

# History of Cochrane Sweden

23 February 2016

PhD student Minna Johansson and Professor Bertil Marklund, Göteborg:  
"AllTrials-kampanjen och varför vi behöver Cochrane i Sverige" (Läkartidningen)

Senior Consultant in Neonatology, Matteo Bruschetti, MD, PhD, University of Lund, contacted Minna, and asked on 14 April the Director of the Nordic Cochrane Centre in Copenhagen, Peter Gøtzsche, whether it would be possible to establish a Swedish branch of the Nordic Cochrane Centre. Matteo visited Peter, and Peter informed people with a Swedish address in Cochrane's address manager software (Archie) on 12 May, that he had started investigating the possibility of establishing a Swedish branch of the Nordic Cochrane Centre in Lund, and asked if they were interested in helping out with these preparations or in becoming involved. In just four days, 30 people replied positively.

# History of Cochrane Sweden

27 June 2016, Exploratory meeting in Lund (16 participants). Major issues:

- Acceptance of systematic reviews as research.
- Cochrane Sweden could do reviews for SBU. SBU reviews not always of high quality. Former director did not believe in meta-analysis. Structure very top down.
- Cochrane Sweden should be the natural first counsellor in healthcare matters.
- Important that everyone is free to criticise anyone in a position of authority, even within the same institution.
- Cochrane Sweden could help the National Board of Health make guidelines.
- Dissemination (knowledge translation in Cochrane jargon): high visibility in the society, collaborate with journalists and newspapers. Trustworthy experts.

# History of Cochrane Sweden

27 June 2016, Exploratory meeting in Lund (16 participants).

Important issues for Cochrane Sweden would be amongst others:

- to support the Swedish universities to include reviews in PhD theses
- to support free access to the Cochrane Library through a national subscription
- to establish workshops on protocol writing
- to ensure an impact of Cochrane Sweden at national level
- to write research articles in Läkartidningen and elsewhere
- to write letters critical of published research, SBU reports or national guidelines

Minna: After I had submitted our article to Läkartidningen, the editors deleted some critical comments we had written about the SBU.

# History of Cochrane Sweden

## Matteo's many reviews, 2014 versus 2016

Country	Reviews	Protocols
DENMARK	86	48
NORWAY	37	14
FINLAND	31	5
SWEDEN	7	8
RUSSIA	4	0
POLAND	3	6
Total	168	81

Country	Reviews	Protocols
DENMARK	96	54
NORWAY	43	15
FINLAND	31	6
SWEDEN	20	8
POLAND	4	7
RUSSIA	4	0
Total	198	90

■ Ett engagemang för en svensk Cochrane-gren skulle gynna forskning och vård i rätt riktning. Det skriver medarbetare vid Karolinska Institutet och Karolinska Universitetssjukhuset i ett debattinlägg.

■ Cochrane tar ställning för att beslut inom hälso- och sjukvård ska vara grundade i bästa tillgängliga evidens och därför borde forskare och kliniker i Sverige bidra på fler fronter.

# Upprop för välgrundad forskning och vård!

**Marie Kanstrup**, legitimerad psykolog, funktionsområde medicinsk psykologi, Karolinska Universitetssjukhuset, och doktorand vid institutionen för klinisk neurovetenskap, KI, och Nationella forskarskolan i vårdvetenskap

**Klas Moberg, Susanne Gustafsson och Carl Gornitzki**, bibliotekarier specialiserade på systematiska översikter, universitetsbiblioteket, KI

**Gustav Nilsson**, med dr, forskare vid institutionen för klinisk neurovetenskap, KI, samt vid Stressforskningsinstitutet, Stockholms universitet

**Maria Rosaria Galanti**, adjungerad professor i epidemiologi, institutionen för folkhälsovetenskap, KI

**MOT BAKGRUND AV DE UTMANINGAR** Karolinska Institutet och Karolinska Universitetssjukhuset står inför uppmanar vi:

**1 FORSKARE OCH KLINIKER** att engagera sig i Cochrane-samarbetet. Om medel delges etableras en svensk Cochrane-gren vid Lunds universitet, som kan samordna initiativ från hela landet.

**2 KAROLINSKA INSTITUTET** och Karolinska Universitetssjukhuset att ta en aktiv roll för att stödja forskning som sammanställer och granskar evidensläget i klinisk relevanta frågor.

