

## **Conversation between Kay Dickersin (Director of the US Cochrane Center) and Elie Hassenfeld, Holden Karnofsky, and Stephanie Wykstra (GiveWell) on September 14, 2012.**

**Note:** This is a set of notes compiled by GiveWell in order to give an overview of the major points made by Kay Dickersin in conversation.

### **Summary:**

GiveWell had a further conversation with Kay Dickersin, Director of the US Cochrane Center (USCC), as a part of our research on funding the Cochrane Collaboration. We primarily discussed what the USCC would do with further funding. Projects that the USCC would fund would depend on the level of funding received via GiveWell. The projects that they would potentially fund include:

- Methodological support hubs based in the US, offering methodological support both to US-based and international Cochrane authors, from any Cochrane review group, including: a network meta-analysis support hub, a general methodological support hub for authors, and an informatics support hub. There do not currently exist any such hubs within Cochrane but Dr. Dickersin told us that she has found this to be an efficient way of involving volunteer clinician authors while maintaining high quality reviews. Roger Soll (Neonatal Group) told the visiting GiveWell group in May 2012 that this model addresses the editors' immediate need for statistical help on certain reviews.
- Funding for new Cochrane Satellites in the US, potentially within areas such as skin; heart; ear, nose and throat; musculoskeletal, and pregnancy/childbirth.
- Further funding for the currently existing US Cochrane entities that have a need for funding to continue their work (ie, HIV/AIDS and Prostate review groups, the US Cochrane Center [main office in Baltimore and San Francisco Branch]). The San Francisco Branch funding would potentially support a GRADE hub to assist authors in producing GRADE tables as well as a hub to assist with Cochrane reviews developed to support World Health Organization guidelines and the Essential Medicines List.
- Funding to support training of authors in the US, a Cochrane visiting fellows program, and a consumer engagement group (Consumers United for Evidence Based Healthcare).

A few other key points

- Due to past lack of funding, several Cochrane review groups and fields based in the US moved to other countries or ceased to exist.
- Dr. Dickersin's view is that paying the full cost of conducting a review would be prohibitively expensive and would lead to fewer reviews produced than if the same funds were available per review, as were available for the infrastructure proposed to support review production. Thus, Dr. Dickersin does not think it's feasible for Cochrane to shift to a model in which the full cost of a review is covered (ie, authors are paid in full for the time it takes to write reviews), rather than relying on the current structure where new reviews are supported both by volunteers and the existing infrastructure of the Collaboration (eg, review management software, training, study registries, editing). Additional infrastructure (ie, methodologic hubs) would stretch funding investment further and would lead to higher quality reviews.

## **Projects that US Cochrane Center (USCC) would carry out with further funding**

### **Methodologic support hubs:**

Dr. Dickersin described a need within the Cochrane Collaboration to have methodologic hubs with staff that provide several different kinds of support for authors. The US Cochrane Center initiated the hub model within Cochrane; other than the methodological support hub dedicated to the Cochrane Eyes and Vision Group, no other support hubs exist within Cochrane now, as far as she knows, although the idea was presented at a plenary session at the 2012 international Cochrane Colloquium and was greeted with enthusiasm.

### **Background:**

Currently, authors receive some limited support from editorial bases. This support consists of:

- Some assistance in the search of Cochrane and other registries for studies to be included in the review (provided by the Trial Search Coordinator within each review group)
- Assistance in editing the reviews, provided by review group editors
- Assistance with using the RevMan software (technical issues, etc.) used to produce reviews
- In some cases, review groups pay statisticians, typically on a very part-time basis, to help support authors.
- Some review groups and all Cochrane centers also provide training in how to conduct reviews

### **Additional support is needed within the following areas:**

#### **General methodological support for authors:**

- A hub providing general methodological support would involve: helping potential authors with appropriate wording of their review topic (ie, developing an answerable question), helping them to develop and implement a protocol, guiding them through the steps of a systematic review, including using the RevMan software to create the reviews, providing advice on which studies to include in the review, which statistical tests to use, and other decisions.
- New authors, especially, often need this support, and a hub providing it would lead to an increase in the number of authors plus an increase in the number of reviews and keeping the reviews up-to-date.

#### **Statistical support:**

Support of this sort would provide assurance of appropriate use of statistical methods in reviews, particularly new methods that people may not know how to implement.

- Members of the Cochrane Collaboration methods groups do research on topics relevant to implementation of new methods, and develop methods standards for the Collaboration as a whole, but they do not have the capacity to support individual authors in implementing these methods.
- An example of a new method is network meta-analysis, which uses “direct” evidence from clinical trials as well as statistical methods to make “indirect” comparisons not

actually made in the trials, to learn about the relative effectiveness of treatments compared head-to-head. There is currently no staff within the Cochrane Collaboration with the expertise and capacity to support authors in the use of this method.

- Other examples of statistical support that is needed include assessment of crossover studies and analyzing studies in which there is a combination of individual and cluster randomization.

