Strategic Plan
2016-2020

Nordic Cochrane Centre
Contents

What is our overall aim? .................................................................................................................................. 3
The Cochrane Collaboration .......................................................................................................................... 3
The Nordic Cochrane Centre .......................................................................................................................... 4
Strategic plan 2016–2020 ................................................................................................................................ 4
  1. Research .................................................................................................................................................. 4
  2. Dissemination of research results and promoting access to them ......................................................... 7
  3. Associate Cochrane centres and Nordic review groups ....................................................................... 10
  4. Partnerships with other organisations .................................................................................................... 12
  5. Cochrane workshops and other courses .................................................................................................. 13
Advisory Board for the Nordic Cochrane Centre ......................................................................................... 14
Acknowledgements ........................................................................................................................................ 14
What is our overall aim?

The strategic plan for the Nordic Cochrane Centre has a broad perspective. Its overall aim is to help citizens, patients, health care professionals and the payers of health care services to choose - or to avoid to use - interventions rationally, in an evidence-based fashion, and with a focus on benefits, harms and costs. Our strategic plan encompasses the goals of the Cochrane Collaboration internationally as outlined in its “Strategy to 2020” and other documents, but goes beyond these. The goals in “Strategy to 2020” are:

**Goal 1: Producing evidence**
To produce high-quality, relevant, up-to-date systematic reviews and other synthesised research evidence to inform health decision making.

**Goal 2: Making our evidence accessible**
To make Cochrane evidence accessible and useful to everybody, everywhere in the world.

**Goal 3: Advocating for evidence**
To make Cochrane the ‘home of evidence’ to inform health decision making, build greater recognition of our work, and become the leading advocate for evidence-informed health care.

**Goal 4: Building an effective & sustainable organisation**
To be a diverse, inclusive and transparent international organisation that effectively harnesses the enthusiasm and skills of our contributors, is guided by our principles, governed accountably, managed efficiently and makes optimal use of its resources.

The Cochrane Collaboration

Updated systematic reviews of randomised clinical trials and other types of clinical research are essential for rational decision making in health care and for guiding the planning of new research. The Cochrane Collaboration is a registered charity, founded in 1993. It publishes the Cochrane Library, which contains more than 9,000 regularly updated systematic reviews of interventions in health care or protocols for such reviews. The Cochrane Collaboration engages close to 40,000 people in over 120 countries. Its organisational structure is described at [http://www.cochrane.org/](http://www.cochrane.org/).

It is a fundamental right that information that is important to the citizens is transparent and available. Few things are more important than having access to reliable information about the benefits and harms of interventions for preventing and treating diseases. Half of the world's population has free access to Cochrane reviews and the other half has free access to abstracts of Cochrane reviews. Our ultimate aim is to provide free access to Cochrane reviews for everyone; currently, our finances have allowed us to provide free access to all Cochrane reviews 12 months after they have been published or updated.
Cochrane reviews are indexed in PubMed. In 2015, the impact factor of the Cochrane Database of Systematic Reviews was 6.0.

The Nordic Cochrane Centre

The Nordic Cochrane Centre is a research and information centre that is part of the Cochrane Collaboration and is located at Rigshospitalet in Copenhagen (http://nordic.cochrane.org/). The Centre and the Cochrane Collaboration were established in October 1993. There are associate centres (until recently called branches) in Finland, Norway, Poland and Russia, and preparations are underway for opening an associate centre in Sweden. The associate centres perform similar work as the Centre, but have less formal obligations.

In addition to the centres, six Cochrane groups are based in the Nordic region: the Hepato-Biliary Group (Denmark), the Colorectal Cancer Group (Denmark), the Anaesthesia, Critical and Emergency Care Group (Denmark), the Work Group: Health & Safety at work (Finland), the Norwegian satellite of the Effective Practice and Organisation of Care Group (Norway), and the Bias Methods Group (Denmark).

The Nordic Cochrane Centre and the three review groups based in Denmark have received core funding from the Danish Government since 2001. Other funders are listed in the Annual Reports (http://nordic.cochrane.org/annual-reports).

The Nordic Cochrane Centre is internationally oriented. Over the years we have had employees from Armenia, Colombia, Denmark, the Faroe Islands, Finland, Germany, Iceland, India, Italy, Moldova, Nigeria, Norway, Pakistan, Spain, Sweden, the UK, and the USA. In addition, unpaid volunteers have helped us from China, Egypt, France, Japan, Netherlands, Poland, Portugal, and Russia.