**3 KAROLINSKA INSTITUTET ATT PRIORITERA** öppna data och andra öppna forskningspraktiker för att stärka vetenskaplig excellens.

# Läkartidningen

DEBATT

## Så blir vi bättre på att delta i Cochranesamarbetet

Sverige är extremt dåligt på att bidra till Cochranebiblioteket. Det är dags för förbättring.



**Inge Axelsson**

barnläkare, professor i medicinsk vetenskap

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2016-12-10

Läkartidningen. 2016;113:ECW7

**DN Debatt**

# ***DN Debatt. "Höj kvaliteten på sjukvården med en satsning på Cochrane"***

**Inge Axelsson**, barnläkare, professor, Östersunds sjukhus och Mittuniversitetet

**Åsa Audulv**, sjuksköterska, fil dr, Mittuniversitetet

**Matteo Bruschetti**, barnläkare, med. dr, Skånes universitetssjukhus

**Katarina Hedin**, allmänläkare, docent, Region Kronoberg

**Minna Johansson**, ST-läkare i allmänmedicin, doktorand, Sahlgrenska akademien

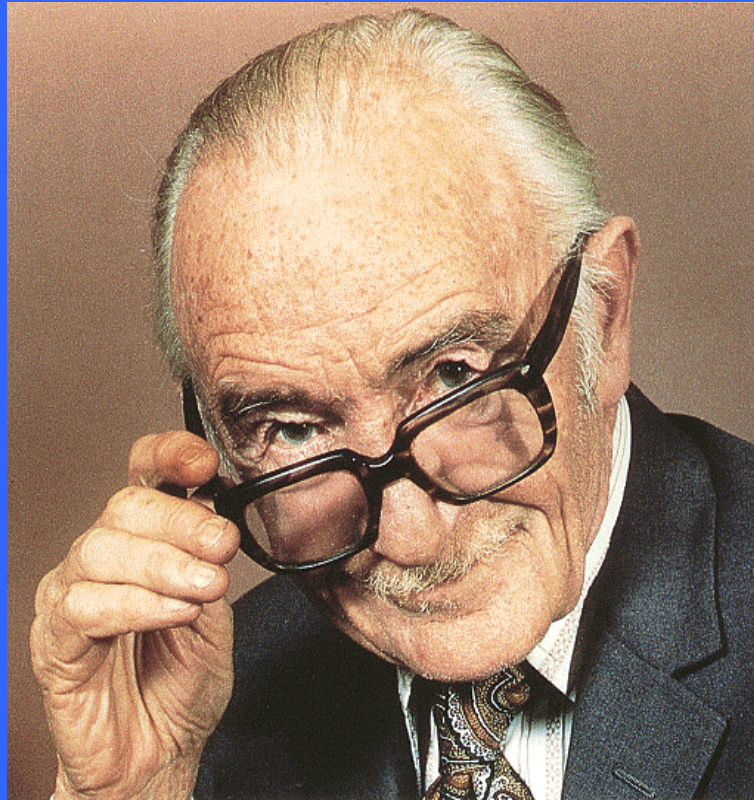
**Mia Tyrstrup**, allmänläkare, doktorand, Lunds universitet

DN 27 feb. 2017



**Evidensbaserad är i dag ett honnörsord. Trots det är Sveriges insats i att bidra till Cochranes medicinska översikter nästan obefintlig. Det finns troligen inga andra åtgärder som så effektivt skulle höja kvaliteten på svensk klinisk forskning och sjukvård som en satsning på Cochrane, skriver läkare och sjuksköterskor.**

- 1. Vetenskapsrådet och andra forskningsfinansiärer måste lämna sin negativa syn på systematiska översikter och istället stödja arbete med systematiska översikter och "Cochrane Sweden".**
- 2. De flesta kliniska doktorsavhandlingar bör börja med ett delarbete som är en systematisk översikt av forskningsområdet.**
- 3. SBU (Statens Beredning för medicinsk och social Utvärdering) bör ges anslag för att återuppta sin avbrutna nationella prenumeration på Cochrane så att det återigen kan nås från alla internetanslutna datorer i Sverige.**



# 1972 Effectiveness and Efficiency

Archie Cochrane (1909-1988) drew attention to our collective ignorance about the effects of health care

# 1976

Outline plans drafted in Cardiff, Wales, for systematic reviews of controlled trials in perinatal medicine

# 1979

“It is surely a great criticism of our profession that we have not organized a critical summary, by specialty or subspecialty, adapted periodically, of all relevant randomized controlled trials.”

