

## Colofon

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Cover painting: Hans Heijmans, 2013 ([www.hansheijman.nl](http://www.hansheijman.nl)). This painting on canvas is called *De dialoog*. The background shows a bridge as a symbol for the role of the patient researcher trying to facilitate the dialogue between patients and researchers. It is not just a bridge, it is the bridge of Zaltbommel. The painting is made by the local artist Hans Heijmans. Zaltbommel is also the place where this thesis has been written.

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**Promotoren:** prof.dr. T.A. Abma  
prof.dr. J.R. Kirwan

*In memory of*  
**David Magnusson**  
*(1953-2013)*

*Vice-chair of the Swedish Arthritis Patient Organisation*

*Chair of the EULAR standing committee of PARE*

*Member of the OMERACT patient panel*

*Soul mate*

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## PREFACE

### **Becoming a go-between**

When I was diagnosed with psoriasis, at the age of 15, I was ignorant about any impact of the disease on my future life. It meant the start of a journey through the world of ineffective treatments prescribed by my dermatologist. Two years later a swollen knee prevented me from doing sports, cycling and, in the end, walking. I visited a long list of health professionals without any success. Although I had a vague suspicion of arthritis, my dermatologist persisted in the belief that arthritis symptoms never start in the larger joints. It was only when I was 23, that an orthopaedic surgeon referred me to a rheumatologist for the first time. She confirmed the diagnosis of psoriatic arthritis within three weeks. At that time the deterioration of the knee made treatment with local corticosteroids unsuitable. An open synovectomy was the only option left. Finally, after ten years, I underwent a total knee replacement at the age of 35.

Looking back I realize that a lot has changed over the last decades, not in the least my role and attitude as a patient. My identity of a naïve and dependent person transformed into that of an informed and autonomous partner, proactively involved in the management of my own disease. Even more: into a researcher, trying to improve arthritis health care on the basis of the concepts of dialogue, partnership and shared decision making.

This dissertation is the result of this journey. Rather than a journey, it reflects the commuting between the world of research and the world of people with a chronic disease. Over the years I have met many patients who, like me, devoted their time and energy to improve health care in their own disease area. I have observed a growing willingness to collaborate constructively with health professionals, although the latter are not always able to effectively deal with this desire. My role as a patient researcher enabled me to become a go-between: Based on my experience of delayed diagnosis, inadequate referrals, ineffective treatments and poor communication, and on the basis of my knowledge of scientific research, I have tried to make health professionals and health researchers more sensitive to the perspective of patients with a rheumatic condition and to prepare patients for their role as collaborative partners. Although the findings in this dissertation are not groundbreaking, I know that the process of doing this research has influenced the collective receptiveness of health professionals to attend to the patients' perspective.

I hope that this study will inspire researchers and patients to start the dialogue on how rheumatology research can contribute to the improvement of the life-world of patients and increase patients' abilities to adapt and to self manage.<sup>1</sup>

1. Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, et al. How should we define health? *BMJ* 2011;343:d4163.