Strategic plan 2016-2020

1. Research

Clinical research is the basis for clinical decisions and hundreds of thousands of randomised trials of health care interventions have been performed. However, many of them are biased by their design or analysis, and selective reporting of outcomes or of whole trials are also common. The biases are so prevalent that almost half the trials included in recent Cochrane reviews were considered to be at a high risk of bias.¹ There are other reasons why published trial reports are often misleading. Trials are often short-term, even for interventions that are used for decades in some patients, and important harms have often been left out, even when they were deadly. This

state of affairs leads to much unnecessary and harmful treatment of patients and to a huge waste, particularly in drug expenditure. It also leads to an undue and wasteful focus on pharmacological interventions compared to effective and safer non-pharmacological interventions.

Therefore, for a given or potential health problem, it is often uncertain which intervention is best or whether it would be best to do nothing. Cochrane reviews are generally more thoroughly done and more reliable than other systematic reviews, and they reduce the uncertainty and bias and lead to better decisions about health care interventions than if we didn’t have them. However, users of Cochrane reviews need to be aware that they are too positive, on average, because of the pervasive flaws in biomedical research and publication, which can only partly be corrected for.

For these reasons, we will prioritise research that aims at elucidating sources of bias in clinical research. We will quantify these in order to reduce their influence and systematic reviews will continue to be highly prioritised.

Our aspiration has always been to produce research of high quality that makes a difference for many people and that may serve as setting a standard for other researchers. We believe we have succeeded quite well with this, as evidenced for example by our 26 publications during 2011-2015 in the big five general medical journals (BMJ, the Lancet, JAMA, Annals of Internal Medicine and New England Journal of Medicine) and the many news stories internationally our research leads to.

The part of our research that focuses on unpublished clinical study reports will continue. In 2010, the Nordic Cochrane Centre set an important precedent. After three years of struggle, which involved a complaint to the European Ombudsman, we succeeded as the first in the world to get access to unpublished clinical study reports and their corresponding protocols at the European Medicines Agency (EMA). This led to a complete reversal of the EMA’s long tradition of secrecy into a policy of openness. However, there have also been set-backs where the EMA has denied access to study reports or have redacted information of vital importance for the needs of independent researchers. We will therefore continue our efforts to help ensure that all results of clinical research, the corresponding trial protocols and all separate agreements between researchers and sponsors, the raw anonymised patient level data, and animal toxicology studies become publicly available. This is absolutely fundamental.

The fight for open science, human rights and respect for the patients without whose altruistic contribution to research there wouldn’t be any data, is a never ending battle. If science cannot be checked or repeated by others, independently from those who did the original research, science ceases to exist.

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Areas we will focus on in particular

One of the most problematic areas in health care is psychiatry. Psychiatric drugs are being prescribed far too much and often in a non-evidence based fashion, although they have many harms. They lead to many deaths and permanently physically and psychologically crippled patients due to development of irreversible brain damage, both of which could have been avoided. Our research in this area aims at providing a more reliable evidence base and it includes clinical study reports we have obtained from the EMA. We and others have demonstrated that not even the voluminous clinical study reports that drug companies submit to drug agencies for obtaining marketing approval for their drugs are reliable, but tend to downplay or omit major harms of drugs.

We will also do systematic reviews of animal studies, as long-term harms are poorly elucidated in human studies.

We will perform systematic reviews of methods to withdraw psychiatric drugs safely, as there is very little knowledge in this crucially important area despite the fact that millions of patients have become dependent on these drugs, and don’t know how to get off them and often get little or no help from their doctors.

We will continue our methodological research aimed at improving the reliability of clinical and observational research and of Cochrane reviews. This work includes assessment of contemporary trial protocols, in order to elucidate if trials are ethically justifiable given what was known or could have been known if a systematic review of previous trials had been carried out. It will also elucidate whether the information offered to the patients corresponds to what was known, particularly in relation to the harms of the studied interventions. We expect that this research will lead to better understanding of the necessity of referring to or conducting systematic reviews when new trials are being planned.

We will continue our work on guidelines for good reporting of research when these are updated. These are:
- CONSORT for randomised trials
- STROBE for observational studies
- PRISMA for systematic reviews
- SPIRIT for trial protocols.