(Archie Cochrane)

1989

Effective Care in Pregnancy and Childbirth

A Guide to Effective Care in Pregnancy and  
Childbirth

The Oxford Database of Perinatal Trials

# 1989-92

Systematic reviews of controlled trials of perinatal care in 6-monthly disk issues of an electronic journal:

The Oxford Database of Perinatal Trials

# October 1992

The Cochrane Centre opens in Oxford, UK

Pregnancy and Childbirth Group registered

Subfertility Group registered

# 1993

Neonatal Group (March)

Stroke Group (August)

Canadian Cochrane Center (August)



# October 1993

Launch of the Cochrane Collaboration  
1st Cochrane Colloquium, in Oxford, UK  
Cochrane Collaboration Steering Group  
Nordic Cochrane Centre  
Baltimore Cochrane Center  
Primary Health Care Field

# December 1993

Cochrane Centres in Europe start to identify reports of controlled trials in general health care journals (European Union funds, Dutch and Italian centres registered in 1994)

US National Library of Medicine agrees to retag MEDLINE records using information provided by the Cochrane Collaboration

May 1994

Cochrane Collaboration Handbook

Review Manager (RevMan) software

# October 1994

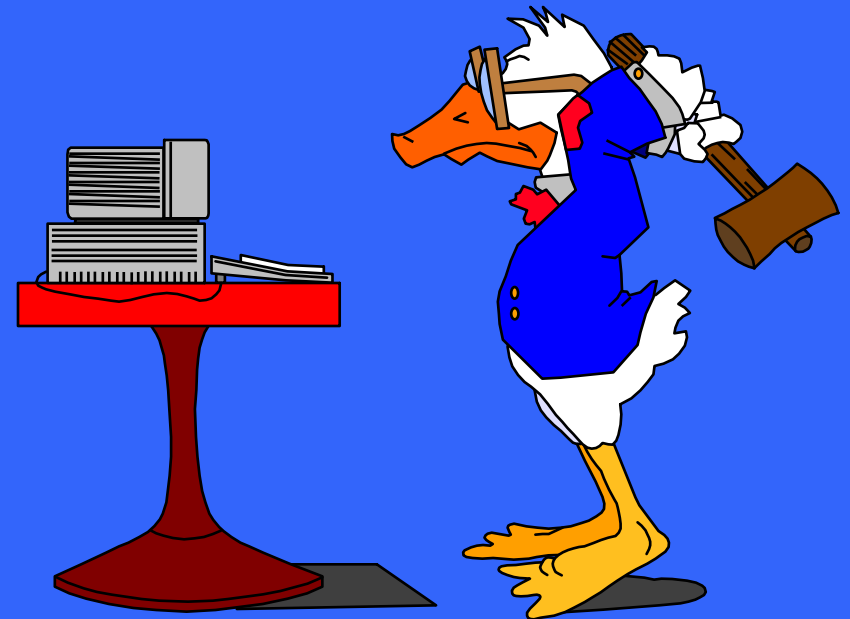
First public demonstration of The Cochrane Database of Systematic Reviews, designed by Update Software at 2nd Cochrane Colloquium, in Hamilton, Canada

December 1994

Empirical Methodological Studies  
Methods Group registered

# February 1995

## Software Development Group established



# April 1995

The Cochrane Database of Systematic Reviews launched in London by the English Minister for Health

# October 1995

Consumer Network registered  
3rd Cochrane Colloquium in Oslo:  
- growing uneasiness





No of Cochrane reviews have increased by 150%



Are we a business or a mission?

Scientific production or dissemination?



# April 1996

Cochrane Library launched by Update Software, quarterly publication on CD-ROM and disk:

Cochrane Database of Systematic Reviews

Database of Abstracts of Reviews of Effectiveness

Cochrane Controlled Trials Register

Cochrane Review Methodology Database

1996: Software development transferred to Copenhagen

# April 1997

Electronic Comments and Criticisms  
System launched within The Cochrane  
Database of Systematic Reviews

# June 1998

Academy of UK Medical Royal Colleges  
officially recognises systematic reviews as  
academically important research

# July 1999

Decision to establish the Campbell Collaboration - a sibling collaboration to the Cochrane Collaboration - to prepare, maintain and disseminate systematic reviews of social and educational interventions

