# FoU Spenshult

Reumatologisk forskning och utveckling

Dignity, identity and quality of life in focus when patients set the research agenda.

Bergsten, U.<sup>1,2</sup>, Bagge, J.<sup>3</sup>, Åkerhielm, C.<sup>3</sup>, Bergman, S.<sup>2</sup>

<sup>1</sup>Department of Rheumatology, Sahlgrenska University Hospital, Gothenburg, <sup>2</sup>R & D Center Spenshult, Oskarström, <sup>3</sup>The Swedish Rheumatism Association, Sweden

## Conclusion

A structured approach involving research partners and members of patient associations generated several new research ideas that now are planned to be developed further.

The patient initiated research agenda complements the established medical view and could improve the knowledge and understanding of what it means to have a rheumatic disease. This gives an opportunity to develop rheumatology care to be more person-centered.

Working with patient initiated research is possible, rewarding and give new perspectives!

### Background

The rheumatic diseases are usually long lasting and often affect the daily life with pain, stiffness and fatigue. Patients' perceptions of their illness and its consequences differ to some extent from the established medical view. This also means that there could be unidentified areas of research that could be of great value for the patients.

The Swedish Rheumatism Association (the national patient organization) and Research- and Development-center Spenshult decided to carry out a joint project to develop patient initiated research in order to increase knowledge and to improve the care of the rheumatic diseases. The aim of the project was to develop and describe new research areas from a patient perspective that not had been adequately covered previously and to initiate projects that patients consider to be of importance for development of rheumatology care.

#### Method

A project team was formed consisting of five research partners (specially educated people with personal experience of a rheumatic disease) and a project manager. The project team used a structured method throughout the project in order to maintain focus at the patient perspective.



The structured method that was used – The dialogue model – is developed with the purpose to promote the dialogue between different stakeholders such as patients and researchers. During the project there were other members of the local rheumatic association engaged focus groups. Experiences were communicated in four focus group interviews and by individuals that had experience of rheumatic disease. The material was analyzed by content analysis research method.

#### Results

The analysis resulted in several research ideas and research areas that were important from the patient perspective. Most of them focused on the patient's dignity, identity and quality of life.

The repeated theme was:

How can a person maintain or improve their quality of life despite chronic illness?

Persons who participated in the focus groups communicated their experiences of having a rheumatic disease and the central point was how life changes when you suffer from a chronic disease and that the "whole life" was affected to different degrees. It was also clear that there are shortcomings in health care and society in terms of providing support and assistance to the person with a rheumatic disease.

Dignity – Identity – Quality of life



## Self-management areas

Weight Pain Sleep Sex

Diet Exercise Knowledge



## Other aspects of the disease

Comorbidity Morbidity

Concerns of the future



## Relationship with others

Relatives

Healthcare professionals

Working society

Society

