



Members present: Hans Lund, Caroline Blaine, Jennifer Yost, Hanna Nykvist, Karen Robinson, Mona Nasser, Klara Brunnhuber

1. **Standard text** – we suggest the following text to be used on our website, Wikipedia etc. We only decided on the order of the key tasks and will discuss the text at our next meeting.

The Evidence-Based Research Network aims to promote:

- *No new research studies without prior systematic review of existing evidence*
- *Efficient production, updating, and accessibility of systematic reviews*

To undertake research without systematically considering what has been done before is unethical, unscientific, and wasteful. New studies should be informed by systematic reviews as to the most appropriate design and methods. Even when presenting new results these should be placed in context by incorporating them in a systematic review of similar earlier studies.

In order to raise awareness of this, we define “Evidence-Based Research” (EBR) as the use of prior research in a systematic and transparent way to inform a new study so that it is answering questions that matter in a valid, efficient and accessible manner.

To meet our aims, we have identified the following key tasks:

- *Development and testing of methods to be evidence based in research*
 - *Collaboration with patients*
 - *Collaboration with other key stakeholders*
 - *Development of Methods to Improve Efficiency Producing and Updating Systematic Reviews*
 - *Monitor the execution of research*
2. **Replacement for Peg** – Peg will unfortunately leave the Steering Group and we will try and find another patient advocate to replace her. We will start by asking Peg for her recommendations.
 3. **AOCB** – next meeting August 16th 17.00 – 18.00 CET