

ECRS

Workshop II

Workshop title: Patient and public involvement in research (PPI-R) – Why, what, when and how?

Organized by: Beverley Lim Høeg, PhD & Pernille Envold Bidstrup, PhD (Working group for PPI-R, Danish Cancer Society Research Center)

Description:

Patient and public involvement in research is becoming increasingly prioritized by funders and journals. This workshop is for anyone interested in learning more about PPI-R, how it can help your research and the challenges you need to prepare for. We'll go through the latest developments in PPI-R, including a brief review of the benefits and challenges of PPI-R. We'll present different examples of PPI-R and you'll hear from a patient that has been involved in helping researchers develop research materials and methods. Finally, there will be a facilitated roundtable discussion of participant cases of PPI-R issues (e.g. how to involve patients in my project? How do we develop a culture for including patients in research in our clinic or department?) where mutual ideas and feedback will be provided on how to implement PPI-R and gain useful patient input.

Learning objectives:

The attendee shall be able to:

1. gain an overview of PPI-R and its current status;
2. understand the benefits and challenges of PPI-R;
3. Implement different ways of involving the patient's perspective in research projects.

Target Audience:

Healthcare researchers and professionals who wish to learn more about PPI-R, so that it can be implemented in their research proposals and grant applications.

Description of presenters:

Beverley Lim Høeg is a psychologist and post-doctoral researcher in the Psychological Aspects of Cancer research group at the Danish Cancer Society Research Center (DCRC). She has been co-coordinator of the patient and public involvement in research (PPI-R) panel at the DCRC since 2019 and has also carried out research on PPI-R. She has experience involving patients in the development of research protocols and materials for clinical trials.

Her research areas include the psychosocial aspects of cancer, the development and validation of patient-reported outcomes (PROs), health literacy, caregiver issues and grief and bereavement.

Pernille Bidstrup is a psychologist, associate professor and heading the Psychological Aspects of Cancer research group at DCRC. She has extensive experience with designing and managing research projects on physical and psychological late effects of cancer in the cancer clinic where patient involvement has become an integral part throughout the project design, implementation and evaluation phases. She has also contributed to developing the PPI-R panel at the DCRC and to integrate this as part of the different patient involvement activities at the Danish Cancer Society.