

Meeting between Cochrane Collaboration representatives and GiveWell at the U.S. Cochrane Center, May 8, 2012.

From the Cochrane Collaboration:

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These notes reflect answers that Cochrane representatives gave during our conversation.

Cochrane Collaboration's aims:

- Cochrane Collaboration's primary aim is to produce high quality systematic reviews of existing health-related research. The organization also trains researchers to do systematic reviews, develops better methods for analyzing and comparing studies in its systematic reviews and educates researchers in the use of these methods, and advocates for evidence-based decision-making within the World Health Organization (WHO), governments, professional associations, consumers and other groups.

Structure of the organization:

- The Cochrane Collaboration uses a multilevel level organizational and governance structure, comprising a group of "entities" that are organized around functions related to conducting and disseminating systematic reviews of the evidence. Each Cochrane organization (or "entity") provides its own governance structure and is responsible for raising its own funding. There is a leadership group - the Steering Committee - that includes members elected from various

Cochrane groups, employs a CEO (the current Executive Director is an interim position), and receives and allocates the royalties from Cochrane's publications.

- There are two types of Cochrane organizations grouped by 1. research topic and by 2. geographical area (see details below).
- The vast majority of those doing reviews with the Cochrane Collaboration do not work full-time for Cochrane Collaboration, but instead are primarily volunteer academic researchers (researchers often are required to cover their salaries via grants, so the less Cochrane-related funding they receive, the more they need to pursue other grants, which can cause them to have less time for Cochrane activities.) Staff located at the Cochrane Collaboration organizations tend to be employed full- or part-time with that Cochrane organization, and do not typically have an academic position for example, center coordinators. Paid staff positions are usually paid for by grants to the specific Cochrane organization (e.g., in the past, the U.S. Cochrane Center coordinator has been paid using funds from grants to the U.S. Cochrane Center).

Break-down of organizations within Cochrane Collaboration:

- The Cochrane Collaboration has 53 “review groups” whose role is primarily to provide direct support for - and editorial review over - volunteers seeking to create systematic reviews. Review groups are organized around health research topics focused on particular aspect of health or health care; examples of review groups are the skin group, eyes and vision, pregnancy and childbirth, public health, and so on.
 - Each review group has its primary location (editorial team) in one specific country, but supports authors from anywhere in the world in their production of reviews relevant to the review group’s topic of research. Some groups have also developed one or more “satellites”. Each satellite consists of an editorial team located in a different country. The primary review group and the satellites work together to produce systematic reviews within their review group research area. The purpose of satellites is to take advantage of country-specific resources and engage local contributors. For example, a U.S. satellite group may be able to get additional funding and increase the number of people engaged in doing reviews (eg, academic volunteers); a US satellite thus adds to what a primary U.K. review group obtains from its funders, increasing the total number of reviews produced in a given time period.
- Cochrane also has 16 “methods groups”, such as the “non-randomized studies methods group,” the “patient-reported outcomes group” and “comparing multiple interventions methods group.” These groups do not produce or edit Cochrane reviews, but work to develop or refine the methods used in Cochrane and other systematic reviews. Methods groups provide peer review and methods advice and assistance to the review groups.
- Cochrane has “fields”, which are organized around specific populations (such as children) or care settings (e.g., emergency and pre-hospital care), rather than biological or health systems. Fields do not produce or edit Cochrane reviews but serve a bridging function between the review groups and a field’s particular constituency. This may be done by encouraging review groups to conduct relevant reviews (e.g., the child health group encourages reviews on health topics that are relevant to children), or by providing peer review or expertise for specific reviews. Fields also use a variety of techniques to make members of their constituencies aware of the activities of the Cochrane Collaboration and of the findings of relevant Cochrane reviews.

