The Cochrane Collaboration: Possible Areas of Support

Ideas for discussion with GiveWell

February 2013

The Cochrane Collaboration's vision is that healthcare decision-making throughout the world will be informed by high-quality, timely research evidence

INTRODUCTION

In December 2012 it was agreed that early in 2013 The Cochrane Collaboration would propose a range of planned initiatives and potential areas of support which GiveWell and its supporters could consider for financial support.

These areas are (in no order of preference):

- The production of high priority, high value Cochrane systematic reviews (Cochrane Reviews) through:
  - Investing in the production and use of Cochrane Reviews in the US
  - Supporting specific subjects for reviews
  - Supporting the development of the Collaboration's cutting edge 'Linked Data' project

- The development of increased capacity in low- and middle-income countries (LMICs) to produce Cochrane Reviews

- Supporting key advocacy & outreach goals of the Collaboration in the coming years, in particular:
  - Investing in the Collaboration's major new translation project designed to make Cochrane content more accessible to billions of people in their own languages
  - Supporting the growth of the Collaboration's advocacy work to ensure national and global health guidelines incorporate the best evidence from systematic reviews; and to help achieve more open access to clinical trial data to give researchers, clinicians and patients the information they need to inform health decision-making

SYSTEMATIC REVIEW PRODUCTION

a. Investment into boosting capacity in the US, for Cochrane needs globally

Systematic review production

The Collaboration could dramatically increase the number of Cochrane reviews and review authors through a strengthened US contribution to the production of its outputs. Investment in US Cochrane infrastructure in the past has led to increased review production and greater capacity globally. The US Cochrane Center's vision is to develop methodological 'hubs', strategically located around the US, and increase the number of review group satellites, so that its volunteer authors have a support system for

conducting Cochrane reviews. In the US, investment in a Cochrane Eyes and Vision Satellite by the National Institutes of Health (2002 to 2012) has resulted in a remarkable increase in US-based review authors, from eight to 150 in just 10 years, a nearly 20-fold increase. This increase is almost certainly related both to locating a new review group in a country where there was previously no locus of activity; and the availability of methodologists to assist the subject area specialists with their reviews. If the number of US-based review groups and satellites were to increase, the Collaboration is likely to enjoy a similar increase in US-based capacity to produce reviews on all topics.

The US Cochrane Center (USCC) can provide centralized methodological support for review authors, specifically on meta-analysis, creation of GRADE tables, incorporation of data from studies using special designs (e.g., cluster randomization), network meta-analysis (analysis comparing multiple interventions simultaneously), analysis of the accuracy of diagnostic tests, and informatics (e.g., identification of relevant research for the reviews; creation of standardized database functionality; and text mining approaches to streamline systematic reviews).

There are several components to being able to accomplish these goals:

- Increased training and education of review authors - approximately US$250,000 over three years will support the US Cochrane Center to provide education and training for review authors
- Establishing methodology 'hubs' to assist review authors - $1,000,000 over three years would provide methodological support teams for systematic review authors
- The creation of new satellite review groups in the US - such as an Effective Practice and Organization of Care satellite. With $250,000 we could provide start-up funds for up to eight review group satellites, helping them to attract new funding.

The US Center will also contribute Cochrane becoming even more patient-centered through its close involvement with the US coalition of consumer groups, Consumers United for Evidence-based Healthcare (CUE). With $200,000 over three years, the Center would provide consumer panels in all subject areas who could peer review protocols and completed reviews, contribute to lay summaries, and help to prioritize Cochrane reviews.

Development of increased capacity in Low and Middle Income Countries (LMICs) to produce systematic reviews

The US Cochrane Center is well placed to increase review production capacity in low- and middle-income countries (LMICs) by providing training fellowships in the US for promising review authors. Cochrane Centres, including the US Cochrane Center, have responsibility for assisting review authors and others from LMICs who wish to contribute. The USCC estimate that a LMICs Fellows program would cost about $65,000 per year per Fellow supported.

