PATIENT PARTICIPATION IN RHEUMATOLOGY RESEARCH

A four level responsive evaluation

Maarten de Wit
We live in a society where developments in health care happen so quickly that it can be hard for people to keep up. There is a growing awareness in many organizations that greater transparency is desirable and that patients and their representatives should play an important role in decision-making processes, to prevent people from losing control over their lives and becoming dependent on health care providers, researchers, (pharmaceutical) industry, government and health insurers. Innovation and quality improvement in health care are not possible without recourse to the everyday experiences and knowledge of patients. Only they are able to identify the practical and existential questions that they have to face, and what they expect of the health care system. Patient organizations therefore advocate greater involvement of all stakeholders and encourage patient participation at all levels.

In this thesis, Maarten de Wit (1961) explores how patients and researchers can create conditions for an open and meaningful dialogue in which both groups have equal opportunities to provide their own knowledge and perspectives, leading to enhanced mutual understanding and a change of research practices in the field of rheumatology. He has 35 years experience of living with a rheumatic disease and has been actively involved for over a decade as a collaborative partner in the development of scientific research. In this book he presents four case studies in which patients work together with researchers at four different levels: Local, National, European and International. Each case study introduces unique findings about factors that contribute to the success or failure of patient participation in scientific research. The author hopes that these findings will inspire and support researchers and research partners in pursuit of a more patient-oriented health care system.