



# Do we need a patient peer mentor program in daily practice and if so, how should this be organized? Results of an explorative focus group study with four key stakeholders in the care of patients with early rheumatoid arthritis

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## Background

**Peer mentoring** = Transferring knowledge, skills and experiences by a patient as an additional education and guidance method for people with the same chronic disease

**Management and support** by an interdisciplinary rheumatology team favors a beneficial disease outcome in rheumatoid arthritis

↳ situation in daily practice:

- Healthcare professionals generally do not experience the disease themselves
- Patients have specific 'experience based' information needs

### Objectives:

- (1) To explore the current experience with, need for and attitude toward implementing peer mentoring in the early disease stage of RA
- (2) To gather ideas for the content and format of a peer mentor program



**Peer mentoring** is probably most beneficial **in the early disease stage** → patients are particularly then faced with threats to their normal life

↳ studied and successfully implemented in other chronic conditions  
↳ but is a new care concept in rheumatoid arthritis

## Methods & stakeholders characteristics

- **Design:** Explorative, user-centered, qualitative focus group study
- **Registration of variables at initiation of focus group:**
  - Socio-demographic variables
  - Clinical variables (patients)
- **Four focus groups:**
  - Topic – and interview guide
  - Field notes
  - Descriptive- methodological- and content report
- **Interdisciplinary research team:**
  - One moderator and two observers
  - Two patient researchers
  - Data analysis by constant comparison method (Qualitative Analysis Guide of Leuven)
- **Total participants: 25**

### Patient organisations (3)



### Patients with early RA



### Rheumatologists



### Rheumatology Nurses



## Results

### Need

#### Perceived interest among target audiences

- questions about additional value of the peer mentor, support for a newly diagnosed patient
- it's a concept that is unknown so not asked for by patients, less inhibition

#### This would be individual and phase –dependent

- stage of life, stage of disease, disease progression

### Mixed feelings

#### The (positive or negative) impact of the peer mentor

- peer mentor as a powerful source
- fear for objectivity loss or loss of control (RA is very specific)
- transmission of false information

### Format - Need for a mental concept

#### Role of professionals

development (& implementation) in co-operation and under supervision of healthcare professionals

#### Matching

with matching disease progression, patient characteristics, stage of life and/or interests (but: heterogeneity could also be interesting)

#### Topics focusing on positive story

Main reason: keeping control about the message that is given by the peer mentor

#### Location

not that important, practical. Perhaps a neutral setting because a hospital could be a boundary

#### Communication forms

depends on the patient (one-to-one, group and use of modern technology because of the approachability)

#### Frequency of contact

depends on the (needs of the) patient and his/her phase of the disease

#### Engagement partner or relatives

not a fundamental part

### Criteria of the peer mentor

#### Well trained = education in coaching:

specific communication – and counseling skills

#### Clear role- + task description

= timely referral to professionals

#### Careful selection

#### Needed Skills

- communication skills
- insight in the disease/functioning with RA
- objectivity: keeping distance from their own story

### Added value

#### Extra dimension

providing disease perspective, reduce impact of RA, get perspective for the future

#### Understanding and recognition

Peer Mentoring

## Key message

### Peer Mentoring

- A new concept that would be largely individual- and phase dependent  
→ as an option to newly diagnosed patients, rather than a standard of care
- Can provide disease perspective and a sense of recognition to newly diagnosed patients

### How ?

- Lack of a formal framework for collaborating with patient experts
- Need for carefully selected and well-trained peer mentors
- Should be developed in co-operation with and under supervision of healthcare professionals.

### Future research

- General practitioner and partners as possible stakeholders
- Combination of different stakeholders in a focus group
- Survey on population level