
CONFERENCE ABSTRACT

Patient and relative partnerships at the Center for Research with Patients and Relatives at Odense University Hospital: building a research unit for and with patients and relatives

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Globally, the 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 (SDU) 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.

Research for and with patients and relatives, or actively involving patients and relatives in all parts of the research process; it is the first of five goals in the 2021-2025 research strategy of OUH and SDU. The strategic document states that: good research will be based on existing knowledge and be strengthened by the patients' own experiences of their illnesses and life situations.

The first action was to establish a center for patients, relatives and researchers to support a culture shift towards patient-oriented collaborative health research and generate knowledge on collaborative health research practices.

The research center ForSa-P opened in January 2022 and embodies co-productive values: 1) patients and relatives have an integral role in the center, with the Center being headed by an academic and patient lead; and 2) all types of knowledge are valued, used and produced. We consider 'involvement' a way of being, not a research method. The Center supports researchers and patients to develop a fruitful and sustainable collaboration and we build a research programme focused on understanding the dynamics of these partnerships and their effect on the research produced and the people involved.

Using a speed-date method, all 44 hospital departments reflected on their collaborations with patients and relatives, and how they plan to work towards 'more active involvement of patients and relatives in all steps of the research process by 2025'. This yielded an in-depth overview of collaborative practices across different departments and different types of research, good practices as well as concerns and limitations. We gained a better understanding of researchers' and patients' questions in relation to collaborative health research, which were translated in researchable

questions on patient involvement (what is a 'good patient' according to a researcher seeking a patient-partner, what is a professional patient and do they contribute differently?).

The research center developed a code of conduct to guide patients and researchers in building partnerships. The center's staff visited several departments to discuss the topic of patient involvement and introduce the code of conduct. In November, patients, relatives and researchers of the research center presented their work at the hospital's annual research week; for the first time, the event was open (and free) to patients and relatives to attend.

In this presentation we reflect on our mission and vision and our achievements one year after the launch of the research center, and two years in the strategic plan 2021-2025.