Co-development of a value-based Code of Conduct: Patients, relatives and researchers working together to create guidelines for meaningful involvement in health research.

Introduction: Coproduced health research where researchers invite patients and relatives to join the research process is gaining momentum in Denmark. Yet, concerns over the lack of practical guidelines or ethical requirements readily applicable in a local Danish context have been voiced in the health research community. Unethical involvement needs to be addressed; and creating value-based guidelines endorsed by all partners embarking onto coproduced research in Denmark could be a first step. The VIP project (Values in Inclusion of Patients and relatives) applied an innovative collaborative method (theme 3) to establish shared values and visions (pillar 1) for coproduced research in Denmark.

Aims and Methods: Aim: To co-design a value-based Code of Conduct for coproduced research with patients and researchers at a Danish university hospital. The Code is a tool to be applied to individual projects or research units, creating conditions to ensure meaningful involvement and full partnership.

Methods: One patient/relative, a PhD student and two researchers planned and organized the project with focus on an equal relationship throughout. The Code of Conduct was co-developed by patients, relatives and researchers via online workshops (due to Covid-19) and a physical event using the World Café method. Practical values and principles which should be guiding the coproduction process were debated as grounds for creating the Code. Participating patients, relatives and researchers were part of the final wording of the document.

Key Findings: Discussing values together and translating them into practical actions was a new exercise for patients and researchers and resulted in greater mutual understanding of values and research ethics. The World Café workshop proved an innovative and enabling way of leveling power indifferences when working together.

A core set of values were equally endorsed by patients and researchers: Thorough organization of the involvement, ensuring clarity of contributions, trust, respect and recognizing different types of knowledge.

Other values of shared power, reciprocity and inherent rights of inclusion, which in the involvement and co-production literature are key, lacked support from the participants. These findings merit
exploring cultural differences in how to do and what to expect from coproduced research. Participants expressed the exercise ignited further reflection to bring back to research units- and projects, hopefully kick-starting a meaningful process of coproduction.

Conclusions: Hospital staff and patients creating a set of core values together resulted in practical guidance on a good research partnership and triggered an ethical debate amongst participants. The next step is to evaluate whether applying the set of values leads to coproduced and ethical research - which all stakeholders as well as research outcomes are known to benefit from.

Implications for applicability/transferability, sustainability and limitations.

The Code is generic and holds values important to both researchers, patients and relatives. It is limited to local use, but future research will confirm its feasibility as a guiding tool at other hospitals in Denmark. Use of the Code in future research will hopefully impact the modalities of coproduction as well as study results. A follow up evaluation is planned.