



Members present: Hans Lund, Jennifer Yost, Karen Robinson, Peg Ford, Marlies Leenaars, Hanna Nykvist

1. **Short report from each participant – Peg** participated in a patient advocate panel at the Cancer Moonshot Summit in San Diego last month. In attendance were researchers, policymakers, industry CEO's and advocates. She mentioned EBR and it was well-received. She is invited to speak at the Cancer Centre Community Advisory Board of Sanford Burnham Prebys Medical Discovery Institute in February. On March 19th she is attending and participating as chair of the first panel discussion titled, "Have we made a difference? Progress in patient/consumer engagement in healthcare decision-making," of CUEs (Consumers United for Evidence-based Healthcare) regional meeting in New York. Immediately following she will be attending Guidelines International Network/North America (G-I-N/NA) Evidence-Based Guidelines Affecting Policy, Practice and Stakeholders (EGAPPS III) Conference.
Karen has been approached by a PhD student who is identifying research gaps. She is already a member of the EBRNetwork.
Hans is supervising a PhD student who wants to do a study of EBR and the patient involvement procedure. Next week there is a meeting in a Danish network where they aim is to set a research agenda for rehabilitation that should be based on patient involvement and the EBR approach. Hans will present the result from the systematic review (Paper #1) and other systematic reviews on patient involvement to identify knowledge gaps and uncertainties.
Marlies has a contact in the Netherlands who wants to get patients involved in research. Amongst other things they have trainings for patients to get involved. She will email contact information to all in the Steering Group.
2.
 - a. We have sent an email to all members asking them to tell us a bit about who they are and why they joined the EBRN. 32% replied. Hanna will also extract info from the emails that have been sent by members previously. Once we have a clear overview of our members Hanna will send the information to all in the Steering Group.
 - b. The JCE editorial group is established. It is made up of Klara Brunnhuber, Karen Robinson, Donna Ciliska, Carsten Juhl and Hans Lund. They had a meeting last week and made some suggestions for how 3 of the first 4 papers could be designed. The Steering Group will get the synopsis before it is sent to Peter Tugwell for approval. One approach for the Background and Discussion papers is to make a systematic analysis of what all various reporting guidelines (PRISMA, CONSORT) suggest for content and outline. Hopefully, we will come up with suggestions of what to follow and what to elaborate on.
 - c. The Editorial Group has a face-to-face meeting in Bergen on April 2 – 4th. It is financed by Western Norway University of Applied Sciences (previously Bergen University College).
 - d. No update on the comment in PubMed.
 - e. We have set up a Facebook Group and everyone needs to try and get people to the page. Any ideas for posts should be sent to Hanna or Peg.
 - f. We will wait to get a LinkedIn account as we are already quite busy with our other social media channels. Will contact members to see if anyone can help.



g. Application to become a partner will be made online from our website. Every two weeks Hanna will prepare a list of potential partners to be voted on by the Steering Group (majority rules). The ones that are approved will have to sign a partnership policy document. This document is almost done and will be sent to the Steering Group for approval next week.

h. Hanna has written a short text about EBR and the consumer perspective based on the discussion in Bergen in November.

3. REWARD + Cochrane Price – A way to get money for our work. Send out

3. **REWARD + Cochrane Price** – We will apply. Hans will send out the criteria and other relevant information.

4. **COST application** – Hans has had a meeting with a Danish organization who are able to help with the COST Application. They will charge between \$8,500 – \$14,200, and expect a bonus if the application is successful. Western Norway University of Applied Sciences might be able to finance it. The organization has not worked with COST applications specifically, but are familiar with EU application procedures.

5. **Future meetings** – Jenny suggested WebEx and we will try that for the next meeting. Hans and Hanna will also look into other possibilities. They will also see if we can set up a common 'project place' where we can gather documents etc. relevant for the Steering Group.

6. **AOCB – Paper #1** - Caroline have been through the reference lists and identified 15-20 new studies. Hans have been doing some analysis so far all articles indicate that no one is really evidence-based. They are not using a systematic approach when doing the background or discussion.

Patient paper – the newsletter on consumer perspective is a starting point for the patients article. Another issue to add was raised by Hans. He is part of a Danish EBR research group where they discussed the issue of patient involvement and what the researchers expect from involving patients. It must be made clear that the EBRNetwork are not advocating to involve patients in the formulation of research questions to get a better *effect* but because the research is more likely to be relevant. Hans also knows a number of people who would like to be part of the paper. He will email the names.