# Table of Content

<table>
<thead>
<tr>
<th>Supplemental Material</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online Supplement 1</td>
<td>1</td>
</tr>
<tr>
<td>Online Supplement 2</td>
<td>5</td>
</tr>
</tbody>
</table>
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@musc.edu

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
## 3. Benefits and barriers

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

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

Other (please specify)
2. What do you see as potential barriers to patient involvement in registries?

<table>
<thead>
<tr>
<th>Barrier</th>
<th>No barrier</th>
<th>Small barrier</th>
<th>Quite a barrier</th>
<th>Important barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult to identify competent patient representatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited opportunities for meaningful involvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients do not feel confident to participate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of awareness of the benefits of patient involvement in registries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of financial resources to implement patient involvement in registries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor experiences with patient involvement in other research projects</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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 to 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.

Open-ended questions

1. How can 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 be obstructive and why?
7. Does anyone wish to share successful stories of PRP involvement?
8. (Does anyone wish to share less successful stories of PRP involvement?)
9. Does anyone wish to add anything else?