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NetENACT

Hello and thank you for your willingness to participate in the PCORnet - Engagement Activity Inventory (netENACT).

The purpose of netENACT is to capture the experiences of PCORI awardees with patient and other stakeholder engagement in research. We plan to administer netENACT questions to principal investigators and to patients and other stakeholders engaged in PCORI funded research projects, as applicable.

For all PCORI projects moving forward, PCORI intends to administer netENACT at baseline and then again at 6 month intervals from contract execution (6, 12, and 18 months) for a total of 4 times.

PCORI will use the information collected from netENACT to enhance understanding of PCORI's portfolio of funded projects, identify promising approaches to engagement of patients and other stakeholders in research, provide guidance to applicants, and support the success of funded investigators. Your participation is part of your contractual obligation. Completion of these questions should take 15-20 minutes.

Identifying information such as your name or contact information will be removed from your response. PCORI will retain the name and contact information of respondents in order to contact them about completing netENACT at 6-month intervals throughout the PCORI project but the respondent's name will be kept separate from his or her response. Each response will be given a unique code in place of the respondent's name. All de-identified responses will be stored in a database, which may be shared in aggregate with network peers or used for research in the future.

We may share our findings with the patient-centered outcomes research community through presentations, publications, or other communications. Any reports summarizing our findings will not contain your names or identifying information. Your responses are not related to project milestones and will not affect project funding.

If you have any questions regarding this data collection effort, please contact us at surveys@pcori.org or 202-370-9508.

Thank you for your time and contribution.

1. Which of the following best describes your role in PCORnet?

- Principal Investigator
- Other scientific investigator
- Lead patient representative
- Other patient or stakeholder representative

2. Are you from a CDRN or a PPRN?

- CDRN
- PPRN

First we are interested in learning about your experience engaging with patients and other stakeholders on research prior to working on this

3. Please rate your level of experience engaging with each of the following stakeholder communities on **health research projects** in ways other than as research participants.

For example, patients can be engaged in deciding the research questions, defining the study characteristics like whom to study, choosing study outcomes, tracking study progress, or sharing study findings.

	-----Level of Engagement----->				
	N/A: I have not engaged in health research projects	No experience	A little experience	Some experience	A great deal of experience
(a) Patient/consumer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Caregiver/family member of patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) Advocacy organization (e.g., patient/consumer or caregiver advocacy organization)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) Clinician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) Clinic/hospital/health systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) Other (please describe on the next page)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Please describe the other stakeholder community you mentioned on the previous page.

5. Please rate your level of experience engaging with each of the following stakeholder communities in **resource building or infrastructure development**.

For example, patients or other stakeholders could be engaged in governance, designing strategies for recruitment and retention, developing informed consent processes, defining privacy and data access policies, and guiding data collection efforts.

	-----Level of Engagement----->				
	N/A: I have not engaged in resource building or infrastructure development .	No experience	A little experience	Some experience	A great deal of experience
(a) Patient/consumer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Caregiver/family member of patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) Advocacy organization (e.g., patient/consumer or caregiver advocacy organization)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) Clinician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) Clinic/hospital/health systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) Other, <i>please specify on the next page</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Please describe the other stakeholder community you mentioned on the previous page.

7. **Now we are interested in learning about your experience in health research prior to working on this .**

Please rate **your** level of experience engaging in **health research projects** in ways other than as a research participant? For example, stakeholders can be engaged in deciding the research questions, defining the study characteristics like who to study, choosing study outcomes, tracking study progress, or sharing study findings.

- I have not engaged in health research projects
- No experience
- A little experience
- Some experience
- A great deal of experience

8. Please rate your level of experience engaging in **resource building or infrastructure development**. For example, stakeholders could be engaged in governance, designing strategies for recruitment and retention, developing informed consent processes, defining privacy and data access policies, and guiding data collection efforts.