We will continue our research on screening, particularly related to cancer, and will continue to perform commissioned systematic reviews for policy-makers. Two such commissioned reviews have proved to be of great importance. The Danish National Board of Health requested in 1999 that we assess mammography screening and later funded our Cochrane review on this, and the

\(^3\) Gøtzsche PC. Deadly psychiatry and organised denial. Copenhagen: People’s Press; 2015.

Danish Parliament asked us in 2008 to assess alpha-1 antitrypsin for treatment of patients with lung disease who have this enzyme deficiency, which we also converted into a Cochrane review. A third Cochrane review of great importance was not requested by policy-makers, but was our own initiative, as there was a pressing need to assess the effects of general health checks. These three reviews have saved over 500 mio Danish crowns annually for Danish taxpayers, which is about 100 times our annual budget (see our Annual Report 2015 and Review at http://nordic.cochrane.org/annual-reports).

Employees of the Nordic Cochrane Centre are authors of 17 Cochrane reviews published in 11 different Cochrane review groups. We will update these as appropriate and will undertake additional reviews of importance for public health.

2. Dissemination of research results and promoting access to them
Dissemination of research results is perhaps even more important than producing them because pivotal results are often unknown to clinicians and policy-makers. This work should not be undertaken lightly and it requires some degree of quality control, since so many original research results and therefore also systematic reviews of such results exaggerate the benefits of interventions and underestimate their harms.

Citizens in Denmark, Iceland, Norway and Poland, and almost all physicians in Finland, have free Internet access to the Cochrane Library. Cochrane reviews are being widely used; in 2015, there were 308,839 downloads from the Cochrane Library in Denmark, Norway, Sweden and Finland.

In Denmark, the national subscription was replaced in early 2007 by local subscriptions at hospitals, universities and other institutions and organisations. It was believed that very few non-professionals used the Cochrane Library, but this belief proved to be wrong. The Nordic Cochrane Centre received numerous complaints about the new arrangement from people who could not get access to the Cochrane Library. Complaints were also addressed to leading health politicians and there were questions in Parliament. The Minister of Health declared two months later that he would investigate the possibilities to remedy the problem, but it took two years and a good deal of lobbying by the Nordic Cochrane Centre before the national subscription was re-established.

The limited access had a dramatic impact on the usage of the Cochrane Library in Denmark. The number of full-text downloads dropped by 46% from 2006 to 2007, whereas it increased in Norway in the same period by 42%.

In Sweden, people had access till 2012, but subsequently, the Swedish HTA institute (SBU) did not renew the national subscription. Subscriptions to the Cochrane Library in Sweden are therefore now local. However, this arrangement is more expensive than a national subscription, and it

strongly limits the citizens’ access to Cochrane reviews, which is not in the public interest. We will therefore work on getting the national subscription re-established in Sweden.

Cochrane reviews are being widely cited in the Nordic area, and we prioritise knowledge translation (which means providing information in a more easily understandable format than reviews). In the Danish Infomedia database, “Cochrane” appeared 544 times in 2015, of which 33 were in national newspapers. The list is not complete, however. For example, there were 9 appearances in radio or TV, which is far below the number of times researchers at the Centre appeared on national radio or TV.

Our Centre is known for producing high-quality research and we have no financial conflicts of interest and strive to avoid other types of conflicts of interest. We are contacted by journalists virtually every day, from many different countries, as it can be difficult for journalists to find knowledgeable people in health care with no conflicts of interest. The problem is so pervasive that two American journalists in 2008 in a bid to disentangle commercial messages from science compiled a list of around 100 independent medical experts that reporters can turn to, which included the Nordic Cochrane Centre’s director.7

We take great care not to be interviewed about issues we know little about. Apart from rather obvious cases, we therefore do not provide specific comments on research, unless we have had an opportunity to assess its reliability ourselves.

We write many newspaper articles and letters to the editors in scientific journals, and upload comments on PubMed abstracts when we find that published research of importance for patients is seriously misleading.

Dissemination of research results to the public

Our approach to dissemination has so far been mostly reactive, but we are gradually becoming more proactive in order to disseminate important research information more effectively to the public.

