

Evaluation of Patient Engagement in the SCNs: Interview Guide

Interview Guide

1. How long have you been or were you involved with the SCNs?
2. Why did you decide to get involved in the SCNs?
3. How well was information about the patient and family advisor role communicated to you when you began your involvement with the SCNs? (*Was the purpose of patient/family engagement clear? Did you understand your role?*)
4. Can you describe how you have been involved?
Probes: *What was your role? How have you contributed?*
5. On a scale of 1-10, with 1 being not good at all, and 10 being excellent, how would you rate the way the SCN team (clinicians, researchers, patient partners) works(ed) together?
Probes: *Please comment on the way the research team worked together (clinicians, researchers, patient advisors)*
How were expectations/instructions communicated?
How comfortable were you in contributing?
6. Would you change anything regarding your involvement with the SCNs? (*e.g. time commitment, expectations, deadlines etc.*) / (**if project has ended**): If you could do it again, what would you change?
7. Sometimes there are challenges when researchers, patients, and other stakeholders work together. Have you encountered any challenges with your involvement in the SCNs?
8. Thinking about your contributions so far, what impact do you think you have had on SCN work?
(considering both short- & long-term impacts, outputs of this work)
Probes: *Impact of your involvement to this specific research project? To health research in general?*
9. How have you benefitted from your involvement?
10. When thinking about your involvement, why do you continue to do what you do?

11. What do you need to strengthen your involvement?
12. What has been your experience working with teams virtually?
Probes: Did you feel like you could contribute, ask questions, raise concerns?
13. Based on your experience, do you have any suggestions for improvements that SCN teams could make when working with patient and family advisors?
14. Do you have any other comments/observations about your experience?