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CONFERENCE ABSTRACT

Sharing our perspectives makes the difference - The co-creation of a PhD project with patients and relatives.

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Globally, focus on user involvement in health research has increased substantially. In Denmark, it is still at an early stage with individual researchers being met with increasing demands without having much experience, guidance, or good practices to act upon. We are a group of researchers affiliated with User Perspectives and Community-based Interventions at the University of Southern Denmark (SD) and the Center for Research with Patients and Relatives (ForSa-P) at the Odense University Hospital (OUH). We work with patients and relatives in several aspects of our work – research and teaching; we share our experiences and learning in a joint session.

This presentation describes our experiences of co-creating a PhD project with a patient partner panel and our findings.

Our goal was to create knowledge on how to engage in research partnerships for PRs and researchers within the health care setting. The PhD contains a review of the literature on health research partnerships, an ethnographic study using interviews, observations and document analysis and a future Delphi study on evaluative frameworks. 5 patients and relatives (the panel) have been involved from the beginning defining the focus with the PhD student, collecting and analysing data, and disseminating findings. We do not consider user involvement a methodology, but rather a philosophy where sharing different perspectives can improve future health research and help our understanding of how to co-design and integrate care with the people needing it.

In the review the panel highlighted aspects they found important and have a section in the review dedicated to their impressions. Together we found that decision-making within research partnerships rests largely with researchers, hence involvement happens on researchers' terms. When PRs where co-authors of papers, they were more often considered partners. PRs report substantial benefits of being involved such as gaining new knowledge and skills – which can support their own engagement in the management of their condition. The review dissemination (still ongoing) will include several outlets aimed at a broad audience.

The ethnographic study (spring 22- summer 23) will further our understanding of supportive structural and personal mechanisms within research partnerships.

Our work in the panel shows that a PhD-collaboration between PRs and a PhD student is feasible, creates new knowledge for the parties involved, creates a joint focus, and ensures the final products incorporate different perspectives. We have encountered several structural challenges in our preliminary data and from our personal experiences of working together as partners, which are necessary to address to support inclusive way of working with people as partners in the health care system. To ensure the user perspective in broad health care we must be aware that involvement approaches require extra time, flexibility, support and focus on relationships.

The findings from our studies and our experiences can help our understanding of how to create partnership with PRs – which is relevant not only in the research setting, but also in a care setting where these partnerships could be key to reach sustainable integrated care.