- N/A: I have not engaged in resource building or infrastructure development
- No experience
- Some experience
- A little experience
- A great deal of experience

9. Based on your experience, how supportive is the culture of your primary organization or institution in engaging **patients or caregivers** in the research process in ways other than as research participants?

- N/A: I am not affiliated with any specific organization or institution related to health research.
- Not at all supportive
- A little supportive
- Somewhat supportive
- Highly supportive

10. Provide an example of how your organization is or is not supportive of engaging with patients in the research process.

11. Based on your experience, how supportive is the culture of your primary organization institution in engaging **front-line clinicians** in the research process?

- N/A: I am not affiliated with any specific organization or institution related to health research.
- Not at all supportive
- A little supportive
- Somewhat supportive
- Highly supportive

12. Provide an example of how your organization is or is not supportive of **front-line clinicians** in the research process.

Now we are interested in learning about partnerships formed prior to or during the development of the proposal.

13. Who initiated your proposal?

- Scientific leader
- Informatics leader
- Patient leader
- Front-line clinician leader

14. Which of the following partnerships are within your network? *Please check all that apply.*

- Organizations
- Patient/caregiver leaders
- Front-line clinician leaders
- Health system leaders
- Other stakeholders
- Other, please specify

15. We would like to ask a few questions about each partnerships you selected in the previous question. Please click on the green button to access the question section for each partnerships. After you have answered the question set, you will be taken back to the table to complete the same question sets for any partnerships you selected.

Group		
Organizations		
Patient/caregiver leaders		
Front-line clinician leaders		
Health system leaders		
Other stakeholders		

1. How many are within your ?

- 1-2 partners
- 3-5 partners
- 6+ partners
- Don't know

2. How many within your network have you worked with **prior to developing** your proposal?

- 0 partners
- 1-2 partners
- 3-5 partners
- 6+ partners
- Don't know

3. For those partnerships that were previously established, on average, how long have you worked with the ?

- 1-2 years
- 3-5 years
- 6+ years

4. Please characterize the type of work you previously engaged in with this ?

- Funded work
- Unfunded work
- Clinical work
- Other, please specify

5. For those partnerships that were newly formed for the proposal, describe how you started a relationship with the for your .

16. What unique knowledge, skills, and/or experiences does your lead patient representative bring to the ?

17. **Now we are interested in understanding more about the work you did on your proposal.**

What unique knowledge, skills, and/or experiences do you bring to the ?

18. Describe what you did for the proposal submitted to PCORI

19. Which of the following stakeholders were engaged in developing the proposal submitted to PCORI? *Please select all that apply*

- Lead patient representative
- Other patient/consumer(s)
- Caregiver(s)/family member(s) of patient
- Advocacy organization(s) (e.g., patient/consumer or caregiver advocacy organization)
- Clinician(s)
- Hospital/clinic/health system leader(s)
- Other, please specify

20. We would like to ask a few questions about each stakeholder group you selected in the previous question. Please click on the green button to access the question section for each stakeholder group. After you have answered the question set, you will be taken back to the table to complete the same question sets for any other stakeholder groups you selected.

Stakeholder type	
<input type="checkbox"/>	Lead patient representative
<input type="checkbox"/>	Other patient/consumer(s)
<input type="checkbox"/>	Caregiver(s)/family member(s) of patient
<input type="checkbox"/>	Advocacy organization(s) (e.g., patient/consumer or caregiver advocacy organization)
<input type="checkbox"/>	Clinician(s)
<input type="checkbox"/>	Hospital/clinic/health system leaders
<input type="checkbox"/>	

1. Describe what the did for the proposal submitted to PCORI.

2. What were your primary reasons for engaging in your proposal? Please be specific regarding the ways in which you expected to impact the proposal.

The following are different levels of engagement that can occur during research projects. Please use these levels to answer the following question.

Information: Researchers describe decisions to patients and other stakeholder partners after decisions are made.

Consultation: Patients and other stakeholders provide feedback to researchers that can inform decision-making. Consultation allows the researcher to obtain views without necessarily being committed to act on them.