Partnerships with guidelines producers to ensure Cochrane reviews serve as the basis of their recommendations

The US Cochrane Center is already a strong partner with clinical practice guidelines producers worldwide, working with the Guidelines International Network (G-I-N). In many instances, for example eyes and vision, US guidelines serve as a starting place for region-specific recommendations, so that these partnerships benefit those outside the US. The Collaboration would like to establish a 'hub' specifically geared to ensuring that Cochrane reviews are available as needed to guidelines producers. The San Francisco Branch of the US Cochrane Center will take the lead on establishing a hub to work with WHO guideline development groups. We estimate that this work will require about $250,000 over three years.

b. Production of systematic reviews on high priority, high impact subjects

We have considered a range of high priority high impact subject areas in which we want to produce Cochrane Reviews. This is not intended to be an exclusive list, but demonstrates the breadth of scope of our 53 editorial groups.

The cost of each of these systematic reviews would be around $150,000 - $225,000 depending on the number of different interventions, what exists already and the complexity of the analysis.

Clinical Areas

- Interventions to improve nutrition in LMICs: Much attention from relief agencies has been directed towards emergency relief of malnutrition. Increasingly, there is a focus on promoting adequate nutrition in such areas
- Conduct reviews requested by WHO to support the development of WHO clinical practice guidelines and the Essential Medicines List
- Interventions aimed at reducing morbidity and mortality from non-communicable diseases (NCDs) in LMICs. There is an increasing awareness of the health problems caused by NCDs in such settings – in particular heart disease, diabetes and smoking related conditions such as COPD
- Interventions to prevent and/or treat hospital acquired infection (HAI): HAIs are a key cause of preventable morbidity and mortality in most health settings and their prevention and treatment are a key priority in most developed countries
- Interventions aimed at improving the health of severely injured members of the armed forces returning from conflict areas
- Interventions aimed at improving the diagnosis of malaria and Tuberculosis in community settings
- Interventions aimed at improving oral health

Public Health

- Interventions aimed at reducing the health impact of poverty

- Interventions aimed at restoring health and health systems following natural catastrophe or conflict

Effective Care and Health Promotion

- Interventions aimed at promoting self care: As health budgets become increasingly constrained world-wide, there is an increasing focus in encouraging interventions that maintain health and prevent illness. Promoting self care is a key aspect of this, aimed at increasing patient autonomy and self reliance

Bias

- Interventions aimed at reducing the distortion that can affect the results of systematic reviews as a consequence of publication and selective outcome reporting bias

c. Linked Data

Cochrane systematic reviews are acknowledged to be the 'gold standard' in their field; and they contain complex and critical data which is vital in guiding effective healthcare decision-making. However, the reviews are difficult and complex to read, and much data which may have wider significance is 'locked in' to the specific review in which it sits. Users of Cochrane Reviews sometimes find it difficult to go through all of the hundreds of pages of text in single reviews; difficult to understand the figures, terminology, and other information within reviews; and hard to compare interventions without reading multiple reviews. This limits the accessibility, usage and usefulness of the reviews.

To address these problems, and to open the data within Cochrane Reviews so that it becomes much more powerful, the Collaboration has launched its 'Linked Data' project. The linked data approach allows the possibility for a machine (i.e., a computer program) to 'read' (really query) a web page or set of pages and return specific portions of interest to the user. Machines, however, aren't good at reading web pages because data on the web is meant for human consumption and machines need the data to be structured. The web is moving from a web of documents to a 'web of data'. At the moment the links on web pages are *between* documents but the data and content *within* web pages and in databases is largely devoid of any "meaning". The semantic web and linked data are a way to move toward a web of data that allows for more meaningful connections between things. When data is properly structured, information can be more easily shared within datasets and across web pages. For example, a semantic web standard called 'GoodRelations' uses linked data markup to enrich search results so that product details can be extracted and presented in search results including photos, price, user reviews and ratings and other information that the user can use to make their purchasing decision.

Linked data offers readers and users an incredibly powerful tool to search, highlight and use information from *The Cochrane Library* and many other key healthcare sources. Fortunately, Cochrane Reviews are structured so their data can be 'linked' together –

but we still need to 'teach' machines how to read them, where to find data within them and how the data is related.

Our experience with the Linked Data project to date has convinced us that it has potential to become an enabling technology for the Collaboration that could allow us to do more with our data. We have created an ontology, a semantic model, for Cochrane Reviews and studies (see: http://data.cochrane.org/ontologies/review/.) and are now testing this model to be sure the inferences it makes are consistent with Cochrane methods and that it can fulfill the use cases and thus the needs of our various end-users.

