposal approved by the CCSG

The CCSG approved one year of funding for ME Support starting from 1 October 2012.

The rationale for the 2012 proposal was to (1) provide MEs with training and support for using the Collaboration's information technologies; and (2) to provide induction training for new MEs and ongoing professional support around all aspects of the ME role. The ME Support team evolved out of previous initiatives, namely Information Management System (IMS) Support and the ME mentoring programme, outlined in the 2012 funding proposal.

In brief, the CCSG approved funding for six posts:

- Five ME Support people, each working one day per week (total equivalent of 1.0 FTE), to support MEs as follows: one for Asia & Oceania (supporting seven Cochrane Review Groups (CRGs)); one for Continental Europe (supporting 11 CRGs); one for North & South America (supporting 10 CRGs); and two for the UK (supporting 25 CRGs).
- One ME Support Manager, working one day per week (0.2 FTE). This role was planned to be, and now is, integrated into the job description of a current member of the Cochrane Editorial Unit (CEU) who has related responsibilities.

Progress since 1 October 2012

Harriet MacLehose (Senior Editor, CEU) joined the ME Support team as the ME Support Manager and, in conjunction with Sally Bell-Syer (ME CCSG representative) and Sonja Henderson (ex-ME CCSG representative), led the recruitment of the ME Support people. As indicated above, we had intended to appoint five ME Support people; however, following the recruitment process we appointed three

ME Support people: Liz Dooley (Australia); Rebecca Gray (USA); and Anupa Shah (UK). Sonja Henderson, who was due to retire in December 2012 and has extensive experience with previous initiatives for MEs, joined the ME Support team in a part-time (approximately 0.2 FTE) team support post until April 2013, with the specific purpose of helping Harriet MacLehose to set up the team.

The team developed a work-plan in the first few months and has made good progress against the planned areas and activities (Appendix 1). We have had to modify some of the target dates as some priorities have shifted or new ones developed, and in response to having a smaller team than anticipated.

In March 2013, the MEs' Executive identified that there are now 63 MEs in the 53 CRGs, 4 MEs in Cochrane Review Group Satellites, and 26 Assistant Managing Editors. ME Support primarily offers support to MEs on the understanding that Assistant MEs are supported by their MEs. The team is working to capacity responding to requests for support by phone and email (we aim to reply to urgent emails in 24 hours and to other enquiries in 48 hours) in addition to the other key activities, such as the training needs assessment and testing and training activities related to Publish When Ready. Over the past few months the team has felt the impact of having fewer than anticipated team members.

Experience over the past few months has shown that there is demand for the team's professional service, both in providing day-to-day support and in contributing to related projects that will impact MEs. We have provided some highlights of work so far.

- Over 70% (37/53) of Cochrane Review Groups have requested help from ME Support between October 2012 and May 2013.
- Between October 2012 and May 2013, the team responded to about 250 queries (corresponds to about 31 per month and 8 per week). Often the team needs to conduct research or liaise with other teams (particularly the IMS team, CEU, and publisher) to resolve the query. Responses and support is provided via email, phone, and Skype (for screensharing).
- The team started tagging queries by topic in April 2013. In April and May we had 81 queries, most related to Archie. Other topics included workflows, publishing, RevMan, management, and the editorial process.
- The team has provided induction training, involving remote training and/or site visit, for new MEs from four CRGs: PaPaS; EPOC Australasian Satellite; Prostatic Diseases and Urologic Cancers; and Neonatal. The team has also provided specialist training to one CRG identified as needing additional training by the CEU. Unlike previous initiatives, the team uses screensharing technologies to support MEs as well as via phone, email, and face-to-face meetings. Some new MEs have chosen these options as part of their induction training (before meeting face-to-face) or, in two instances, in preference to a face-to-face meeting. We anticipate that this mode of support will increase with time and will reduce costs associated with site visits to new MEs.
- The team supported the development and roll-out of the new continuous publishing model for Cochrane Reviews (known as Publish When Ready) by (1) participating in the second round of testing of the new publishing technology system as part of the Publish When Ready development process and (2) developing training materials for MEs.

The team developed a training needs assessment survey for MEs in collaboration with the Training Working Group Co-ordinators and Steve McDonald, Sally Bell-Syer (MEs' Executive co-convenor and ME representative on the Training Working Group) and Jessica Thomas (IMS Team Manager). We had a good response rate (over 80%) and are using the results to develop a training programme for MEs and identify the responsibilities of the different teams in delivering this.

Revised objectives for ME Support

The CEU aims to ensure that *The Cochrane Library* maintains its reputation as the international source of trustworthy, independent, and relevant information to guide healthcare decisions. The CEU works to support CRGs and other entities to ensure that *The Cochrane Library* continues to meet the varied needs of users, and appropriately reflects the commitment of CRG teams and authors.

