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Patients as Partners in Research

Researcher Surveys

EVALUATING THE PATIENT PARTNERSHIP IN RESEARCH

Initial Survey
Mid Project Survey
End Project Survey

Authors and Patient Advisors:

Alies Maybee

SPOR Team Lead

amaybee@sideren.com

Brian Clark

Annette McKinnon

Emily Nicholas Angl

Overview

Purpose

The researcher surveys are designed to understand the actual experience of researchers when they partner with patients and caregivers on a project where the patients and/or caregivers are members of the research team.

Description

There are three draft surveys:

- Initial - to be delivered in the early stages of the partnership
- Mid Project - to be delivered about half-way through the research project
- End Project - to be delivered after the research is completed and while it is in the KT phase

The questions have been developed by those of us who are patient/caregiver partners on research teams and represent areas we have identified as important aspects of our experience with researchers.

Developing the Surveys

The questions have been developed by the four authors who are patient/caregiver partners on research teams and represent areas we have identified as important aspects of our experience.

We developed the surveys based on our own experiences as patient/caregiver partners on over 10 research teams not all of which were funded. The projects covered a range from purely quantitative to mixed methods to qualitative. The topics ranged from ICU interventions to indicator development to clinical interventions in various settings from the home to acute care.

We validated the comprehension of the questions with a group of researchers who had no part in the development of the questionnaires.

We have also developed three similar surveys for patients and caregivers partnering in research that are meant to follow closely the questions asked of researchers for comparison purposes.

Deploying the Surveys

All three surveys are meant to be completed by each person at different points in time. In order to track a respondent's experience over the course of the project and respect confidentiality, we suggest adding a numeric identifier field. Each respondent invited would be given a numeric identifier. For each of the three surveys the respondent fills out, they would use the same number so as to track their responses over time.

We suggest the survey responses should only be reported on in aggregate to protect as much as possible the confidentiality of the respondents. Respondents should be notified that every attempt will be made to keep the information confidential and permission will be sought if we determine the information in a report could identify a respondent. The file with the information about the tracking numbers should be kept confidential and maintained securely by the team deploying the survey.

Authors

In addition to partnering on various research teams, the authors all have a variety of experiences as patient and family advisors from the hospital to the local health authority to the quality council and

other healthcare associations and organizations. These experiences have enriched our understanding of partnership in research.

Acknowledgements

Initial Survey

Questions for Researchers Partnering with Patients

Help us to understand your experience of partnering with patients and caregivers on a research team so we can learn what partners could use for support in future. This is the <u>first</u> of 3 surveys we are asking you to complete: An initial one early in the research project, one during the middle of the project and one near the end when the results are done and being sent out.

A BIT ABOUT THE PROJECT

1	What is the project or topic name?	_____
2	How long is this project?	# of months _____
3	What is the main funding agency for the project?	_____
4	Who is the project lead (principal investigator)?	_____
5	Who is your patient partner contact person for the team on this project?	_____
6	Where is the core team located?	City_____ Prov/Terr_____
7	How many patients/caregivers are partners on your research team? *(Do not include patients/caregivers on an advisory panel.)*	_____
8	When your patient/caregiver partners started with the team, at what stage was the project? *(Select one)*	• Working on the LOI (Letter of Intent) or EOI (Expression of Intent) • Working on the application • Funding received and project in process

RECRUITING PATIENT/CAREGIVER PARTNERS (NOT PANELISTS)

9	How did you find patient/caregiver partners for your research team? *(Pick all that apply)*	• Patient or caregiver organization • Personal connections • Other _____

10	Was it difficult to find patient/caregiver partners for your team?	(*Use a 7 point scale*) (1) Very difficult --- (7) Very easy
	Comments	_____
11	Did you establish a profile of the type of person you wanted as a patient/caregiver partner prior to looking for candidates?	Y/N
12	Did the application timeframe allow you enough time to find and brief the patient/caregiver partners so that they could participate fully in the application process?	Y/N
13	Did the application process include financial support for the process of recruiting and orienting patient/caregiver partners to your research team?	Y/N
	If yes, did you feel the support was sufficient?	_____
14	Did the funding agency supply non-financial support for the process of recruiting and orienting patient/caregiver partners eg: training, orientation tools, etc. ?	Y/N
	If yes, what were they and were they sufficient?	_____
15	Have you had training on patient oriented research (POR)?	Y/N
	Comments	_____

