



**Patient Participation from the Patient's Preferences,  
that's what Counts**

av

**Kristina Luhr**

**Akademisk avhandling**

Avhandling för medicine doktorsexamen i hälso- och  
vårdvetenskap,  
som kommer att försvaras offentligt  
fredagen den 4 maj 2018 kl. 09.00,  
Prismahuset Hörsal 1, Örebro universitet

Opponent: Docent Åsa Muntlin Athlin  
Institutionen för medicinska vetenskaper, Uppsala universitet

Örebro universitet  
Institutionen för hälsovetenskaper  
701 82 ÖREBRO

## Abstract

Kristina Luhr (2018): Patient participation from the patient's preferences, that's what counts. Örebro Studies in Care Sciences nr 74.

Patient participation is a core element in legislation in most western countries today. From the patient's perspective, patient participation includes respect, equality, sharing of knowledge, joint planning, and self-management. However, participation is not always experienced, and the patient's experiences and preferences are seldom mapped.

The general aim of this thesis was to enhance the knowledge on patient participation from the preferences of patients with long-term conditions in outpatient healthcare by evaluating a measure (The Patient Preferences for Patient Participation: the 4Ps) on patient participation and by investigating a self-management programme's impact on patient participation.

Qualitative evaluations of the 4Ps included Think Aloud interviews with patient experts (n = 11) and research experts (n = 10) in Study I. Psychometric evaluations were performed in Study II (n = 108) and after amendments in Study III (n = 150). Effects of the self-management programme on patient participation were investigated in a randomised controlled trial with the 4Ps as the outcome measure in Study III (n = 118), and in Study IV were influences investigated qualitatively in nine focus group interviews (n = 36).

The 4Ps was found to be sufficiently valid and reliable. As measured with the 4Ps, patients with long-term conditions had both set preferences in and experiences of patient participation, regardless of randomised to a self-management programme or not. Qualitatively the programme was found to include patient participation and to influence self-management.

The use of diverse methods was beneficial and complementary. The sufficiently valid and reliable 4Ps can fill the gap of a measure to map preferences for and experiences of patient participation. Patients with long-term conditions have set preferences for participation. The self-management programme can be applied to influence participation and future responsibilities.

*Keywords:* Patient Participation, Patient Preferences, Measure, Content Analysis, Psychometric Evaluations, Self-Management, Long-Term Conditions

Kristina Luhr, School of Health and Sciences, Örebro University, SE-701 82 Örebro, Sweden, kristina.luhr@oru.se