ME Support plans to contribute to this mission by including a new objective (number four) to provide:

- (1) MEs with training and support for using the Collaboration's information technologies;
- (2) ongoing professional support around all aspects of the ME role;
- (3) induction training for new MEs; and
- (4) support to CEU projects that will directly impact MEs (at the discretion of the ME Support Manager).

Proposals and discussion

We would like to see ME Support continue beyond 30 September 2013, and this is endorsed by the MEs' Executive. There has been a great deal of investment in setting up the ME Support team, and we would like to ensure stability for this support service and for the current team members by seeking funding for an additional three years (starting 1 October 2013 and ending 30 September 2016).

We would also like to advertise for two more ME Support people to bring the team up to the originally planned capacity of five ME Support people. Job descriptions and person specifications are in Appendix 2 (ME Support Person) and Appendix 3 (ME Support Manager).

We are seeking funding to continue ME Support for the next three years: 1 FTE for the five ME Support people (each person on 0.2 FTE); and 0.2 FTE for the ME Support Manager. There have been savings this year because we budgeted for five ME Support people but in fact funded three ME Support people (0.2 FTE each) and one ME Support team support person (approx 0.2 FTE for 6 months).

Summary of recommendations

We recommend that funding for the ME Support team, at its originally conceived capacity, is continued for an additional three years.

Resource implications

Using current known and anticipated costs, we are seeking funding of £59,255 or £79,255 for 2013/2014 (former includes the 2012/2013 underspend), £81,633 for 2014/2015, and £84,082 for 2015/2016.

Appendix 4 (restricted access) details the known costs to date for the ME Support team for 2012/2013 (Table 1). There will be a surplus of at least £20,000 against the £78,571 allocated to ME Support for this period. It also provides a budget breakdown for the proposed new funding period, 2013 to 2016 (Table 2).

Impact statement

Should this proposal be accepted, MEs will continue to receive professional day-to-day support as well as training and support for new initiatives affecting Cochrane Review production and publication. Without ME Support, other teams would need to be in the position to provide similar levels of induction and training, and ongoing support to MEs.

The team's current contracts end of 30 September 2013. An early assessment of this proposal would (1) ensure continuity in the current ME Support team and (2) allow us to advertise for two posts to provide the additional capacity needed by the team.

Decision required

Approval of the proposal.

Appendices

Appendix 1. Managing Editor (ME) Support project work-plan: 2012 to 2013

ME Support objective

The objective of ME Support is to provide induction training, ongoing training, and support to MEs in all aspects of their role within a Cochrane Review Group. This will be accomplished through activities in the following areas:

- 1. Recruit a ME Support team and set up effective team processes, management, and training to support the ME Support team's work.
- 2. Provide support on any aspect of the ME role, and induction training as required, to individual MEs.
- 3. Contribute to the Collaboration's training programme for MEs.
- 4. Contribute to the development of training resources for MEs.
- 5. Communicate ME Support's activities and achievements to the Collaboration, and be proactive in engaging with MEs.
- 6. Evaluate the use of ME Support and report back to the Collaboration.

No.	Area	Activity	Target date	Status ⁱ
1.	(1) Recruit a ME Support team and set up effective team processes, management, and training to support the ME Support team's work	ME Support Manager to recruit the ME Support team in consultation with Sally Bell-Syer and Sonja Henderson.	October 2012	Completed
2.		COU/CEU to ensure contracts for staff in place.	December 2012	Will be finalized, June 2013
3.		ME Support staff to keep a time log and submit at the end of each month to the ME Support Manager.	Ongoing	
4.		ME Support team to participate in team teleconferences at least monthly; and to join one face-to-face meeting.	Ongoing	
5.		Set up a ME Support webpage on the CEU website, and	December 2012	Completed

Work-plan 2012/2013

		include information about the ME Support team on the CEU website.		
6.		Set up an email account(s) for ME Support; and set up systems for tagging and categorizing support queries.	January 2013	Completed
7.		Evaluate customer helpdesk support software Fogbugz as a tool to work in conjunction with the ME Support email account, and implement if agreed.	January 2013	Completed
8.		ME Support staff to assist the ME Support Manager to identify and develop a bespoke induction programme, and thereafter ongoing training needs and learning programmes.	December 2012	Training needs identified; working through training
9.	-	Team members to join the Collaboration's network of trainers.	November 2012	Completed
10.		Liaise with central teams to give ME Support advance warning and information about relevant policies and procedures relating to all aspects of the ME role in which ME Support will need to provide training or support.	Ongoing	
11.	(2) Provide support on any aspect of the ME role, and induction training as required, to individual MEs	Provide support to MEs on any aspect of the ME role in their region by phone, email, or online virtual support (e.g. via remote meeting and desktop sharing software) when required.	Ongoing	
12.	-	Arrange induction training for MEs within four weeks of starting in post; and follow-up training as needed.	Ongoing	
13.		Develop a policy for providing support to CRG satellites.	February 2013	Finalize, but include in policy manual and communicate
14.	(3) Contribute to the Collaboration's training programme for MEs	Identify ongoing training needs of MEs, in conjunction with the ME Support Manager, Cochrane Training Co-ordinator, and others.	March 2013	Training needs assessment survey completed and plan being discussed and drawn up
15.]	Provide ongoing training to MEs on all aspects of the ME role	Ongoing	Plans in progress based on

