Methods An interactive, qualitative design is used. Experiences from patients/next-of-kin in NSK working groups are explored using interviews. A deductive content analysis is used to analyze data where the findings are related to Carman’s model; describing patient involvement at different levels; organizational design and governance and policy making with a continuum of engagement (consultation, involvement and partnership and shared leadership). Persons with own experience are included in the research group. We collaborate with patient organizations and different groups within the NSK.

Results We present preliminary results since the study is ongoing. Patient and next-of-kin representatives experience that they have been fully accepted as participants in the national groups by the healthcare professionals. They express that their suggestions and lived experience have been appreciated and incorporated during the process of producing clinical pathways. Also, they express that they have been properly introduced to their assignment. Being more than one representative in a group is experienced as favorable. From the narratives, it is clear that different perspectives are presented depending on whether the representative come from a patient organization or not.

Discussion The value of patient participation is still under debate. Some professionals doubt that the patient perspective will bring something new to the table and consider themselves as advocating the patient perspective.

We address the experience of participating in national groups connected to the NSK and the prerequisites for a successful patient participation.

REFERENCES