### **Support for Cochrane reviews that will be used in WHO practice guidelines:**

In 2007, the World Health Organization began to base their guidelines on systematic reviews, following an external critique of their existing processes. Accordingly, the San Francisco Branch of the US Cochrane Center provides a support hub for authors doing Cochrane reviews that will aid WHO in producing their evidence-based guidelines. In addition, the WHO Essential Medicine List (EML) began using systematic reviews to support the selection of medicines in 2005. The SF Branch also provides support for reviews for the EML.

### **GRADE support hub:**

- Reviews must include a table for assessing the overall strength of evidence (a GRADE table). This feature of reviews is meant to assist those who will use the reviews (professional societies, those making guidelines, etc), since it helps show what the overall quality of evidence is for a particular topic or question. Authors often need guidance in preparing the GRADE table; a hub for GRADE support, based at the San Francisco Cochrane Center, would be able to support Cochrane authors both in the US and internationally.

### **Informatics hub:**

- The Agency for Healthcare and Research Quality (AHRQ) has provided support for one of its Evidence-based Practice Centers (EPCs) to develop a database to store data extracted for systematic reviews, and this database would be made accessible to anyone who wants to use the data. The US Cochrane Center is using this database and is doing some pilot testing of it now. An informatics hub support would guide authors in contributing to and use of the database.

### **Further funding for US Satellites**

Research has shown that authors in a given country are more likely to write a Cochrane review if the relevant review group is located in or has a branch (“satellite”) in their own country. When a new satellite is started, there is evidence that review authors increase within that topic area, in the region where the satellite is started. For example, the number of US-based authors increased from 8 to 172 since the founding of the Eyes and Vision Review Group Satellite in the US in 2002.

One reason for this may be that researchers in a given country are more likely to know other researchers in that country than they are to know researchers outside of the country, and are more inclined to work with people who they know than with people they don’t know. There is also simply more impetus to work on a Cochrane review if Cochrane is better known in one’s own country; Cochrane is not as well known in the US as in countries like the UK, where many more review groups are based.

Starting further satellites in the US would be likely to increase the number of authors and thus the number of reviews produced on all topics. Potential areas for satellites are in nearly all Cochrane areas, but the USCC knows of specific immediate interest in: skin, heart, ear nose and throat and communications disorders, musculoskeletal system, and pregnancy/childbirth. Typically, funding would be used to support a managing editor of the satellite, who is responsible for coordinating with authors as they produce their reviews. The leader of a satellite is typically an editor in the review group who is responsible for raising additional funds for their operations. Kay said that the USCC wants the satellites that we fund to be led by people who have demonstrated dedication to Cochrane. One reason for this is that she thinks that they would be more likely than others to continue to maintain their satellites in short periods of an absence of funding, and also more likely to find funding to maintain their satellites.

Funding for methodological support hubs will make it easier for people to start satellites in the US, because there will be a better source of support for authors in writing reviews. So, starting both the new support hubs for authors and new satellites is a very good idea in terms of building capacity and increasing the number of reviews produced overall.

### **Visiting fellows**

The US Cochrane Center in Baltimore and San Francisco Branch currently host a few visiting “fellows” from other countries who have their own funding support (eg, from the Pan American Health Organization), and they would like to increase the number of fellows they are able to host, particularly those from developing countries. The US Cochrane Center offers training in which the fellows participate, where the Center trains them how to write a Cochrane review. Fellows also work with senior Center staff one-on-one to assist with writing a review. In addition to the immediate benefits of producing new reviews and training a new person to do Cochrane reviews, visiting fellows go on to train other researchers in their countries on how to do systematic review. For example, in early 2012 the US Cochrane Center hosted a clinician from the West Indies who enrolled in the 8-week Johns Hopkins course on conducting a systematic review, also enrolled in a 3-day course on how to do a Cochrane review, and worked on a Cochrane review with the Associate Director of the US Cochrane Center. Free housing was provided by the US Cochrane Center for 2 months.

Ordinarily, if fellows want to take a university-sponsored course, they would typically have to pay their own tuition. The US Cochrane Center would like to offer fellowships, covering both tuition as well as living expenses.

### **Training Cochrane authors**

There’s a lot of demand from US researchers for training on how to do a systematic review. The US Cochrane Center holds biannual workshops for this, and would like to hold more. The current training sessions are only for those who are going to be writing a Cochrane review. These workshops represent an enormous amount of work and preparation; with further funding, the US Cochrane Center would be able to hire a training coordinator to do much of this work, and perhaps host the workshop in multiple locations.

## **Consumer engagement**

The Cochrane Collaboration includes consumers in every stage of producing its reviews. For language and other reasons, a first step is often to engage patients and consumers at the local level, before they venture into international efforts. The US Cochrane Center started and hosts a network called Consumers United for Evidence Based Healthcare (CUE), for consumer and patient groups interested in all areas of healthcare who wish to promote evidence-based medicine. The idea behind CUE was that when new research findings are publicized (eg, findings that hormone therapy for post-menopausal women does not prevent cardiovascular events as was previously thought), there would be an educated group of consumer advocates who could explain the findings to their constituencies.