		as required, both face-to-face and using remote training facilities. This will involve contributing to the development and facilitation of appropriate workshops at regional meetings and the annual Cochrane Colloquium.		above
16.		Help with the implementation of new Collaboration policies, procedures, and innovations (e.g. roll-out of Publish When Ready in 2013 and workflows) that have training and support implications for MEs.	Ongoing	Completed testing for Publish When Ready and developing training materials for MEs
17.	(4) Contribute to the development of training resources for MEs	Revise and periodically update the ME training checklists (induction and IMS) as needed.	Ongoing	
18.	_	Work with the MEs' Executive to develop an online portal for MEs.	February 2013	Completed
19.	(5) Communicate ME Support's activities and achievements to the MEs, and being proactive in engaging with MEs	Develop communication with MEs to share information about and from ME Support.	January 2013	Via CEU Bulletin to date, but planning a bespoke ME Support bulletin
20.	_	Agree a proactive approach or approaches to engage MEs with ME Support.	February 2013	In discussion
21.	(6) Evaluate the use of ME Support and report back to the MEs' Executive and Collaboration	Evaluate the use of ME Support on a monthly basis in terms of numbers of queries coming to ME Support, number of CRGs using ME Support, geographical location of CRGs/MEs using ME Support, types of queries resolved by ME Support; response times for queries to be resolved.	Ongoing	Developing systems to collect data for support requests; data available from March
22.	_	Obtain feedback from MEs about ME Support to help with the evaluation of ME Support and to inform future plans.		To do – aim for after the Quebec Colloquium
23.		Prepare a report on ME Support activities, based on the work- plan, for the Collaboration's mid-year meeting and a follow- up report for the 2013 Colloquium CCSG meeting, and interim reports as requested. Reports to be included within the Editor	March 2013 and October 2013	Ongoing (brief report prepared as part of Editor in Chief's CCSG report for mid-

		in Chief's reports.		year meetings)
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Green = good progress; Amber = some delays; Red = alarm bells; Purple = not yet started.

Appendix 2. Post title: Managing Editor Support Person

Job description

For part-time, regional Managing Editor (ME) Support Person: 5 posts (North & South America, Asia & Oceania, Continental Europe & Africa, UK [2 posts])

Hours

Applicants must be able to commit the equivalent of at least 1* full day per week (0.2 FTE) to this role spread over a full week or month as required. Other arrangements may be considered.

*Asia & Oceania (7 CRGs) = 1 day per week; Continental Europe and Africa (11 CRGs) = 1 day per week; North & South America (10 CRGs) = 1 day per week; 2 x UK (25 CRGs) = 1 day per week each: i.e. total of all 5 posts equivalent of 1.0 FTE.

Salary

Salary will be dependent on experience and local circumstances.

Terms of employment

The start date is 1 October 2012 and is available until October 2013 in the first instance. If the appointee is already employed at an editorial base of a Collaborative Review Group (CRG) and is continuing in this employment, it is anticipated that her/his current employing organisation will remain the same.

Location

If already employed at an editorial base of a CRG, it is anticipated that the appointee will be able to work from there. Otherwise, appointees may be able to work from home or from the offices of another Cochrane Entity.

Responsible to

ME Support Manager.

Contact with

Managing Editors (MEs) and other staff at editorial bases of Cochrane Review Groups (CRGs) within the ME Support Person's region; Cochrane Editorial Unit (CEU) staff; Information Management System (IMS) team staff; the four other regional ME Support Persons; Cochrane Operations Unit staff; The Cochrane Collaboration's Training Co-ordinator; other staff members and entities within The Cochrane Collaboration.

Aim

To provide induction training, ongoing training and support to MEs in all aspects of their role within a CRG. An ME's role is outline in the ME job description in the Cochrane Policy Manual.¹

Duties

1. Induct new MEs into their role (will involve site visits).

¹ <u>http://www.cochrane.org/policy-manual/3295-recruitment-managing-editor</u>

- 2. Identify ongoing training needs of MEs, in conjunction with ME Support Manager and others, and provide ongoing training to MEs on all aspects of the ME role as required, both face-to-face and using remote training facilities. This will involve contributing to the development and facilitation of appropriate workshops at regional meetings and annual colloquia.
- 3. Provide support to MEs on any aspect of the ME role in their region by phone or email when required.
- 4. Keep up-to-date with The Cochrane Collaboration policies and procedures relating to all aspects of the ME role, and raise with ME Support team and Manager when MEs have queries relating to these.
- 5. Support the ME Support Manager in identifying and developing his/her own induction programme, and thereafter ongoing training needs and learning programmes.
- 6. Contribute to the preparation of reports relating to ME Support.
- 7. Support the ME Support Manager to develop and implement a communication strategy to inform the Collaboration about activities and achievements, and help with the implementation of new Cochrane Collaboration policies and procedures.

