

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

Survey Instructions	<input type="radio"/> English <input type="radio"/> Deutsch						
Have you worked as a patient/clinician advisor on a research project prior to this one?	<input type="radio"/> Yes <input type="radio"/> No						
Please describe your experience as patient/clinician advisor.	_____						
Was the research team introduced to you?	<input type="radio"/> Yes <input type="radio"/> No						
Did someone of the research team introduce you to the other project advisors?	<input type="radio"/> Yes <input type="radio"/> No						
Was the SALuBRITY patient and public involvement (PPI) project described to you before you started working with the team?	<input type="radio"/> Yes <input type="radio"/> No						
Was there enough time for you to learn about the SALuBRITY PPI project before you agreed to participate as patient/clinician advisor?	<input type="radio"/> Yes <input type="radio"/> No						
Was there enough time for you to get to know the other project advisors before the SALuBRITY PPI project started?	<input type="radio"/> Yes <input type="radio"/> No						
Were the communication tools explained to you before the SALuBRITY PPI started?	<input type="radio"/> Yes <input type="radio"/> No						
Did you and the research team discuss your role on the team?	<input type="radio"/> Yes <input type="radio"/> No						
Were the roles of the other members of the project team explained to you?	<input type="radio"/> Yes <input type="radio"/> No						
Do you feel you are equipped to contribute to the SALuBRITY PPI project?	<table border="0" style="width: 100%;"> <tr> <td style="text-align: left;">not at all</td> <td style="text-align: right;">totally</td> </tr> <tr> <td colspan="2" style="text-align: center;"> </td> </tr> <tr> <td colspan="2" style="text-align: center;"> <i>(Place a mark on the scale above)</i> </td> </tr> </table>	not at all	totally			<i>(Place a mark on the scale above)</i>	
not at all	totally						
<i>(Place a mark on the scale above)</i>							

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?

very uncomfortable very comfortable

 (Place a mark on the scale above)

How comfortable did you feel speaking up in the meetings?

very uncomfortable very comfortable

 (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?

never definitely

 (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 SALuBRITY 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

Have you worked with patient and/or public advisor on a research project prior to this one?

- Yes
 No

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

Did you establish a profile of the type of person you wanted as a patient/caregiver partner prior to looking for candidates?

- Yes
 No

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

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

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

not at all totally

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(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?

very uncomfortable very comfortable

 (Place a mark on the scale above)

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

very uncomfortable very comfortable

 (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?

never definitely

 (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

What 3 things could be done better to improve your experience?

1

2

3

Do you feel the patient/clinician partnership was productive and enriched the quality and relevance of the SALuBRITY trial?

Yes No

Do you have any concerns about partnering with patients/clinicians at this point?

Yes No

What was most challenging when partnering with patient/clinician advisors?

Where do you think patient/clinician involvement mattered the most?