In 2012, we updated our information leaflet to women to help them better decide in an evidence-based fashion whether they want to go to mammography screening. The official information given to women in all countries is of low quality, seriously biased, and persuasive in nature. We published our own leaflet for the first time in the BMJ in 2006 in a paper where we criticised the official UK leaflet quite substantially.8 Voluntees in many countries have found it valuable and have translated it into 15 languages (see http://nordic.cochrane.org/mammography-screening-leaflet), and our persistent criticism of national leaflets has led to important changes.

Other examples of providing information to the public are three evidence-based books published in 2012, 2013 and 2015, about mammography screening, the drug industry and psychiatry, respectively, which have generated wide interest.\textsuperscript{9} \textsuperscript{10} \textsuperscript{11} The two most recent books have been translated into many languages including small language areas such as Danish, Dutch, Finnish and Swedish.

The general public has a very low confidence in the drug industry. Many people therefore have a keen interest in being guided about the benefits and harms of drugs and about which types of drugs it would be prudent to avoid taking. We see the books as important contributions to the goals of the Cochrane Collaboration, as they help the citizens make more informed decisions about the drugs they are being offered by their physicians, who rarely know much about drugs that go beyond what the drug industry has told them. This is an important reason why prescription drugs are the third leading cause of death after heart disease and cancer, and why psychiatric drugs also seem to be a major cause of death. We must therefore do our utmost to reduce drug consumption in our societies. One way to do this is to inform our citizens that drugs are far more dangerous than they think they are and very often don’t have the benefits they are supposed to have.

Journalists are also aware of these issues, and after the publication of these books, the Centre’s director has been contacted by over 50 TV crews and filmmakers and has participated in over 20 radio shows and numerous news broadcasts in more than 15 countries. The Centre’s deputy director is also often in the media. Dissemination via the media, particularly in TV documentaries, can be highly effective as it reaches so many people. We will therefore consider, also in future, writing books or booklets about health care interventions.

In 2016, we employed a communication specialist who helps us with:

- responding to requests for information from patients and professionals
- developing our website into a more lively and interactive one
- writing or translating press releases
- arranging Cochrane workshops, meetings, PhD courses and symposia
- maintaining e-mail lists and address directories for Cochrane contributors and research collaborators
- investigating whether it would be worthwhile to use social media
- monitoring journalist contacts and their interests, and press coverage
- assisting in literature searches, screening of abstracts and other research tasks

\textsuperscript{11} Gøtzsche PC. Deadly psychiatry and organised denial. Copenhagen: People’s Press; 2015.
Cochrane policies and the public we serve

Although the Cochrane Collaboration is an evidence-based organisation, decisions are sometimes made without looking for, or respecting, the evidence. We also tend to be too much inward-looking when we make Cochrane policies. We need to ask more often what the public we serve wants. If, for example, we asked the public whether they are happy that our current policy allows up to half of the authors on a Cochrane review to have financial conflicts of interest in relation to a drug company whose product is being evaluated, it is pretty clear what the answer would be. We will therefore work on getting acceptance that we need to rewrite our commercial sponsorship policy so that it will no longer allow such authors on Cochrane reviews. More generally, we will work on ensuring that Cochrane policies serve the public’s needs and wishes as closely as possible.

3. Associate Cochrane centres and Nordic review groups

The production of Cochrane reviews in a country is related to whether or not the country hosts a Cochrane centre or affiliated centre, or Cochrane review groups (which are responsible for the editorial processing of reviews and therefore have a similar function as more traditional medical journals).

Countries that established a Cochrane presence early have a larger review production per 1 million inhabitants. This is particularly clear in the Nordic area were the review production is very high. Measured as number of Cochrane reviews per million inhabitants, Denmark was ranked 6, Norway 10 and Finland 11 in the world in 2010. The chronology for Cochrane presence in the Nordic area is:

1993 Nordic Cochrane Centre (Denmark)
1996 Cochrane Hepato-Biliary Group (Denmark)
1996 Placebo Methods Group (Denmark; disbanded in 2001)
1997 Norwegian Branch of the Nordic Cochrane Centre
1997 Finnish Branch of the Nordic Cochrane Centre
1998 Cochrane Colorectal Cancer Group (Denmark)
1999 Russian Branch of the Nordic Cochrane Centre (Russia; deregistered in 2007)
1999 Non-Randomised Studies Methods Group (Denmark; transferred to the UK in 2002)
2000 Cochrane Anaesthesia, Critical and Emergency Care Group (Denmark)
2003 Methodology Review Group (Norway; transferred to the UK in 2009)
2006 Norwegian Satellite of the Cochrane Effective Practice and Organisation of Care Group
2010 Cochrane Work Group: Health & Safety at work (Finland)
2015 Polish Branch of the Nordic Cochrane Centre
2015 Russian Branch of the Nordic Cochrane Centre (Tatarstan)
2016 Cochrane Bias Methods Group (Denmark; transferred from Canada 1 January 2016)

