Appendix E– Evaluation PPI

The patient/caregiver and researcher partner surveys are designed to understand the actual experience of all involved participants, when researcher partner with patients and caregivers on a project, where patients and/or caregivers are members of the research team.

The patient/caregiver and researcher surveys serve as a template and the number of questions and surveys are adapted to our project.[14] The experience is collected after the kickoff meeting (initial survey) and after completing all participation activities of the PPI project (end project survey).

Initial Survey Advisors

<table>
<thead>
<tr>
<th>Survey Instructions</th>
<th>English</th>
<th>Deutsch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you worked as a patient/clinician advisor on a research project prior to this one?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Please describe your experience as patient/clinician advisor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the research team introduced to you?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Did someone of the research team introduce you to the other project advisors?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Was the SAuBRRITY patient and public involvement (PPI) project described to you before you started working with the team?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Was there enough time for you to learn about the SAuBRRITY PPI project before you agreed to participate as patient/clinician advisor?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Was there enough time for you to get to know the other project advisors before the SAuBRRITY PPI project started?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Were the communication tools explained to you before the SAuBRRITY PPI started?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Did you and the research team discuss your role on the team?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Were the roles of the other members of the project team explained to you?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you feel you are equipped to contribute to the SAuBRRITY PPI project?</td>
<td>not at all</td>
<td>totally</td>
</tr>
</tbody>
</table>

(Note a mark on the scale above)
# End Survey Advisors

**Survey Instructions**

- **English**
- **Deutsch**

How comfortable do you think you are now with your understanding of the SALubRITY patient and public (PPI) project?  

<table>
<thead>
<tr>
<th>Very uncomfortable</th>
<th>Very comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Place a mark on the scale above)

How comfortable did you feel speaking up in the meetings?  

<table>
<thead>
<tr>
<th>Very uncomfortable</th>
<th>Very comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Place a mark on the scale above)

Did you feel the team listened to you and absorbed your input?  

- Yes
- No

Did any of the researchers on the team have problems dealing with patient/clinician partners?  

- Yes
- No

What was the nature of the problem?  


Did the research team work with you to accommodate for your challenges and ensure that it is easy for you to participate?  

- Yes
- No

In your opinion, did your insights and comments impact the decisions of the future SALubRITY trial?  

<table>
<thead>
<tr>
<th>Never</th>
<th>Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Place a mark on the scale above)

Did you share your personal experience as a patient/clinician as part of your role as advisor on the SALubRITY PPI project?  

- Yes
- No

What preparation would have been useful to have before being involved in this PPI project?  


If you could start over again as a patient/clinician advisor, what would you do differently?  


What 3 things did you learn from the experience as a patient/clinician advisor on a multidisciplinary team?  

1


2


3


What 3 things could the research team have done to improve your experience?  

1


2


3
Do you feel the patient/clinician partnership was productive and enriched the quality and relevance of the SALoBRITY trial?  
☐ Yes  ☐ No

Do you have any concerns about partnering with researchers at this point?  
☐ Yes  ☐ No

What was most challenging when partnering with researchers?  
________________________

Where do you think your involvement mattered the most?  
________________________
## Initial Survey Researchers

**Survey Instructions**

- [ ] English
- [ ] Deutsch

1. Have you worked with patient and/or public advisor on a research project prior to this one?
   - [ ] Yes
   - [ ] No

2. Please describe your experience with patient and/or public advisors.

3. Did you establish a profile of the type of person you wanted as a patient/caregiver partner prior to looking for candidates?
   - [ ] Yes
   - [ ] No

4. Was there enough time for the patients/clinicians to learn about the SAluBRITY PPI project before they agreed to participate as patient/clinician advisor?
   - [ ] Yes
   - [ ] No

5. Was there enough time for the patient/clinician advisors to get to know the other project advisors before the SAluBRITY PPI project started?
   - [ ] Yes
   - [ ] No

6. Do you feel you and your team are well prepared to work with patient/clinician advisors on this SAluBRITY PPI project?

   - [ ] Not at all
   - [ ] Somewhat
   - [ ] Totally

   (Place a mark on the scale above)
## End Survey Researchers

### Survey Instructions
- English
- Deutsch

### How comfortable do you think patient/clinician advisors are with their understanding of the SALuBRITY PPI project?

<table>
<thead>
<tr>
<th>very uncomfortable</th>
<th>very comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Place a mark on the scale above)

### Did the patient/clinician advisors speak up and contribute at most meetings?

<table>
<thead>
<tr>
<th>very uncomfortable</th>
<th>very comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Place a mark on the scale above)

### Did you feel you and the research team listened to and absorbed the inputs of the patient/clinician advisors?
- Yes
- No

### Did any of the researchers on the team have problems dealing with patient/clinician partners?
- Yes
- No

### What was the nature of the problem?


### Did the patient/clinician advisors’ comments during the member checking process affect the final outcome of the SALuBRITY PPI project?
- Yes
- No

### Did you work with the patient/clinician advisors to accommodate for their challenges and ensure that it is easy for them to participate?
- Yes
- No

### In your opinion, did the insights and comments of the patient/clinician advisors impact the decisions of the SALuBRITY trial?

<table>
<thead>
<tr>
<th>never</th>
<th>definitely</th>
</tr>
</thead>
<tbody>
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<td></td>
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</tbody>
</table>

(Place a mark on the scale above)

### Did the patient/clinician advisors share their personal experience as a patient or clinician on the SALuBRITY PPI project?
- Yes
- No

### Did you feel you and your team were well prepared to work with patient/clinician advisors on the SALuBRITY PPI project?
- Yes
- No

### If you could start over again, what would you do differently?


### What 3 things did you learn from the experience of partnering with patients/clinicians?

1. 
2. 
3. 


<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>What 3 things could be done better to improve your experience?</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Do you feel the patient/clinician partnership was productive and enriched the quality and relevance of the SALImpT trial?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Do you have any concerns about partnering with patients/clinicians at this point?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>What was most challenging when partnering with patient/clinician advisors?</td>
<td></td>
</tr>
<tr>
<td>Where do you think patient/clinician involvement mattered the most?</td>
<td></td>
</tr>
</tbody>
</table>