OTHER REQUIREMENTS

- 8. Keep a weekly time log and submit at the end of each month to the ME Support Manager.
- 9. Participate in regular telephone conferences, sometimes outside of normal office hours.
- 10. Join The Cochrane Collaboration's network of trainers.
- 11. Other tasks required by the ME Support Manager.

Person specification

ESSENTIAL

- 1. Experience of working as an ME in a CRG editorial base (preferably for at least two years within the last three years) or have working knowledge of the role of ME.
- 2. Knowledge and experience of The Cochrane Collaboration's Information Management System, i.e. Review Manager (RevMan) and Archie.
- 3. General IT proficiency, including proficiency in email, Microsoft Word, Excel, and PowerPoint, and use of the Internet.
- 4. Excellent organisational skills.
- 5. Understanding of and sensitivity to the needs of individual CRGs
- 6. Fluency in English (both written and spoken).
- 7. Exceptional written, verbal, and presentational skills.

- 8. Self-motivated, and ability to work as part of a virtual team and ability to work independently.
- 9. Flexibility and willingness to travel.
- 10. Good time-management skills.

DESIRABLE

- 1. Experience as a trainer/facilitator
- 2. Training or teaching qualification

Additional information

It is essential that the successful candidate has direct, practical experience of a CRG editorial base so this post will be of interest to current MEs who would like to continue in their current job on a part-time basis and combine it with this post.

Training and orientation will be provided.

Appendix 3. Post title: Managing Editor Support Manager

The Managing Editor (ME) Support Manager's role will be integrated into the job description of a current member of the Cochrane Editorial Unit (CEU) who has related responsibilities. We therefore do not plan to advertise it separately. It is important that the ME Support Manager's role is 'embedded' in the CEU given that professional editorial advice and guidance is the responsibility of the CEU. This role is anticipated to require a commitment of up to 1 day per week (0.2 FTE).

Responsible to

The Cochrane Library Editor in Chief.

Contact with

Five regional ME Support staff (Asia & Oceania, Continental Europe, North & South America, UK [2 posts]); CEU staff; Cochrane Operations Unit staff; Information Management System (IMS) team in Copenhagen; MEs' Executive; Training Co-ordinator.

Aim

To provide professional governance and support to the ME Support team.

Duties

- 1. Supervise recruitment of ME Support staff.
- 2. In conjunction with ME Support staff, prepare a tailored induction training programme for ME Support staff (including IMS training as required).
- 3. Work with ME support staff to identify ongoing training needs of the individuals in the ME Support role, and ensure that professional training and support is available to ME Support staff as required.
- 4. Review ME Support staff performance annually.
- 5. Ensure that training needs of MEs are regularly assessed, and that these needs are addressed via a range of programmes, working with the ME Support people and Training Co-ordinator
- 6. Oversee provision of data to The Cochrane Collaboration on the work of ME Support as required.
- 7. Develop and implement communication strategy; to include contributions to the CEU Bulletin on issues that arise out of ME support that are relevant to CRGs.
- 8. Participate in regular telephone conferences, sometimes outside of normal office hours
- 9. Manage the ME support budget

Endorsement of the Declaration of Istanbul on Organ Trafficking and Transplantation Tourism

Document prepared by: Angela Webster (Deputy Co-ordinating Editor, Cochrane Renal Group), Christian Gluud (Co-ordinating Editor, Cochrane Hepato-Biliary Group), Dimitrinka Nikolova (Managing Editor, Cochrane Hepato-Biliary Group), Harriet MacLehose (Senior Editor, Cochrane Editorial Unit), David Tovey (Editor in Chief, Cochrane Editorial Unit)

Submitted for approval to: The Cochrane Collaboration Steering Group (CCSG) on 22 July 2013

Purpose

To seek the CCSG's endorsement of the Declaration of Istanbul on Organ Trafficking and Transplantation Tourism.

Urgency

Medium.

Access

Open.

Background

The Declaration of Istanbul on Organ Trafficking and Transplantation Tourism (<u>http://www.declarationofistanbul.org</u>; reproduced in Appendix 1) was developed in response to unethical practices that do occur with organ trafficking, transplant commercialism, travel for transplantation, and transplant tourism. Published in 2008, it has since been endorsed by over 100 organizations. See Appendix 2 for further information about events that led to its development.