There will be many more steps after this testing has been completed in the final development of the technology, and the Linked Data project will be a multi-year investment by the Collaboration requiring more than $750,000 USD over the next three years.

CAPACITY BUILDING IN LMICs

Evidence syntheses are the foundation for informed decision-making by citizens, consumers, healthcare professionals, managers and policy-makers to improve the effectiveness and efficiency of healthcare and healthcare systems. They are used directly by decision-makers and to develop knowledge tools (e.g., patient decision aids, clinical practice guidelines, policy briefs) for all of these audiences. Evidence syntheses also help to identify future research needs of decision-makers; and building capacity to conduct evidence syntheses strengthens local health research capacity, helps identify local priorities, and can provide a vehicle for better linkages between researchers and local decision-makers.

The benefits of evidence syntheses are likely to be even greater in low- and middle-income countries (LMICs). However, there are currently insufficient evidence syntheses addressing the specific healthcare needs of decision-makers in LMICs, and often there is also insufficient capacity to conduct evidence syntheses in these countries. In addition, the methods of evidence synthesis for some types of evidence particularly relevant to health system issues in LMICs are lacking.

The Collaboration, as an organisation at the forefront of evidence-based healthcare efforts, and with many of its 28,000 members working in or from LMICs, is now addressing these problems directly through the launching of the *Cochrane Initiative to Build Global Capacity in Systematic Reviews* in economically developing countries. After a competitive tender process it has commissioned four centres to undertake initial training in evidence syntheses, assisted by some financial support from the American Institute for Research. The four centres are:

I. Pontificia Universidad Católica de Chile
II. South Asian Cochrane Network & Centre, India

III. Aga Khan University, Pakistan
IV. Stellenbosch University - South African Cochrane Centre, South Africa

Four other institutions submitted credible applications that would have been funded if resources had been available. In addition, the Canada's International Development Research Centre (IDRC) invited a funding application from one other institution (Makerere University, Uganda); and – through its Global Health Research Initiative - has just funded Cochrane to produce in the coming months an environmental scan to map evidence synthesis producers and users so that a more detailed plan can be established.

The Collaboration has taken a strategic decision to support this *Global Initiative* in the next five years with both human and financial resources. We are also building a coalition of organizations interested or already working in this area which includes The Campbell Collaboration, The Alliance for Health Systems and Policy Research (which has established four evidence synthesis centres to build capacity and conduct evidence syntheses relevant to health system decision-makers in LMICs), the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), and the International Initiative for Impact Evaluation (3ie).

A full strategic plan and multi-year budgets will be drawn up once the mapping exercise described above is completed, and the Collaboration would be looking for funders to support this work over the next decade through contributions on a regular or one-off basis. At least $750,000 USD is likely to be required over the first five years of the Cochrane project.

In addition, part of The Cochrane Collaboration's agreed work plan with the World Health Organization (WHO – see below) involves building capacity among WHO staff (both centrally and regionally) related to conducting and using Cochrane reviews. The San Francisco Branch of the US Cochrane Center will conduct two training workshops per year in WHO regions to build such capacity. These workshops for WHO regional staff will cost approximately $70,000 per workshop.

ADVOCACY & OUTREACH

a. Translation of Cochrane content

The Cochrane Collaboration believes its mission of informing healthcare decision-making around the world through the production and dissemination of high-quality timely research evidence is best served when there is the widest possible access to our products in ways that are simple and free of cost at the point of use. Indeed, 'promoting access … through strategic alliances, and by promoting appropriate prices, content and media to meet the needs of users worldwide' is one of the Collaboration's ten fundamental organizational principles.

More than half the world's population already has one-click access to Cochrane content including more than 5,300 Cochrane Reviews in *The Cochrane Library* through licenses or free access through the Collaboration's low- and middle- income countries access programme. In its new publishing contract with international publisher John Wiley & Sons Ltd, the Collaboration will make available all Cochrane Reviews and updates published from February 2013 to everyone free of charge and open access twelve months after publication.

