The health research system has generated an enormous amount of knowledge and innovation that has allowed many to live longer, fuller lives. However, there are concerns about the supply-driven characteristic, in the sense that research is driven by the interests of researchers. It is expected that patient participation in health research will improve the relevance and quality of health research as the experiential knowledge of patients can complement the scientific knowledge of researchers. Giving patients a more active role in health research could lead to a system innovation towards a more needs-oriented system.

This thesis mainly focuses on two different approaches whereby researchers and patients collaborate: patient participation in health research agenda setting and patient participation in the conduct of health research. It argues that patients are capable to articulate their needs for health research in a facilitated process when attention is paid to inclusion strategies and the broader context of patients’ life. Important facilitators for patient participation in the conduct of health research are open-mindedness, willingness to experiment and learn, recognizing the fact that it takes joint efforts and regular dialogues to build structural relationships, being proactive and motivated. Furthermore, it is important that both researchers as patients are supported in their collaboration.