Angela Webster, Deputy Co-ordinating Editor of the Cochrane Renal Group, asked for the Declaration of Istanbul to be included in the agenda of the Co-ordinating Editors' Board meeting in September 2012 (Auckland Cochrane Colloquium). A Webster raised the issue of including research conducted illegally in Cochrane Reviews and provided an example from the Cochrane Renal Group in which the author considered that two of the trials were unethical. The Cochrane Renal Group in response decided to endorse the Declaration of Istanbul and develop a plan of action to make the Group's actions consistent with that endorsement. As this had implications for the Collaboration as a whole, A Webster brought this to the attention of David Tovey, Editor in Chief, and the Co-ordinating Editor's Board. The Co-ordinating Editors discussed A Webster's paper. A range of views expressed, but all were generally supportive of the Declaration.

The two Cochrane Review Groups principally affected by the endorsement of this policy are the Cochrane Renal Group and the Cochrane Hepato-Biliary Group. Over the past few months, A Webster, Christian Gluud and Dimitrinka Nikolova (Co-ordinating Editor and Managing Editor of the Hepato-Biliary Group, respectively), and David Tovey and Harriet MacLehose have progressed with plans around seeking the Collaboration's endorsement of the Declaration (this paper). Together, we

have developed a decision framework for implementing the Declaration in individual Cochrane Reviews (Appendix 3) and are discussing a framework for tagging the unethical studies in Specialized Registers and the Cochrane Central Register of Controlled Trials (CENTRAL). These frameworks, and related information about the Declaration of Istanbul, will be located in the Cochrane Editorial and Publishing Policy Resource.

Dr Webster has been in contact with members of the Declaration of Istanbul Custodian Group, and, should the CCSG approve this endorsement, will work with the members to publicize this position.

Proposals and discussion

To endorse the Declaration of Istanbul on Organ Trafficking and Transplant Tourism ('Declaration of Istanbul'), which ensures that the organs obtained in transplant research were acquired ethically in all respect of patients' autonomy and integrity (<u>www.declarationofistanbul.org/</u>).

As stated on the Declaration of Istanbul website (www.declarationofistanbul.org/):

"The Declaration is not a legal document, nor did those involved in its creation sign it. Rather than compelling compliance with the principles of the declaration, it is hoped that the principles and the proposals it outlines will guide and inspire better practices in transplantation. With this in mind, *endorsement* of the Declaration has been sought amongst the many professional societies associated with transplantation medicine.

Societies that officially endorse the Declaration are urged to uphold the principles of the Declaration in their activities and in the practice of their members. They are further encouraged to strive towards achievement of the proposals suggested in the Declaration.

Endorsement not only promotes ethical practice within particular professional societies, it helps to convey the weight of public and professional support for the Declaration, thus encouraging health authorities and policy makers to adopt legislation and support activities that facilitate the goals of the Declaration.

Endorsement of the Declaration does not entail compliance with all the proposals it suggests, however it does require those who endorse it to rigorously apply the ethical principles of the Declaration in their policies, practice and activities. To facilitate this, the following suggestions have been made for organizations which endorse the Declaration:

- require that speakers at scientific and educational meetings on clinical organ transplantation disclose whether the clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul.
- have an established mechanism for determining the appropriateness of accepting presentations on clinical organ transplantation based on the disclosure of a consistency with the Principles of the Declaration of Istanbul.
- establish mechanisms to promote, implement and uphold the Declaration (for example, through ethics committee activity, awards and membership criteria)."

We propose that the Collaboration will respond to the three suggestions as follows:

- members of relevant Cochrane Review Groups will make disclosures as stated above;
- assess Cochrane Colloquia proposals for presentations on clinical organ transplantation against the Declaration; and
- develop frameworks for implementing the Declaration in Cochrane Reviews and studies identified as contravening the Declaration in Cochrane Review Group Specialized Register and CENTRAL.

Summary of recommendations

To endorse the Declaration of Istanbul on Organ Trafficking and Transplant Tourism ('Declaration of Istanbul').

Resource implications

None.

Impact statement

The two Cochrane Review Groups most likely to be impacted by this endorsement are the Cochrane Renal Group and the Cochrane Hepato-Biliary Group. Co-ordinating Editors from both groups are contributors to this proposal.

Appendix 1. Declaration of Istanbul

Reproduced in its entirety from:

www.declarationofistanbul.org/index.php?option=com_content&view=article&id=78&Itemid=54

Preamble

Organ transplantation, one of the medical miracles of the twentieth century, has prolonged and improved the lives of hundreds of thousands of patients worldwide. The many great scientific and clinical advances of dedicated health professionals, as well as countless acts of generosity by organ donors and their families, have made transplantation not only a life-saving therapy but a shining symbol of human solidarity. Yet these accomplishments have been tarnished by numerous reports of trafficking in human beings who are used as sources of organs and of patient-tourists from rich countries who travel abroad to purchase organs from poor people. In 2004, the World Health Organization, called on member states "to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs" (1).

To address the urgent and growing problems of organ sales, transplant tourism and trafficking in organ donors in the context of the global shortage of organs, a Summit Meeting of more than 150 representatives of scientific and medical bodies from around the world, government officials, social scientists, and ethicists, was held in Istanbul from April 30 to May 2, 2008. Preparatory work for the meeting was undertaken by a Steering Committee convened by The Transplantation Society (TTS) and the International Society of Nephrology (ISN) in Dubai in December 2007. That committee's draft declaration was widely circulated and then revised in light of the comments received. At the Summit, the revised draft was reviewed by working groups and finalized in plenary deliberations.

