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## Online Supplement 1



### RODS survey patient involvement in registries

#### 1. Personal details

Dear Participant,

Thank you for your time and willingness to fill in this survey about patient involvement in the design and management of rheumatology registries. This survey is conducted in the context of the EULAR course on registries and observational drug studies (RODS). Below we ask for some personal information, your view on the (potential) benefits of patient involvement and on your view on potential barriers. Filling in the survey should not take longer than 5 minutes.

If you have a question about this survey, please send an email to: [loreto.carmona@inmusc.eu](mailto:loreto.carmona@inmusc.eu)

##### 1. What is your primary background?

(mark all that apply)

- Academic researcher
- Researcher working for pharma
- Rheumatologist
- Health professional (non-rheumatologist)
- PhD Student
- Person living with a rheumatic condition
- Other (please specify)

##### 2. What is your country of residence?



## RODS survey patient involvement in registries

### 2. Relevance of patient involvement in registries

1. In your opinion, how could patients be involved in the development and running of registries?

2. What is your experience with patient involvement in the design and management of registries, cohorts or longitudinal observational studies? (mark all that apply)

- none
- I have worked with patients in designing these studies
- I have conducted patient focus groups
- I have undertaken patient interviews
- I have involved patient organisations in the recruitment of study participants
- I have involved patients in our research or management team
- Other, namely (please specify)

3. How important is patient involvement in registries for you (0 is not important; 100 is very important)?

0 100

4. How would you rate the current level of patient involvement in registries in the field of rheumatology (0 is completely absent; 100 is full involvement)?

0 100



## RODS survey patient involvement in registries

### 3. Benefits and barriers

#### 1. What do you see as potential benefits of patient involvement in registries?

	No benefit	Small benefit	Quite a benefit	Important benefit
Inclusion of research questions that are relevant to patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient information that is better understandable for the target audience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved recruitment of patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reduction of missing data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More funds for establishing and maintaining a registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gives legitimacy to the final research outcomes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Better dissemination of findings among patients and their organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help in the analysis and interpretation of research findings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inclusion of outcomes that are relevant to patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

## 2. What do you see as potential barriers to patient involvement in registries?

	No barrier	small barrier	Quite a barrier	Important barrier
Difficult to identify competent patient representatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Limited opportunities for meaningful involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients do not feel confident to participate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of awareness of the benefits of patient involvement in registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of financial resources to implement patient involvement in registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor experiences with patient involvement in other research projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

## 3. If we may approach you for additional information, please provide your name and an email address.

Name

Email address

Thank you for filling in this survey!

**Online Supplement 2****PRP in registry project**  
**focus group - interview schedule****Interview guide for the focus groups for the study on involvement of PRPs in registries and observational studies:**

*At first, we would like to welcome you again and thank you for participating in this focus group study. In this group discussion we will aim draw a picture on the current perspectives of involvement of patient research partners in registry studies. This will include to evaluate the current state of PRP involvement in registries and the stages of research they are involved. Additionally potential opportunities and pitfalls in PRP involvement can be addressed.*

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**Open-ended questions**

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1. How can be PRP be involved in conducting registry research?
  2. The role of PRPs in specific areas?
    - A Formulating objective(s)?
    - B Research questions?
    - C Research design?
    - D Selecting outcomes? Which data to be collected?
    - E Promoting recruiting to the registry?
    - F Collection and analysis of data
    - G Dissemination of results
    - H Evaluation of registry output / performance?
  3. Are there any obstacles or barriers to PRP involvement at any of the research phases?
  4. Are patient research partners equal partners to the rest of the team?
  5. Can the involvement of PRPs be supportive and why?
  6. Can the involvement of PRPs as obstructive and why?
  7. Does anyone would like to share successful stories of PRP involvement?
  8. (Does anyone would like to share less successful stories of PRP involvement?)
  9. Does anyone wish to add anything else?
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