November 1999

Non-Randomised Studies Methods  
Group registered  
based in Copenhagen

# 14 Cochrane centres in the world

Nordic Cochrane Centre is located in  
Copenhagen at Rigshospitalet

Funded by government

Associate centres in:

Norway, Finland, Poland, Russia and Sweden

# Cochrane review and methods groups

52 review groups in the world

> 7,000 researchers and others, > 9,000 reviews and protocols

Nordic area:

- Cochrane Hepato-Biliary Group (DK)
- Cochrane Colorectal Cancer Group (DK)
- Cochrane Anaesthesia, Critical and Emergency Care Group (DK)
- Cochrane Work Group: Health & Safety at work (SF)
- Norwegian Satellite of the Cochrane Effective Practice and Organisation of Care (EPOC) Group

Cochrane Bias Methods Group (DK)



# Academic recognition

Cochrane reviews by Gøtzsche published also in the big five (N Engl J Med, JAMA, Lancet, BMJ, Ann Intern Med):

Bleeding varices	BMJ
Antifungal agents	BMJ, JAMA
Corticosteroids for RA	BMJ
House dust mites	BMJ
Placebo	N Engl J Med
Screening mammography	Lancet, BMJ
Health checks	BMJ, JAMA

# Cochrane Database of Systematic Reviews

Impact factor: around 6.

Ranked 13 out of 153 in the Medicine,  
General & Internal category.

Kaiser Permanente (non-profit health care plan) regards Cochrane reviews as their primary "trusted source" when searching for the evidence

# Academic recognition

Why are most academics so obsessed about collecting new data, rather than trying to learn from the data we already have?



(Iain Chalmers, founder of the Cochrane Collaboration)

Ph.d. thesis, University of Copenhagen 2005

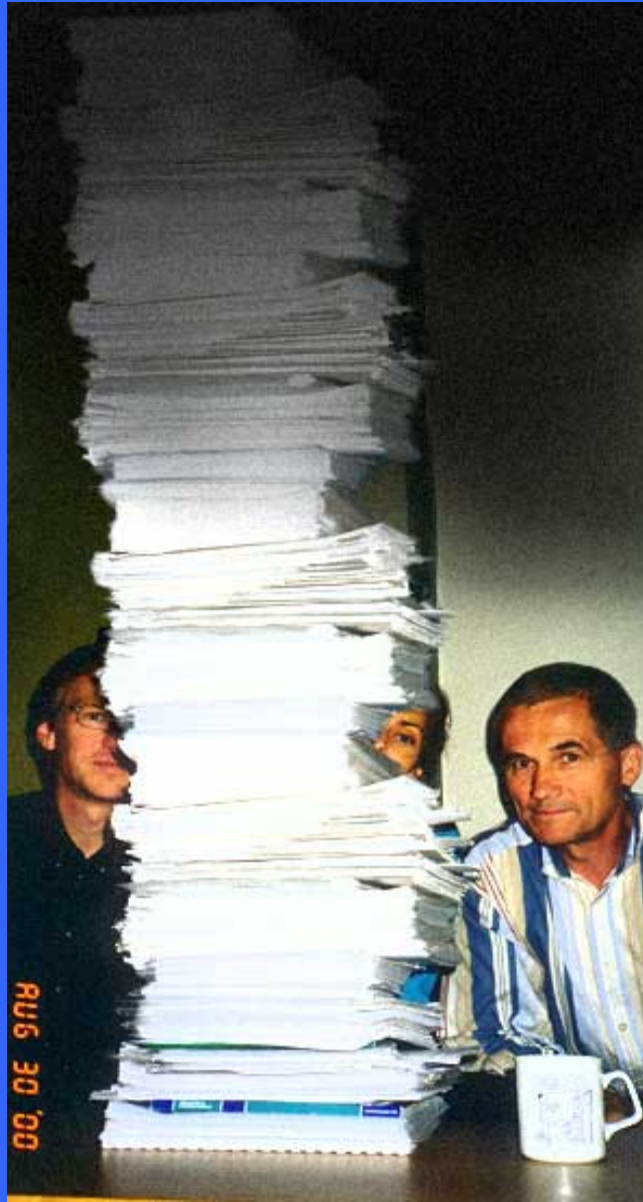
4 Cochrane reviews

# Effect of limiting subscription to health professionals

Number of full-text accesses (pdf or html)  
(April-Oct for Denmark, Jan-Oct for Norway):

	<u>Denmark</u> 		<u>Norway</u> 	
2005	16,676		26,266	
2006	23,431	+40.5%	35,287	+34.3%
2007	12,776	-45.5%	50,117	+42.0%

# Weight of the evidence



But where  
is the  
reliable  
evidence?