This Declaration represents the consensus of the Summit participants. All countries need a legal and professional framework to govern organ donation and transplantation activities, as well as a transparent regulatory oversight system that ensures donor and recipient safety and the enforcement of standards and prohibitions on unethical practices.

Unethical practices are, in part, an undesirable consequence of the global shortage of organs for transplantation. Thus, each country should strive both to ensure that programs to prevent organ failure are implemented and to provide organs to meet the transplant needs of its residents from donors within its own population or through regional cooperation. The therapeutic potential of deceased organ donation should be maximized not only for kidneys but also for other organs, appropriate to the transplantation needs of each country. Efforts to initiate or enhance deceased donor transplantation are essential to minimize the burden on living donors. Educational programs are useful in addressing the barriers, misconceptions and mistrust that currently impede the development of sufficient deceased donor transplantation; successful transplant infrastructure.

Access to healthcare is a human right but often not a reality. The provision of care for living donors before, during and after surgery–as described in the reports of the international forums organized by TTS in Amsterdam and Vancouver (2-4)–is no less essential than taking care of the transplant recipient. A positive outcome for a recipient can never justify harm to a live donor; on the contrary, for a transplant with a live donor to be regarded as a success means that both the recipient and the donor have done well.

This Declaration builds on the principles of the Universal Declaration of Human Rights (5). The broad representation at the Istanbul Summit reflects the importance of international collaboration and global consensus to improve donation and transplantation practices. The Declaration will be submitted to relevant professional organizations and to the health authorities of all countries for consideration. The legacy of transplantation must not be the impoverished victims of organ trafficking and transplant tourism but rather a celebration of the gift of health by one individual to another.

Definitions

Organ trafficking is the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation (6).

Transplant commercialism is a policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain.

Travel for transplantation is the movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes. Travel for transplantation becomes **transplant tourism** if it involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centers) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population.

Principles

- 1. National governments, working in collaboration with international and nongovernmental organizations, should develop and implement comprehensive programs for the screening, prevention and treatment of organ failure, which include:
 - a. The advancement of clinical and basic science research;
 - b. Effective programs, based on international guidelines, to treat and maintain patients with end-stage diseases, such as dialysis programs for renal patients, to minimize morbidity and mortality, alongside transplant programs for such diseases;
 - c. Organ transplantation as the preferred treatment for organ failure for medically suitable recipients.
- 2. Legislation should be developed and implemented by each country or jurisdiction to govern the recovery of organs from deceased and living donors and the practice of transplantation, consistent with international standards.
 - a. Policies and procedures should be developed and implemented to maximize the number of organs available for transplantation, consistent with these principles;
 - b. The practice of donation and transplantation requires oversight and accountability by health authorities in each country to ensure transparency and safety;

- c. Oversight requires a national or regional registry to record deceased and living donor transplants;
- d. Key components of effective programs include public education and awareness, health professional education and training, and defined responsibilities and accountabilities for all stakeholders in the national organ donation and transplant system.
- 3. Organs for transplantation should be equitably allocated within countries or jurisdictions to suitable recipients without regard to gender, ethnicity, religion, or social or financial status.

a. Financial considerations or material gain of any party must not influence the application of relevant allocation rules.

- 4. The primary objective of transplant policies and programs should be optimal short- and long-term medical care to promote the health of both donors and recipients.
 - a. Financial considerations or material gain of any party must not override primary consideration for the health and well-being of donors and recipients.
- 5. Jurisdictions, countries and regions should strive to achieve self-sufficiency in organ donation by providing a sufficient number of organs for residents in need from within the country or through regional cooperation.
 - a. Collaboration between countries is not inconsistent with national self- sufficiency as long as the collaboration protects the vulnerable, promotes equality between donor and recipient populations, and does not violate these principles;
 - b. Treatment of patients from outside the country or jurisdiction is only acceptable if it does not undermine a country's ability to provide transplant services for its own population.
- 6. Organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited. Because transplant commercialism targets impoverished and otherwise vulnerable donors, it leads inexorably to inequity and injustice and should be prohibited. In Resolution 44.25, the World Health Assembly called on countries to prevent the purchase and sale of human organs for transplantation.
 - a. Prohibitions on these practices should include a ban on all types of advertising (including electronic and print media), soliciting, or brokering for the purpose of transplant commercialism, organ trafficking, or transplant tourism.
 - b. Such prohibitions should also include penalties for acts—such as medically screening donors or organs, or transplanting organs—that aid, encourage, or use the products of, organ trafficking or transplant tourism.
 - c. Practices that induce vulnerable individuals or groups (such as illiterate and

impoverished persons, undocumented immigrants, prisoners, and political or economic refugees) to become living donors are incompatible with the aim of combating organ trafficking, transplant tourism and transplant commercialism.

