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## Lessons for optimalization of patient participation in guideline development

Lia van der Ham, Jacqueline Broerse, Saskia van Veen  
*Vrije Universiteit, Amsterdam, Netherlands*

Active patient participation in guideline development is an emerging phenomenon. Arguments for patient participation are enhancement of legitimacy of decision making and increased quality and relevance of the results. However, patient participation in guideline development is methodologically still in an early stage of development.

Several initiatives are undertaken, but systematic reflections and scientific publications on this topic are limited. Patient participation requires additional resources, while evidence on the effectiveness is still lacking. To gain more insight in methods and conditions that enhance the effectiveness of patient participation, an exploratory study was conducted on the current practice of patient participation in guideline development particularly in the Netherlands.

A literature study took place and semi-structured interviews (n = 46) were conducted among patient representatives, specialists and other parties involved in guideline development. They were identified by studying guideline reports and through the snowball method.

The results show that in the Netherlands, patient participation currently takes place in most multidisciplinary guideline development trajectories. The methods mostly used are the inclusion of a patient (representative) in guideline development committees, and consultation of patients through focus groups and/or questionnaires.

The results indicate that effectiveness of current initiatives, amongst others, seems to depend on characteristics related to the disease, the level of professionalization of the patient organization, and the attitude of involved professionals. Many conditions have to be fulfilled particularly if patients are to effectively participate in guideline development committees.

Among respondents there was no consensus on the most effective form of patient participation in guideline development. It is generally recommended to include patients from the initial phase of guideline development; formulating the key questions is often considered to be the most important stage of involvement.

Various recommendations are made; largely based on the Dutch situation and implications might be different in other contexts.