Collaboration: Researchers, patients, and other stakeholders have an active partnership. Patients and other stakeholders work directly with the researcher to ensure that their perspectives are consistently understood and incorporated in decision making, and have greater ownership of the project.

Patient/stakeholder direction: Also known as "user control," patients and other stakeholder(s) are empowered to have control over the research process and the final decision-making.

21. Indicate the level at which each of the following stakeholders were engaged in developing the proposal.

	-----Level of Engagement----->			
	Information	Consultation	Collaboration	Patient/stakeholder direction
(a) Lead patient representative	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Patient/consumer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) Caregiver/family member of patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) Advocacy organization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) Clinician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) Hospital/clinic/health systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. Please indicate the level at which you were engaged in developing the proposal.

	-----Level of Engagement----->			
	Information	Consultation	Collaboration	Patient/stakeholder direction
(a) Lead patient representative	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Please rate how much you influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing the network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Building clinical database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Plans for size and diversity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patients in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Collaborations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Creating standardized network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) RC7: Sharing data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(h) RC8: Administrative and financial accounting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Electronic Health Records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Please rate how much you influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Data standardization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Complete data capture	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patient and clinicians in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Recruiting cohorts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) RC7: Sharing resource	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) RC8: PRO and trial data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Capacity to support trials and embed research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Human subjects oversight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(k) RC11: Data security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(l) RC12: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(m) RC13: Management plan and centralized monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(n) RC14 Efficient use of resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now we are interested in learning more about the influence of patients and other stakeholders on the proposal and what you have learned about stakeholder engagement.

25. Thinking about the patients and caregivers engaged in developing the proposal, please rate how much patients or caregivers influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing the network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Building clinical database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Plans for size and diversity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patients in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Collaborations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Creating standardized network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) RC7: Sharing data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) RC8: Administrative and financial accounting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Electronic Health Records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Thinking about the patients and caregivers engaged in developing the proposal, please rate how much patients or caregivers influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Data standardization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Complete data capture	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patient and clinicians in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Recruiting cohorts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(g) RC7: Sharing resource	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) RC8: PRO and trial data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Capacity to support trials and embed research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Human subjects oversight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(k) RC11: Data security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(l) RC12: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(m) RC13: Management plan and centralized monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(n) RC14 Efficient use of resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. Describe the specific impact(s) of engaging with *patients and caregivers* on the final proposal related to . What was changed or different because *patients and caregivers* were engaged in the proposal development process?

28. Describe the specific impact(s) of engaging with *patients and caregivers* on the final proposal related to . What was changed or different because *patients and caregivers* were engaged in the proposal development process?

29. Thinking about the *front-line clinicians* engaged in developing the proposal, please rate how much *front-line clinicians* influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing the network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Building clinical database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Plans for size and diversity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patients in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Collaborations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Creating standardized network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) RC7: Sharing data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) RC8: Administrative and financial accounting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Electronic Health Records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Thinking about the *front-line clinicians* engaged in developing the proposal, please rate how much *patients or caregivers* influenced the final content of the proposal submitted to PCORI related to each of the following proposal review criteria (RC#). By influenced, we mean affected or contributed to decision making of the final product.

	-----Amount of Influence----->			
	None	A small amount	A moderate amount	A great deal
(a) RC1: Describing network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) RC2: Data standardization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) RC3: Complete data capture	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) RC4: Patient and clinicians in governance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) RC5: Systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) RC6: Recruiting cohorts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) RC7: Sharing resource	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) RC8: PRO and trial data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) RC9: Capacity to support trials and embed research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(j) RC10: Human subjects oversight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(k) RC11: Data security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(l) RC12: Biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(m) RC13: Management plan and centralized monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(n) RC14 Efficient use of resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. Describe the specific impact(s) of engaging with *front-line clinicians* on the final proposal related to . What was changed or different because *front-line clinicians* were engaged in the proposal development process?