Proposals

Consistent with these principles, participants in the Istanbul Summit suggest the following strategies to increase the donor pool and to prevent organ trafficking, transplant commercialism and transplant tourism and to encourage legitimate, life-saving transplantation programs:

To respond to the need to increase deceased donation:

Governments, in collaboration with health care institutions, professionals, and non-governmental organizations should take appropriate actions to increase deceased organ donation. Measures should be taken to remove obstacles and disincentives to deceased organ donation.

In countries without established deceased organ donation or transplantation, national legislation should be enacted that would initiate deceased organ donation and create transplantation infrastructure, so as to fulfill each country's deceased donor potential.

In all countries in which deceased organ donation has been initiated, the therapeutic potential of deceased organ donation and transplantation should be maximized.

Countries with well established deceased donor transplant programs are encouraged to share information, expertise and technology with countries seeking to improve their organ donation efforts.

To ensure the protection and safety of living donors and appropriate recognition for their heroic act while combating transplant tourism, organ trafficking and transplant commercialism:

- 1. The act of donation should be regarded as heroic and honored as such by representatives of the government and civil society organizations.
- 2. The determination of the medical and psychosocial suitability of the living donor should be guided by the recommendations of the Amsterdam and Vancouver Forums (2-4).
 - a. Mechanisms for informed consent should incorporate provisions for evaluating the donor's understanding, including assessment of the psychological impact of the process;
 - b. All donors should undergo psychosocial evaluation by mental health professionals during screening.
- 3. The care of organ donors, including those who have been victims of organ trafficking, transplant commercialism, and transplant tourism, is a critical responsibility of all jurisdictions that sanctioned organ transplants utilizing such practices.
- 4. Systems and structures should ensure standardization, transparency and accountability of support for donation.
 - a. Mechanisms for transparency of process and follow-up should be established;

- b. Informed consent should be obtained both for donation and for follow-up processes.
- 5. Provision of care includes medical and psychosocial care at the time of donation and for any short- and long-term consequences related to organ donation.
 - a. In jurisdictions and countries that lack universal health insurance, the provision of disability, life, and health insurance related to the donation event is a necessary requirement in providing care for the donor;
 - b. In those jurisdictions that have universal health insurance, governmental services should ensure donors have access to appropriate medical care related to the donation event;
 - c. Health and/or life insurance coverage and employment opportunities of persons who donate organs should not be compromised;
 - d. All donors should be offered psychosocial services as a standard component of follow-up;
 - e. In the event of organ failure in the donor, the donor should receive:

i. Supportive medical care, including dialysis for those with renal failure, and

ii. Priority for access to transplantation, integrated into existing allocation rules as they apply to either living or deceased organ transplantation.

- 6. Comprehensive reimbursement of the actual, documented costs of donating an organ does not constitute a payment for an organ, but is rather part of the legitimate costs of treating the recipient.
 - a. Such cost-reimbursement would usually be made by the party responsible for the costs of treating the transplant recipient (such as a government health department or a health insurer);
 - b. Relevant costs and expenses should be calculated and administered using transparent methodology, consistent with national norms;
 - c. Reimbursement of approved costs should be made directly to the party supplying the service (such as to the hospital that provided the donor's medical care);
 - d. Reimbursement of the donor's lost income and out-of-pockets expenses should be administered by the agency handling the transplant rather than paid directly from the recipient to the donor.
- 7. Legitimate expenses that may be reimbursed when documented include:
 - a. the cost of any medical and psychological evaluations of potential living donors who are excluded from donation (e.g., because of medical or immunologic issues discovered during the evaluation process);
 - b. costs incurred in arranging and effecting the pre-, peri- and post-operative phases of

the donation process (e.g., long-distance telephone calls, travel, accommodation and subsistence expenses);

c. medical expenses incurred for post-discharge care of the donor;

d. lost income in relation to donation (consistent with national norms).

References

- 1. World Health Assembly Resolution 57.18, Human organ and tissue transplantation, 22 May 2004, <u>http://www.who.int/gb/ebwha/pdf_files/WHA57/A57_R18-en.pdf.</u>
- 2. The Ethics Committee of the Transplantation Society (2004). The Consensus Statement of the Amsterdam Forum on the Care of the Live Kidney Donor. Transplantation 78(4):491-92.
- 3. Barr ML, Belghiti J, Villamil FG, Pomfret EA, Sutherland DS, Gruessner RW, Langnas AN & Delmonico FL (2006). A Report of the Vancouver Forum on the Care of the Life Organ Donor: Lung, Liver, Pancreas, and Intenstine Data and Medical Guidelines. Transplantation 81(10):1373-85.
- 4. Pruett TL, Tibell A, Alabdulkareem A, Bhandari M, Cronon DC, Dew MA, Dib-Kuri A, Gutmann T, Matas A, McMurdo L, Rahmel A, Rizvi SAH, Wright L & Delmonico FL (2006). The Ethics Statement of the Vancouver Forum on the Live Lung, Liver, Pancreas, and Intestine Donor. Transplantation 81(10):1386-87.
- 5. Universal Declaration of Human Rights, adopted by the UN General Assembly on December 10, 1948, <u>http://www.un.org/Overview/rights.html.</u>
- Based on Article 3a of the Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Supplementing the United Nations Convention Against Transnational Organized Crime, <u>http://www.uncjin.org/Documents/Conventions/dcatoc/final_documents_2/convention_%20t_raff_eng.pdf</u>.