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Referring again to our review production in 2010, in issue 1, 2011 of The Cochrane Library, 128 reviews and 58 protocols were listed with a contact address in the countries for which the Nordic Cochrane Centre was responsible:

<table>
<thead>
<tr>
<th>Country</th>
<th>Reviews</th>
<th>Protocols</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>66</td>
<td>31</td>
</tr>
<tr>
<td>Norway</td>
<td>28</td>
<td>11</td>
</tr>
<tr>
<td>Finland</td>
<td>24</td>
<td>9</td>
</tr>
<tr>
<td>Sweden</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Russia</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Poland</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

The five Nordic Countries have quite similar research traditions, and Denmark, Finland and Sweden produce about the same number of randomised trials per million inhabitants. The very small production of Cochrane reviews in Sweden, which is the biggest Nordic country, is therefore striking. It may not only be related to the absence of Cochrane groups, but also to the strong tradition Sweden has for health technology assessment, which has involved many specialists in its work who see this as their primary task, rather than producing Cochrane reviews. We have tried for many years to establish a Cochrane presence in Sweden and it is very likely that this will happen soon, in the form of an associate centre in Lund. There are now more Cochrane reviews with a Swedish contact address than in 2011, but this is mainly because an Italian doctor moved to Sweden and took the reviews he had produced in Italy with him. He is first author on more Cochrane reviews than the total of all other Cochrane reviews with a Swedish contact address.

We will explore the possibilities to work more closely with the associate centres for mutual benefit, e.g. in writing strategic plans and arranging international workshops and symposia. We will monitor the performance of these centres through their annual reports.

We will also help get more satellites of existing Cochrane review groups established. As the work in these groups expands constantly, it can be of great value to establish satellites in other countries. Spreading the activities will have the additional advantage of making the Cochrane Collaboration less vulnerable to unfortunate funding decisions, which may potentially affect all Cochrane groups in a country.

An important task for a centre is to resolve conflicts, e.g. between authors and editors or between Cochrane groups and central Cochrane management. We have over the years resolved numerous such conflicts and have brought some of the cases to the Cochrane funding or publication arbiters. We will continue to help when needed.

Another task is to support review groups. We will continue to hold semi-annual meetings with the editors of the review groups based in Denmark where, among other things, we discuss avenues for funding.
4. Partnerships with other organisations

In Denmark, it has always been respected and highly valued that the Nordic Cochrane Centre is completely independent of any political interests and institutions, and has full academic freedom to criticise anything we feel merits critique, even procedures at the hospital that hosts the centre.

Informal strategic partnerships with other organisations can be highly valuable. If partnerships are being formalised, however, they can sometimes turn out be counter-productive. Formalised collaboration inevitably leads to increased bureaucracy in the form of working out mutually satisfactory agreements, which may involve protracted and burdensome negotiations with lawyers on both sides, and may involve regular meetings and exchange of information, which may always not be productive.

Formal partnerships can be a threat to academic freedom, not only when they involve the pharmaceutical and device industries, which the Cochrane Collaboration does not allow, but also when public institutions are involved. As an example, described in detail in our book on mammography screening, the Nordic Cochrane Centre entered a collaborative agreement with the newly established Danish Institute for Health Technology Assessment (HTA) in 1998, which provided important funding for our Centre. However, the institute tried - quite obviously for political reasons - to interfere inappropriately with the Centre’s ongoing Cochrane review on mammography screening, which the institute had funded. According to Cochrane policy, it is not allowed for a funder to interfere with the scientific process.

We have also had good experiences with formal partnerships. More recently, we established a fruitful partnership with the Danish National Board of Health. A PhD from our Centre who had studied bias in systematic reviews was employed full-time at the Board of Health to help with the production of evidence-based national guidelines. The deputy director of our Centre was employed two days a week as a methods consultant on the guidelines.

