

Patients and clinicians involvement in a systematic review: A Norwegian experience

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Background: The Regional Knowledge Translation Centre in Oslo commissioned a group of patient representatives, clinicians, and researchers (N=9) to conduct a systematic review on effects of cancer rehabilitation.

Objectives: To involve patient representatives, clinicians and researchers in the development of a systematic review about the effects of multidisciplinary psychosocial interventions in cancer patients, and to prioritize the need of further research.

Methods: We gave four workshops over 18 months to support patients, clinicians and researchers. On the first workshop, the topic was general information on how to write a systematic review, how to pose a research question and how to set selection criteria. We reached consensus by discussions on e-mail. The second workshop focused on literature search and selection of articles. The third workshop focused on assessing risk of bias, meta-analyses, and GRADE. At the fourth workshop, the participants discussed the results and prioritized the need of further research. Prior to each workshop, the participants were send written material about the workshop's topic. Each workshop included an introduction of the topic, hands on exercises, small group and plenary discussions. All group members were offered financial compensation for attending the workshops including preparation and were invited to participate as co-authors of the article.

Results: The project group decided on the research question, selection criteria, commented on search strategy and the results, and the need for further research. Of importance, the patient representatives gave valuable perspectives on the choice of intervention and outcomes, the interpretation of the results and the need of further research. One patient representative and two researchers participated as co-authors of the submitted systematic review. They participated in selecting studies, assessing the risk of bias and judging the quality of evidence, as well as commenting the manuscript. In addition to the four workshops, they joined regular meetings focusing on conducting the systematic review.

Conclusions: Through education, small group discussions, hands on exercises, and available written material, patient representatives, clinicians, and researchers contributed in a patient-focused systematic review and prioritized the need of further research.

Patient or healthcare consumer involvement: Systematic reviews on effects of cancer rehabilitation are important to patients and patient organisations who are advocating for better follow-up of cancer survivors. To be given a chance to participate in this systematic review was an unique learning experience. However, to become a success, it requires a project leader with a genuine interest in including patients' perspectives and experience in teaching systematic reviews. The patient representatives need to be highly motivated to participate as a co-author, as conducting a systematic review is a challenging and time-consuming activity. Patient involvement in systematic reviews contributes to better evidence and better health decisions.