Appendix 2. The development of the Declaration of Istanbul

The following text is based on information available on the Declaration of Istanbul website: <u>http://www.declarationofistanbul.org/</u>.

In 2004, the World Health Assembly urged member states to take measures to protect the poor and vulnerable from transplant tourism and to address the wider problem of international trafficking of human organs and tissues.

In December 2006, representatives from The Transplantation Society met with representatives of the International Society of Nephrology and conceived the idea of developing a formal Declaration that would serve to inspire and unite all those engaged in combating unethical practices in organ transplantation. On April 30 2008, more than 150 representatives of scientific and medical bodies from 78 countries around the world, including government officials, social scientists and ethicists were convened in Istanbul, Turkey to work on the drafting of the Declaration of Istanbul. Working groups were assigned to develop the various components of the Declaration and the results of their meetings were presented at plenary sessions for approval.

The Declaration of Istanbul was derived from the consensus reached by the participants at the Summit in those plenary sessions. The Declaration of Istanbul was first published on 5 July 2008 in *The Lancet*. It has been subsequently published in several medical journals and translated into more than a dozen languages.

The Declaration is not a legal document, nor did those involved in its creation sign it. Rather than compelling compliance with the principles of the declaration, it is hoped that the principles and the proposals it outlines will guide and inspire better practices in transplantation. With this in mind, *endorsement* of the Declaration has been sought amongst the many professional societies associated with transplantation medicine. See http://www.declarationofistanbul.org/index.php?option=com_content&view=article&id=74&Itemid=56 for a list of endorsing societies, organisations, and funding bodies.

Appendix 3. Draft framework for implementing the Declaration of Istanbul in Cochrane Reviews

Developed by Angela Webster (Deputy Co-ordinating Editor, Cochrane Renal Group), Christian Gluud (Coordinating Editor, Cochrane Hepato-Biliary Group), Dimitrinka Nikolova (Managing Editor, Cochrane Hepato-Biliary Group), Harriet MacLehose (Senior Editor, Cochrane Editorial Unit), Noémie Aubert Bonn (Intern, Cochrane Editorial Unit), and David Tovey (Editor in Chief, Cochrane Editorial Unit)

- Follow the flowcharts below: Figure 1 (for implementing in Cochrane Reviews) and Figure 2 (for creating awareness at the title registration stage).
- Include, exclude, or place trials in "awaiting assessment" that don't contravene, do contravene, or may contravene the Declaration of Istanbul, respectively, according to Figure 1.
- Implement this policy prospectively (and not to Cochrane Reviews already published). For updates, apply preferably to all trials or if not explain why (and state approach taken).
- Although the Declaration of Istanbul was announced in 2008, the same approach will be used for all trials regardless of publication date because the Declaration of Helsinki includes relevant statements about the ethical conduct of trials.
- Include a statement in the methods sections of Protocols and Reviews to say that this is being addressed, such as: [*We didn't agree wording, but here is some suggested text that can be edited.*]
 - Protocols: We will assess each potentially relevant trial against the Declarations of Helsinki and Istanbul, and we will include only those that have a low risk of contravening the Declarations.
 - Review: We have assessed each potentially relevant trial against the Declarations of Helsinki and Istanbul, and we have included only those that have a low risk of contravening the Declarations.

Flowcharts

Figure 1. Declaration of Istanbul: flowchart to assess trials for inclusion in Cochrane Reviews (including Protocols and Updates)



¹ High-risk trials: countries at risk of using transplanting organs from executed prisoners and having centres of transplant tourism. The Declaration of Istanbul Custodian Group (DICG) executive has agreed in principle to produce a list of countries of interest where there is concern about recent human organ trafficking; list will be available and updated on the DICG website www.declarationofistanbul.org (email from Jeremy Chapman, 16 July).

² By reading trial report (or record on trial register if applicable) and, if needed, contacting trial authors; authors may find it helpful to ask Cochrane Centres for help with contacting trialists in their country or region.

³ Declaration of Helsinki covers most of the requirements included in the Declaration of Istanbul and therefore we assume a low risk of contravening the Declaration of Istanbul if these are met.

⁴ Such as using organs obtained illegally, for example from executed prisoners, or under commercial arrangements of organ trading.

Figure 2. Flow chart for new titles