- The Cochrane Collaboration also includes Cochrane “Centers” for particular countries or regions (e.g., the U.S. Cochrane Center); there are 14 such centers. Some Centers have developed “branches” in other regions or countries. This often occurs when a group of individuals wishes to take on the Center role in their country but lacks the resources or experience to do so. In some cases, Centers have provided mentorship to their branches resulting in the branch becoming a full Center in its own right. For each country that does not have its own center or a branch, Cochrane has designated a “reference center” that has agreed to take on the Center roles for Cochrane contributors in that country. Cochrane Centers and their branches are responsible for general support, not systematic reviews on particular topics. They hold workshops and seminars for authors to train them in Cochrane review methods (it is a Cochrane requirement that within a team of authors, there is at least one author that has previous experience writing a Cochrane review or taking part in a Cochrane workshop/seminar.) Centers also have the primary responsibility for public-facing speaking engagements and other events, and for raising awareness of the Cochrane Collaboration in general. They work to establish new Cochrane groups (review groups, satellites, etc.) They advocate on cross-cutting issues, such as the general issue of emphasizing evidence in health care.
- One of the “fields”, the Consumer Network, focuses on consumer involvement in Cochrane reviews. Consumers help to write the “plain language summaries” which accompany all Cochrane reviews, which help translate the technical language in reviews into language that consumers can understand. Consumer groups also provide input on which review topics they’d like to see covered by Cochrane Collaboration and provide peer review feedback on the review protocols and completed reviews.

Funding:

- The Cochrane Collaboration is a not-for-profit organization and does not have a centralized fundraising system. Instead, as noted earlier, the organizations (or “entities”) are responsible for raising their own funding (the review groups, methods groups, fields and geographic Centers must all raise their own funds for their activities.)
- The reason for doing fundraising separately rather than having one centralized fundraising department and distributing funds to separate groups is, according to the Cochrane representatives that we spoke to, that (a) it is quite a bit easier to raise funds for a group when that group is based within the country where the fundraising is taking place; (b) health research funding tends to be based on specific conditions, populations, etc., so it is helpful to be organized around specific conditions, populations, etc.

Further specifics about selected Cochrane groups’ funding:

- Cochrane Canada includes the Canadian Cochrane Centre based in Ottawa, six review groups covering diverse areas, three methods group, and one field. Approximately 20 staff and 10 faculty-level leaders are involved in its work. These staff work with contributors around the world to complete reviews; for example, the Cochrane Effective Practice and Organisation of Care group has two staff who work with over 600 individuals around the world and have completed over 80 reviews and have 40 ongoing reviews. Cochrane Canada produces around 10% of all Cochrane reviews. The Canadian Cochrane Centre manages the main grant from the Canadian Institutes of Health Research (including subcontracting to the various entities).
- The Neonatal Group (based in the United States) has a contract with the National Institutes for Health (NIH) to complete 10 new reviews and 20 updated reviews per year.