CUE provides a highly accessed online course on evidence-based healthcare (offered free of charge); a Facebook group where relevant articles and resources are shared; and a burgeoning set of resources on the CUE website. The individuals and groups who are part of CUE share with one another their knowledge and information about research and healthcare organizations that are using evidence to inform their practice. No other group like CUE exists anywhere in the world.

The US Cochrane Center previously had a grant to host annual meetings for CUE that were popular and very well-attended, but the grant ended in September 2012 and so the US Cochrane Center can no longer host these meetings or support a modest infrastructure for CUE. They are requesting funding to host such meetings in the future.

### **Other topics:**

#### **The impact of lack of funding for US Cochrane entities**

Several Cochrane entities in the US have ceased to exist (and/or moved to other countries) because of lack of funding. The Sexually Transmitted Disease review group moved to Brazil, and the Diagnostic Test Accuracy group, with one convenor formerly based in the US, is now based in Birmingham in the UK. The Headache Pain review group satellite has closed. The Behavioral Medicine field and the Health of Older Persons field have ceased to exist (a “Cochrane field” is an entity which promotes the production of reviews targeted at a certain population or on certain types of interventions, and is not limited to a certain health topic area, as review groups are).

Two US-based Cochrane review groups – the Prostatic Diseases and Urologic Cancers review group and the HIV/AIDS review group – have very little funding and their continuation is at risk. Though the HIV/AIDS group does have some grant funding - which it is using to support an HIV/AIDS satellite in South Africa - it has very little other funding for its own use, and will likely lose its coordinator in December 2012. With further funding, the USCC would support these groups.

The US originally had four Cochrane centers: San Antonio, Boston, San Francisco and Baltimore. The centers in San Antonio and Boston shut down due to lack of funding, and the center in San Francisco does not have current funding and is much less active as a result.

## **Funding Cochrane in the US vs. in other countries**

In the US, academic medical researchers have to raise their own salaries through grants whereas in most other countries, universities cover researchers' salaries. For this reason (salary coverage), it's more difficult for medical researchers in the US to spend time working on Cochrane reviews than for some of the major contributors to Cochrane from other countries. On the other hand, we have very well-trained people in the US, which makes it a good place to recruit new authors to write reviews.

The US Cochrane Center is underfunded, and many (though not all) Cochrane Centers in other countries also have concerns about being underfunded. Some places with government-funded healthcare systems (e.g., Canada and the UK) are supported much more significantly by the government.

Infrastructure funding is hard to come by, regardless. Grant funding is mainly aimed at addressing a particular project or testing a particular hypothesis. What is needed is the infrastructure to train and support review authors, generally, to ensure high quality and up-to-date reviews. Because they are concerned with a particular subject area, review groups may be in a better position to attract funding than Centers overall, because Centers work in the general area of "doing systematic reviews in healthcare".

## **High cost of Cochrane reviews**

Because Cochrane reviews are so thorough, they can be extremely expensive – and would cost on the order of \$100,000 or more per review if there were no existing international Cochrane infrastructure. Review costs depend in part on how many studies need to be summarized and the complexity of the research question, and for these reasons the cost of a review is not easy to specify ahead of time. Sometimes, people think that the cost of reviews is unnecessarily high, because reviews done by some other organizations can cost far less, for example \$10,000 per review. However, such reviews often tend to be superficial, and producing a reliable systematic review costs much more.

### **View on the idea of funding people to write reviews:**

Supporting the Cochrane review process, which includes depending on a combination of paid staff and authors, volunteer authors, and use of the Cochrane infrastructure, is a more cost-efficient way of getting systematic reviews completed than supporting each individual part of the review separately. Funding individuals to write reviews is not feasible; for example, many review authors are clinicians, and the amount of money that would be needed to compensate clinicians for their time is prohibitively high. Having a clinician on an author team is very useful because of their direct experience with the question being addressed.

## **The use of evidence in guidelines**

Many professional organizations that disseminate clinical practice guidelines do not rely on systematic reviews for their guideline production, rather the guidelines are consensus-based. The

Cochrane Collaboration would like to see more organizations have evidence-based guidelines and is encouraging partnerships between review groups and professional societies. The Cochrane Eyes and Vision Group, US Satellite is partnering with professional societies in eyes and vision to offer guideline support, and other review groups have similar partnerships.

### **The Good Ventures “quick grant” to the US Cochrane Center**

The US Cochrane Center received a \$100,000 grant from Good Ventures. 40% was given to the HIV/AIDS group and the San Francisco Branch of the US Cochrane Center and 60% is being used by the US Cochrane Center in Baltimore, where part of it is funding a Coordinator position.