

# Identifying Key Variables for Inclusion in a Smartphone App to Support Clinical Care and Research in Patients with Rheumatoid Arthritis

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## Background

Treatment for patients with rheumatoid arthritis (RA) is guided by monitoring changes in disease severity.

At present, patients do not routinely record disease severity between clinic visits.

The REMORA study (REmote MOnitoring in Rheumatoid Arthritis) is designing, building and evaluating a smartphone app to collect electronic patient reported outcomes (ePROs).

ePROs relating to disease severity will be collected directly from patients on a routine basis.

These data will then be linked to the electronic patient record (EPR) and a research database.



## Aims

To determine:

- Which ePROs and other data relating to disease activity should be included in the app [what to record]
- The frequency with which these data should be captured [when to record]
- How these data should be captured (e.g. numeric data, free text diary) [how to record]

## Methods

Qualitative interviews were conducted with a purposive sample of key stakeholders to explore the study aims: 10 RA practitioners (clinicians, nurses and physiotherapists), 12 RA researchers (with a range of research backgrounds and interests) and 18 patients with RA (3 men, 15 women, ages 32 – 84)

A thematic analysis using a framework structured on the above aims was used to explore the following:

- the range of ePROs identified by participants
- the frequency with which participants felt specified ePROs should be recorded
- the format in which ePROs could be captured
- areas of consensus/divergence with regard to 'what, when and how' ePROs could be recorded

The stages of data analysis are summarised in table 1:

**Table 1:**  
Stages of obtaining consensus regarding the components of the app

1	Interviews were conducted with practitioners and researchers regarding their preferences.
2	ePROs identified were tabulated and discussed with the REMORA PPI (patient and public involvement) group, and the table refined. Adjustments included improving the clarity of question wording (e.g. '24 hours' rather than 'day')
3	Patients were interviewed regarding their preferences and also asked to feedback on tabulated suggestions.
4	The research team analysed the interviews to identify components which had widespread consensus across the stakeholder groups (such as pain, joint swelling). Suggestions made less commonly (such as diet, exercise) were documented, but not included in the final question sets.
5	PPI group members reviewed the suitability of the app prior to the commencement of the pilot.

## Results

### What to record

All of the stakeholders (patients, practitioners and researchers) wanted to capture information on changes in disease activity and the impact of the disease (physically and emotionally). However, patients wanted to record additional information to give greater context, such as the kind of day or week they were having. This was considered important information to understand the changes in symptom control.

### When and how to record

- Practitioners and researchers wanted ePROs relating to disease activity and their impact on patients to be recorded regularly using existing validated tools. However, they could see the value of patients recording 'ad hoc' events. (such as triggers of disease activity) in the form of free text.
- Patients mainly suggested recording 'notable events' (such as flares) as they occurred in free text format. However, they could understand how the routine recording of symptoms could be beneficial for clinical consultations and self-management.

The final app therefore comprised :

- ePROs to be recorded on a regular basis in numeric format (which were linked to the EPR)
- a free text diary (for patient use)

**Table 2:**

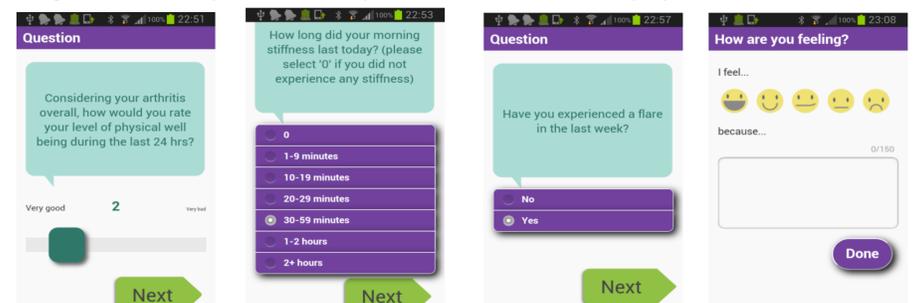
**Final data set showing frequency of recording, question sets and mode of data capture**

Frequency	Question Set	Mode of Data Capture	
Daily	Pain	10 point visual analogue scale	
	Difficulty with physical activities		
	Fatigue		
	Sleep difficulties		
	Physical wellbeing		
	Emotional wellbeing		
Weekly	Coping	Fixed 7 point scale (radio button)	
	Morning stiffness		
	Number of tender joints		Numeric value
	Number of swollen joints		
	Global assessment of wellbeing		10 point visual analogue scale
	Employment status		Yes/No response (radio button)
	Impact on hours worked		Numeric value
Experienced a flare	Yes/No response (radio button)		
Monthly	Description of flare	Free text box	
	Health Assessment Questionnaire (HAQ) impact of disease on daily activities including function, mobility and grooming	Fixed point scales (radio button) -plus free text entry box	

## Conclusions

Consensus on the key components of the smartphone app was achieved following a process of consultation with patients, practitioners and researchers (table 1).

Key components identified (table 2) have been incorporated into the 'app in readiness for piloting within clinical practice'. Exemplars of the formats are displayed below.



## Further information



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The REMORA smartphone app is being developed in conjunction with the Health eResearch Centre (HeRC) at the University of Manchester