- The Eyes and Vision Group, U.S. Satellite, has a major grant from the National Eye Institute to conduct reviews and updates, offer education and training, and engage the eyes and vision practitioners in evidence-based healthcare.
- The Prostatic Disease and Urologic Cancers Review Group has been unable to obtain funding and is threatened with closing.
- The Complementary Medicine field has been supported by grants from the NIH.
- The Justice Health field is a new Cochrane group and has start-up support from a variety of sources, including the university where the group's convenor is located.
- WHO pays about \$15,000 per review that the Cochrane HIV/AIDS group does for them.
- Estimating the full effective cost of a Cochrane review is difficult. In addition to Review Group costs, there are the costs of other organizations in the Cochrane Collaboration (especially methods groups and Cochrane Centers) that provide different kinds of support. Much of the work is done by volunteers who are accomplished academics and whose time should thus arguably be valued highly. The overall effective cost is probably closer to \$100,000-\$200,000 (not including the costs of updating reviews) than \$15,000, according to the people in the meeting. The financial costs alone (excluding volunteer labor) are around \$70,000 per review according to GiveWell's estimate (based on the total costs of all the organizations in the Collaboration and the total reviews produced in 2011).
- Royalties from access to *The Cochrane Library* and to specific reviews are about 2.5 million British pounds per year. These funds are allocated by the Cochrane Steering Committee, and they are used for organization-wide (i.e., core infrastructure) needs, for example a central Editorial Unit that ensures standardization and quality of the reviews, information technology (e.g., the software that authors and editors use as they are working on reviews, website management), and the Central Operations Unit.
- Governments provide funding to Cochrane in cases when they are paying their citizens' healthcare costs and want to know what works the best. There is much less government funding for Cochrane in the U.S. than in countries with national healthcare systems. In the U.S., many funders, for instance the National Institutes of Health (NIH), are oriented around hypothesis-testing research and provide funds by disease topic; they don't fund infrastructure such as Cochrane geographic Centers, methods groups, etc. The National Library of Medicine has paid for special projects but not for infrastructure. A specific example of this is that the director of the U.S. Cochrane Center would like to receive funding for 95% of her time to work on Cochrane-related projects (she receives no funding for her U.S. Center work now).
- Countries in which Cochrane is best-funded by governments: UK, Australia and Canada. In all three countries, the funding for Cochrane is set aside in such a way that it does not compete with funding proposals for other types of science.
 - In the UK, Cochrane is funded through the National Institutes for Health Research (NIHR) from the research budget.
 - In Australia, Cochrane used to be funded through the Department of Health and Aging and then it was moved to National Health and Medical Research Council (NHMRC).
 - Canada had to create a new program for Cochrane funding because it didn't fit into the traditional funding mechanisms. Now the funding comes from the Canadian Institutes for Health Research (CIHR).
- Past funding sources for the U.S.-based HIV/AIDS review group
 - They have received some funding from the Centers for Disease Prevention and Control (CDC) in the past, mostly related to U.S. President's Emergency Plan for AIDS Relief (PEPFAR), as well as the state of California and a few local foundations (the Kaiser Family

Foundation is one of them). Department for International Development in the UK (DFID) has funded a few reviews in the past, and the government of Brazil has also provided some funding.

- USAID has had a problematic relationship in funding universities, because there's a clause attached to USAID funding which says that USAID has pre-publication approval rights. Cochrane's HIV/AIDS group not received funding from USAID.
- Gates Foundation has not been interested in funding Cochrane activities in the past; its emphasis so far has been on funding "solutions" (e.g., new technologies) rather than ongoing infrastructure projects.
- Past funding sources for the U.S. Cochrane Center
 - The U.S. Cochrane Center has received conference grants from Agency for Healthcare Research and Quality (AHRQ); one grant was for 5 years (2002-2007 at \$500,000 per year) and one was for 3 years (2007-2010 at \$100,000 per year). The first grant also helped Consumers United for Evidence-based Healthcare (CUE) get started. These grants have now been discontinued.
- There was previously a sexually-transmitted diseases (STDs) group based in the U.S., but it couldn't get funding. It re-started in Brazil with the promise of funding there, but the funding was not delivered. Now this group is attempting to start in Colombia with some support from New Zealand.

Other groups doing systematic reviews:

- Agency for Healthcare Research and Quality (AHRQ) has 14 Evidenced-based Practice Centers (EPCs) in the U.S. that do systematic reviews. These are mostly reviews that are important to an American doctor and other American stakeholders. Unlike Cochrane, the EPCs do not aim to keep their reviews updated with new research.
- The EPCs have their own manual on methods, and they have a parallel system to Cochrane's. Though there are a lot of the same people at both, there is not a lot of direct collaboration between the groups.

Review process:

- Authors (academic volunteers), working with editors, lead the process for suggesting review topics, writing reviews and then keeping them updated with new research. The process begins with authors registering the review title and describing the process (or "protocol") they will follow in completing the review, including the question that they will ask, the criteria for selecting studies to include in the systematic review, and so on. The editors review the author's submission and either accept the proposal, request changes, or reject the proposal. After the process for the review is announced and confirmed, the protocol outlining the proposed question and methods to be used in the review is published in *The Cochrane Library* and any changes made to the process (changing the selection criteria, etc) must be described clearly and published within the final review.
- The next stage of the review process is to identify relevant literature, abstract data, and synthesize evidence. There are "trials search coordinators" within each review group who provide advice on the search for relevant studies. At least two authors read and agree on studies that will be included in the review. If questions arise about particular studies, the Cochrane authors contact the authors of the specific studies. If Cochrane review authors find

studies questionable in some way, and these problems are not resolved, then the studies are not included in the review or they are included but the issues with them are noted. (This process of questioning studies and contacting authors about potential problems has uncovered fraud, flawed randomization schemes, and other problems.)