# Cochrane Sweden: getting involved

From the meeting in Lund in June 2016

Many people are obsessed with impact factors, but they should instead ask: In what ways have the research contributed to helping patients or save money?

“Annual Report 2015 and review” for the Nordic Cochrane Centre explains that just three of the centre’s systematic reviews have spared Danish taxpayers DKK 500 mio annually, or 100 times more than the centre’s annual budget (<http://nordic.cochrane.org/>)

In the near future, people who contribute to the Cochrane Collaboration could perhaps write under their name that they are members of the Cochrane Collaboration.

# New arrangements

Members are those who make a substantive contribution to Cochrane's work, e.g., peer reviewing, translating or authoring.

When someone achieves Member status they will be asked to agree to our terms and conditions of membership, which will state that Members should act in accordance with Cochrane's principles and policies, and that Cochrane reserves the right to withdraw member status should a member contravene this.

**Membership is time limited.**

People who work in the drug industry cannot become members or "supporters" (which is less than being a member)



# The goals in “Strategy to 2020”

*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.

# Possible contributions

- peer reviewer of protocols and reviews
- author of new Cochrane reviews or updates
- author of umbrella reviews
- fundraiser and lobbyist
- methodologist, quality improvement always needed
- establishment of Swedish satellites of review groups
- roles in the upcoming big review groups, senior editors needed
- handsearching journals have stopped in our area
- dissemination and knowledge translation
- raising well-founded criticism

# Krafttag krävs mot intellektuell bias

En högre vetenskaplig nivå samt krafttag mot intellektuell bias i expertgrupper är nödvändigt för att upprätthålla förtroendet för Socialstyrelsens rekommendationer.

I juni 2016 publicerade Socialstyrelsen en rekommendation om screening för bukaortaaneurysm [1]. Vi inkom med en rad invändningar mot det vetenskapliga innehållet i remissversionen [2]. Mindre ändringar gjordes i den slutliga rekommendationen [3], men i stort har våra invändningar inte bemötts.

Utredningen är tydligt vinklad för screening; evidens som talar för har genomgående presenterats på ett sätt som är tveksamt ur ett vetenskapligt och etiskt perspektiv och evidens som talar emot har systematiskt ignorerats.

# New arrangements

CRG: Cochrane review group

CRGs should be grouped into seven 'networks':

- Acute and emergency care
- Cancer
- Cardiovascular
- Brain and mind
- Long-term conditions and ageing
- Women, children, and families
- Organization of care and public health

Each of these networks will be led by a Senior Editor, who will receive funding support in order to contribute at least one day per week.

# Dissemination and knowledge translation

Norwegian centre very active in disseminating results from Cochrane reviews.

- How should we do this?
- If we recommend a review that others subsequently raise justified criticism against, we might lose some of our credibility.
- What if we don't know enough about the particular area?

Example from Cochrane Norway's Annual Report 2016:

## **Demenssscreening av personer over 65 år**

This review is about sensitivity and specificity.

But does screening for dementia do more good than harm? No!

Gøtzsche PC. Deadly psychiatry and organised denial. Copenhagen: People's Press; 2015.

<http://www.kunnskapssenteret.no/publikasjoner/demenssscreening-av-personer-over-65-ar>

# Dissemination and knowledge translation

## Social media

Useful but also problematic. Can be great time-consumers and people can be very rude, like when they drive a car.

Matteo is currently the only one who can send anything around on behalf of Cochrane Sweden and the only one who can use the logo for Cochrane Sweden.

# Cochrane Spokesperson Policy

Please note:

We have a strict Spokesperson Policy.

If you are expressing a view about Cochrane-related issues you should state clearly that you are speaking in a personal (or other professional) capacity unless you have been expressly authorized to represent Cochrane.

Cochrane contributors may sometimes be asked or wish to comment on published reviews. In doing so they can speak freely, including expressing views that are critical. However, the contributors should make clear that they are expressing personal opinions.

<http://community.cochrane.org/organizational-info/resources/policies/spokesperson-policy>