32. Describe the specific impact(s) of engaging with *front-line clinicians* on the final proposal related to . What was changed or different because *front-line clinicians* were engaged in the proposal development process?

33. Did engaging with patients and other stakeholders impact the proposal development process in any ways that were undesirable?

- Yes
 No

34. Please describe the undesirable situation and how it was resolved

35. Describe the specific impact(s) of engaging in the final proposal. What was changed or different because you were engaged in the proposal development process?

36. Did engaging with other stakeholders impact the proposal development process in any ways that were undesirable?

- Yes
 No

37. Please describe the undesirable situation and how it was resolved.

38. Please describe whether any specific stakeholder perspective(s) (e.g., patient, clinician, etc.) were particularly helpful for the development of your proposal and why.

39. Please describe any other additional impacts that engaging with patients or other stakeholders had on the proposal development, your relationships with the patient or stakeholder communities, or your work outside this specific project.

40. How prepared were you to engage with each of the following stakeholders?

	N/A: I did not engage with this stakeholder	Not prepared at all	A little prepared	Somewhat prepared	Very prepared
(a) Patient(s)/consumer(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Caregiver(s)/family member(s) of patient(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) Advocacy organization(s) (e.g., patient/consumer or caregiver advocacy organization)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) Clinician(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) Hospital/clinic/health systems leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) Other, please specify on the next page	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

41. Please describe the other stakeholder group you mentioned on the previous page.

42. For each of the following stakeholder groups, please click on the green button to answer some additional questions about being prepared to engage with these

groups.

Stakeholder group

1. In what ways were you not prepared to engage ?

2. What would be useful to you in the future to better prepare you for engagement with ?

43. Based on your experiences developing a proposal, what initial learnings can you offer to others about how to engage patients and other stakeholders in developing a proposal for resource building or infrastructure development?

44. Overall, how valuable were the contributions of patients and other stakeholders for the development of the proposal?

- Not valuable at all
- A little valuable
- Somewhat valuable
- Very valuable

Now we are interested in learning more about the way researchers, patients, and/or other stakeholders have worked together during the proposal development process.

45. Please rate the following:

	Not at all	A little	Somewhat	A great deal
(a) There was clear communication about <u>how</u> stakeholder input was incorporated into decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Stakeholder input was incorporated into the decision making process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) I was satisfied with the decision making process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) The roles of all stakeholders were clearly stated.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) I understood my role in the proposal development process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) The researchers understood the role of patient engagement.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) Patient partners understood their role in infrastructure development.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) I was familiar with writing a proposal similar to this one.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) I was prepared to engage with other stakeholders.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

46. Please rate the following:

	Not at all	A little	Somewhat	A great deal
(a) The appropriate stakeholder groups were included.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(b) Stakeholders were given adequate opportunity to share their perspective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(c) The stakeholder representation was balanced (not dominated by particular perspectives).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(d) Meetings or other stakeholder interactions were scheduled to enable full participation by all partners.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(e) I was satisfied with the level of engagement of the other stakeholders.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(f) The understanding of different view points was encouraged.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(g) The investigators were responsive to input from other stakeholders.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(h) A sense of partnership was established among the investigators and other stakeholders.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(i) Information was shared equally among all partners.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. Are there any other principles or considerations that you feel are important for engaging stakeholders that are not captured here? If so, which ones?

48. Do you have plans to collect **information about the experiences** of patients and other stakeholders engaged in the development of your (e.g., satisfaction with role, perceived value of their contributions)?

- Yes
- No

49. Do you have plans to assess the **influence** of engaging patients and other stakeholders on the development of the ?

- Yes
- No

50. PCORI is interested in capturing rich descriptions of patient and other stakeholder engagement in PCORnet resource building or infrastructure development. We would like to encourage you to share vignettes about your experience with stakeholder engagement to further illustrate what seems to be working well, or not so well, in your network.

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