However, for billions of non-English language speakers the immense resources of Cochrane Reviews and the data stored in the *Library* are largely closed to them because of the language the material is written in. Over the last few years the Collaboration has made significant efforts to expand the accessibility of the *Library* to non-English language speakers, and this now includes the following highlights:

- A strategic commitment to make Cochrane content available in at least the six official languages of the World Health Organization (Arabic, Chinese, English, French, Russian and Spanish)
- Non-English abstracts and plain-language summaries are included and appropriately signposted on the Collaboration's *Summaries* website (summaries.cochrane.org)
- It is now possible to browse the *Cochrane Summaries* site in multiple languages, including Chinese
- *La Biblioteca Cochrane Plus* (BCP) is an additional collection to *The Cochrane Library,* produced by the Iboamerican Cochrane Network and containing hundreds of the Collaboration's systematic reviews with full texts translated into Spanish and other exclusive databases in Spanish
- There are now over 2,000 French translations available on *Cochrane Summaries* with 600 more currently in progress
- The French Cochrane Centre has been researching and developing specialized machine translation software to improve accuracy levels and speed up the pace of translations into French
- Selected abstracts of systematic reviews from the *Library* have been translated into Portuguese by the Brazilian Cochrane Centre

However, much more still needs to be done to improve the accessibility of Cochrane Reviews to non-English language speakers. Therefore, at its 2012 Colloquium the Collaboration's Steering Group (Governing Board) identified translation of Cochrane content as a major priority for the organization and signalled its intention to invest in this area over the next five years. A scoping document that identifies the key strategic priorities and approaches the organization should adopt is being prepared and will be presented to the next major meeting of the Collaboration in Oxford, UK, in March 2013. It will consider translation options for:

- Cochrane Reviews (including abstracts, plain-language summaries, summary of findings tables, etc.)
- Podcasts and media releases
- Content on cochrane.org (Getting involved, About Us, impact stories, news features, blogs, policies, etc)
- Translation of trial reports (for use by review authors)
- Training materials (standard author training materials, online learning modules, etc)
- Guides and manuals (*Cochrane Handbook*, MECIR Standards, editorial resources and checklists, etc)
- Colloquia (content of website, simultaneous translation).

The details of this strategy will be known after this meeting, but the Collaboration needs additional financial resources to transform its vast content into languages which will help to transform usage across the world. It is anticipated that this strategic priority will demand at least $500,000 USD over the next five years.

b. Advocacy & Access to Clinical Data

The Collaboration has a unique position in the healthcare world in being widely admired for its independence of view, quality of output and integrity of approach. However, it has not always utilized this strong reputation to advocate systematically for policy change to support its mission (of improving healthcare decision-making by ensuring it is informed by high-quality, timely research evidence). The Collaboration has decided to build a stronger advocacy and profiling platform that will aim to influence national and international healthcare decision-makers; but it will require additional resources and the help of external partners and expertise to make this transition.

In 2011 the Collaboration was made an official partner of the World Health Organization, including a seat on the World Health Assembly, providing the organization an opportunity to promote evidence-based healthcare at the highest levels of international policy-making. In 2013 WHO reaffirmed this relationship, commending the Collaboration for "the continuing dedication of the organization … in support of the work of WHO". At the same time the Collaboration has expanded its efforts to support and influence the WHO's work on producing guidelines for national health systems around the world – to ensure that these are fully informed by the most accurate research data.

Significant progress has therefore been made through this partnership, but the Collaboration could achieve much more by engaging more intensely with WHO in these arenas and also through national government lobbying and campaigning. Support from external Collaboration partners and funders would help the organization begin to meet this challenge, in Geneva and around the world.

In addition, the Collaboration is playing a leading part in the growing international campaign to call on responsible bodies to ensure that all clinical trials (past and present), for all treatments, are registered, and that the full methods and the results are reported. A major breakthrough took place in December 2012 partly as a result of Cochrane's pressure when the European Medical Agency (EMA) announced that it would ensure the proactive publication of clinical trial data in Europe and promised to have a policy in place by January 2014.

Cochrane's role in the 'All Trials' and 'Open Data' campaign issues – including the highly-publicised struggle with Roche to publish all of the trials data linked to Oseltamivir (Tamiflu) - is central but the lack of its own campaign resources and expertise has limited its leadership possibilities: for more details see http://www.cochrane.org/news/tags/authors/sense-about-science-announces-alltrials-campaign-launch-and-petition and http://www.bmj.com/tamiflu. Support from GiveWell would therefore allow the Collaboration to expand its general advocacy work, and its leadership in these two specific campaigns, which – building on the successes already achieved – would transform the openness and transparency of trials data and the ability of policymakers, clinicians, researchers, academics and patients themselves to make informed judgements about healthcare.