- Finally, authors use Revman software (created and made freely available to the general public by the Cochrane Collaboration) to enter data for use in the review and write the review; their editors work with them to check and revise the reviews.
- Individuals external to the Cochrane Collaboration are asked to review the systematic review and it is revised accordingly by the authors before the review is published in *The Cochrane Library*. This peer review step is handled by the Cochrane Review Group editorial team.
- As new research is done, the systematic reviews become dated and must be re-visited in order to stay up to date. Cochrane is committed to updating reviews; how often it is necessary to update a particular review depends on the new research that becomes available.

Cochrane Collaboration's impact:

- Special collections of high impact reviews can be found at: <http://www.thecochranelibrary.com/view/0/collections.html>
- A list of the "top ten Cochrane reviews" is here: <http://ccnc.cochrane.org/news/where%E2%80%99s-evidence-top-ten-list-cochrane-reviews>
- There are a couple different kinds of cases in which Cochrane Collaboration had an impact. One case is where there are high-quality studies showing that a particular practice is helpful/harmful, and yet practice is not in line with the evidence. There have been cases in which the Cochrane Collaboration published a systematic review showing that the total pool of evidence presents a strong case for a particular conclusion, a well-known organization such as NIH endorsed the systematic review), and this subsequently impacted practice.
 - One such case is the case of antenatal corticosteroids. In 1980s, 18 RCTs collectively implied that antenatal corticosteroids were an effective treatment for mothers who were at risk of giving prematurely. However, only a relatively small percentage (about 20%) of mothers who were at risk were given this treatment presumably because though the 18 RCTs collectively implied that the treatment is effective, no single RCT implied this entirely its own. The Cochrane review, which aggregated the evidence from the 18 RCTs, argued that the practice is effective and came out around 1992; NIH endorsed the review in 1995. There was an increase in usage of the treatment from around 20% to about 80% during the 1990s, with steep increases in usage corresponding roughly with the dates of the Cochrane review and the NIH endorsement.
 - Another case is that of postnatal steroids for infants. The Cochrane review on this treatment showed there was a significantly increased risk of cerebral palsy when it was used. After the Cochrane review was published, there was an American Association of Pediatrics endorsement of the review, and usage rates changed. We were given the slides summarizing this case, but we have not independently vetted their figures and calculations.
- Another kind of impact of Cochrane systematic reviews is highlighting the gaps where further research is needed. Cochrane told us that there have been further trials done on the basis of the need that meta-analysis has shown, including trials on Prophylactic Indomethacin, Vitamin A, Emollient Ointments, DART Trial, Inositol, caffeine. We have not yet requested or examined details of these cases.

Cochrane Collaboration's audience:

- Cochrane's audience is the public, patients, health professionals, policymakers, researchers, and health decision-makers globally. Cochrane representatives at the meeting named several healthcare groups that use its reviews as a major input into their guidelines, such as the National Institute for Health and Clinical Excellence (NICE) in the U.K. and professional associations such as the American Academy of Ophthalmology. WHO uses Cochrane HIV/AIDS reviews and reviews produced by a number of other groups (eg, Effective Practice and Organization of Care, Pregnancy and Childbirth, Infectious Diseases, Health Promotion) as a factor in determining its guidelines, and has also commissioned a large number of reviews.
- Cochrane reviews are the most-visited pages on the National Institute of Child Health and Human Development (NICHD) website
- *The Cochrane Library*
 - A search of The Cochrane Library took place every second; a Cochrane abstract was viewed every 2 seconds; a full text article was downloaded every 3 seconds. Data are from a [Freiburg presentation](#) in 2009, and usage has increased since then.
- Cochrane reviews are often cited in academic research papers, leading to a high "impact factor" (measured by number of citations to Cochrane reviews). *The Cochrane Library* is within the top 10 of general medical journals worldwide; in addition, the Neonatal group reviews' impact factor is #1 among journals in the field of pediatrics.
- Cochrane reviews are freely available to half the world's population through national licenses for internet users with in-country IP addresses, and all Cochrane review abstracts are freely available. Also, full reviews are available for free to the HINARI countries. The Cochrane Collaboration does not have data on the percent of its users that are experts vs. non-experts.