In 2012, we published a Cochrane review showing that general health checks do not reduce morbidity or mortality, whereas they increase the number of new diagnoses and therefore are likely to be harmful. Our review led the Danish Minister of Health to cancel her plans about introducing health checks in Denmark, whereas the reaction in the UK, which already had them, was completely different. The National Health Service (NHS) had claimed that health checks were evidence based and effective. However, after our review, a Department of Health representative told BBC that the NHS Health Check programme was based on “expert guidance” and referred to observational studies that based their conclusions on surrogate outcomes, which are highly unreliable in this context. Although the intervention doesn’t work, the “NHS Health Check

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programme is currently part of the health delivery infrastructure in England, so NICE seeks to support its effective delivery.” This illustrates the potential danger of formal partnerships. NICE ought to be an independent HTA institute, but it seems that it is not allowed to come to its own conclusions when a political decision has been made.

We prefer to avoid entering into formal partnerships with other organisations in order to maintain our full academic freedom, which allows us to choose from case to case to establish informal partnerships with no strings attached if we find it useful for the Cochrane Collaboration or for our other activities. The informal partnerships are often valuable in terms of feeding back to us what the most pressing needs are, not only in terms of which reviews need to be done or updated but also related to more general issues such as increased transparency and data sharing in health care research.

We collaborate informally with many people and institutions all over the world and are active members of some of them. These include independent patient organisations, consumer organisations and other bodies, e.g. the Trans Atlantic Consumer Dialogue, the International Society of Drug Bulletins, Council for Evidence-based Psychiatry (UK), Critical Psychiatry Network (UK), International Institute for Psychiatric Drug Withdrawal, and the AllTrials campaign.

We also collaborate with the European ombudsman and members of the European and other parliaments; have given talks in four different parliaments and have been invited to Congressional hearings in the United States. As explained in our 2014 Annual Report, the Centre’s director is active at the political level in the European Parliament as a scientific lobbyist. Helped by the various informal partnerships that were not tightly bound by any particular political fractions, the EU Parliament succeeded in changing the European Commission's proposed revision of the Clinical Trials Directive completely, from being pretty poor and maintaining the secrecy around drug trial results to ensuring that clinical trials data became both accessible and transparent. In 2016, members of the EU Parliament tried to get the Centre’s director elected for a vacant post at the Management Board of the European Medicines Agency, but a political majority pointed at another candidate, an MEP.

5. Cochrane workshops and other courses

For many years, we have offered four Cochrane workshops annually, two for protocols and two for review completion. We also offer people to get advice over the phone, in writing or at one-to-one meetings, and we hold workshops in other countries if there are a sufficient number of people with registered review titles or with data for a review, most recently to support the establishment of the associate centres in Poland and Russia.

We have conducted a series of PhD courses of relevance for the production and understanding of Cochrane reviews and of the principles for evidence-based medicine and plan to conduct more such courses, and also courses on how to get safely off psychiatric drugs, which is difficult for many patients because they have become addicted to the drugs.
Advisory Board for the Nordic Cochrane Centre

The Advisory Board for the Nordic Cochrane Centre provides advice and support about the strategic direction for activities within the Centre. The members are:

Douglas Altman, Professor of Statistics in Medicine, Oxford, UK
Gerd Antes, Director, German Cochrane Centre
Mike Clarke, former Director, UK Cochrane Centre
Sine Jensen, Senior Health Adviser, Danish Consumer Council
Cindy Mulrow, Editor, Annals of Internal Medicine
Maryann Napoli, Associate Director, Center for Medical Consumers, USA
Drummond Rennie, Editor, JAMA
David Tovey, Editor-in-Chief, the Cochrane Collaboration
Erick Turner, Department of Psychiatry, Oregon Health & Science University

Acknowledgements

The Cochrane Collaboration is registered as a charity and it is the responsibility of all contributors and groups to secure their own funding. The staff at the Nordic Cochrane Centre are grateful for the financial support received from our funders and the voluntary help received from many people and institutions since the Centre was founded in 1993 (see Annual Reports and Strategic Plans on [http://nordic.cochrane.org/](http://nordic.cochrane.org/)). Currently, the funders for the Centre or its projects are:

- Danish Government
- Laura and John Arnold Foundation
- University of Copenhagen