Room for more funding:

- Overall within Cochrane Collaboration, there are about 5,000 completed reviews and Cochrane estimated that 10,000-15,000 more reviews that they would like to complete.
- Opportunities for expansion of current status :
 - The Neonatal Group in the U.S. needs support to keep up with innovative methods - introduced/explored by the Cochrane methods groups - for use in its reviews, including diagnostic accuracy reviews, indirect comparison reviews and how to incorporate cluster trials. Support could be in the form of a centralized methodological infrastructure or hub (for example provided by the US Cochrane Center, see below).
 - The HIV/AIDS review group has several projects that it would do with further funding. It could use about \$300K per year. There are about 100 more reviews that it would like to complete. The cost for 5-6 more reviews is about \$300K, after which the marginal cost per review would be lower because the needed central costs (for editorial staff, etc.) would be covered. This group would also like to do more education of authors, outreach to authors, re-visiting prevention guidelines, training and more outreach education in Africa.

Currently, the director of the HIV/AIDS group does not have funding to attend annual Cochrane Colloquia (he has been to two of them in the last twenty years). He does not

have funding for other travel either; he will soon travel to Africa to do Cochrane . work with small amounts of funds from the South African Medical Research Council.

The Cochrane representatives attending also stressed that the HIV/AIDS group is particularly underfunded and will have to cut its managing editor if it does not raise more funding.

- The U.S. Cochrane Center’s funding priorities include support for existing U.S. review groups (including the HIV/AIDS group), potential creation of new review groups and satellites in the U.S. (there used to be four review groups in the U.S. and now there are only two; there is particular interest in a new Heart satellite), funding for a methods hub groups that would serve all review groups and provide authors with assistance on the methodology of reviews (eg, the Neonatal group’s expressed needs), increasing the Center’s contact with the public, hosting a conference for consumers, building IT infrastructure for systematic review data , and paying a full-time coordinator salary.

Representatives stressed that the U.S. Cochrane Center is particularly underfunded (other countries, with single-payer health care systems, tend to be more supportive of geographical Cochrane Centers). It will have to cut its only employee (the coordinator) if it does not raise more funding than expected. (The US Cochrane coordinator position is not funded at the current time and this employee is being covered on other projects until Fall 2012).

The Director of the U.S. Cochrane Center is not receiving any funding for this work, but she would like to receive funding for 95% of her time to spend solely on Cochrane-related work. In addition, there is currently no funding for the Associate Director.

The San Francisco Branch currently has no outside funding for its center duties. The Branch was originally formed with \$300,000 of funding from the Garfield Foundation for a specific project (criticism management) that has been completed. The Director of the SF Branch receives some institutional funding to support her time (approximately 20%), but the Branch lost its coordinator due to lack of funding 2 years ago. With funding, the San Francisco Branch would provide training and advocacy activities in the western region of the U.S., and would provide methodological support for use of “GRADE”, the method now used to summarize the evidence in tabular format.

Recommendations of people/groups for GiveWell to speak with :

- Agency for Healthcare and Research Quality (AHRQ)
- World Health Organization (WHO) – NIH/AIDS, Guidelines, Reproductive Health, Research Policy and Cooperation
- National Institutes of Health (NIH institutes that fund Cochrane such as NEI, NICHD, NCCAM, and those that do not such as NHLBI)
- The National Library of Medicine
- Veteran’s Administration Health Services R&D
- Kaiser Family Foundation
- Professional societies such as the American Academy of [Ophthalmology](#) and the American College of Radiology

- Academic librarians (who use Cochrane reviews), for instance the Medical Libraries Association
- Milbank Memorial Fund
- Alliance for Health Policy and Systems Research