BRINGING THE PATIENT/CAREGIVER PARTNERS ON BOARD

16	After the patient/caregiver partners were recruited and identified, when did they actually come on board? (*Select one*)	• Working on the LOI (Letter of Intent) or EOI (Expression of Intent) • Working on the application • Funding received and project in process
17	Did the PI or someone else introduce each team member to the patient/caregiver partners?	Y/N
18	Were the patient/caregiver partners introduced to the rest of the team?	Y/N
19	Were the patient/caregiver partners told about the project before they started working with the team?	Y/N
20	Have you worked with a <u>patient/caregiver partner</u> on a research project prior to this one?	Y/N

MEETING THE TEAM

21	Did the principal investigator (PI) or someone else introduce the patient/caregiver partners to the other team members?	Y/N
22	Did the PI or someone else introduce each team member to the patient/caregiver partners?	Y/N
23	Have you worked with a patient/caregiver partner on a research project prior to this one?	Y/N

BRIEFING PATIENT/CAREGIVER PARTNERS

24	Was there enough time for the patient/caregiver partners to learn about the project and get to know the other team members prior to submitting the application?	Y/N/ Joined after application submitted
25	Did the PI or other team member describe the project to the patient/caregiver partners before they started working with the team?	Y/N

If you answered "No" or "Joined after application submitted" to question 24, skip the following questions and go to question 29.

26	How did the team explain the project to the patient/caregiver partners at the start? *(Pick all that apply)*	• Sent funding application • Sent other briefing documents • Held meeting or teleconference
27	If there was a meeting or teleconference to explain the project to the patient/caregiver partners, who did the briefing? *(Select one)*	• PI or main project person • Someone else (role) _____ • No meeting/ teleconference
28	If there was a meeting or teleconference to explain the project, was it for patient/caregiver partners only or for the whole team? *(Select one)*	• Patient/caregiver partners only • The whole team
29	Were the communication tools the team is using explained to patient/caregiver partners? *(examples: teleconference, web-based meetings like GoToMeeting, any shareware or central file storage, online calendar)*	Y/N

DEFINING AND UNDERSTANDING ROLES

30	Did you have a discussion with the patient/caregiver partners about their role on the team?	Y/N
31	Were the roles of the other members of the team explained to the patient/caregiver partners?	Y/N
	Comments	_____

DEVELOPING THE LETTER OF INTENT (LOI) OR EXPRESSION OF INTEREST (EOI)

Skip the following questions in this section if the patient/caregiver partners joined the team during the application phase or after the project was funded.

32	A Letter of Intent or Expression of Interest was required.	Y/N

If you answered "No" to question 32, skip the following questions and go to question 35.

33	Was there enough time for patient/caregiver partners to learn about the project and get to know the other team members prior to submitting the Letter of Intent or Expression of Interest?	Y/N/Not applicable
34	Did your team send copies of the Letter of Intent or Expression of Interest drafts to patient/caregiver partners for review?	Y/N/Not applicable

DEVELOPING THE APPLICATION

Skip the following questions in this section if the patient/caregiver partners joined the team after the project was funded.

35	Were the patient/caregiver partners actively involved in discussing the application?	Y/N
36	Is working on the application a task that you think a patient/caregiver partner on the team should do?	(*Use a 7 point scale*) (1) Never --- (7) Definitely
	Comments	_____

If you answered "No" to question 35, skip the following questions and go to question 43.

37	Was there enough time for you to get to know the patient/caregiver partners prior to submitting the application?	Y/N
38	Were you invited to participate in a strengthening workshop put on by the funder to improve the application?	Y/N
39	Did your team send copies of the funding application drafts to patient/caregiver partners for review?	Y/N

40	Were patient/caregiver partners involved in the development and wording of the research question?	Y/N
	Is this work you think patient/caregiver partners should do?	(*Use a 7 point scale*) (1) Never --- (7) Definitely
41	Were the patient/caregiver partners asked to draft the Patient Engagement section of the application?	Y/N
	Comments	_____
42	Is writing parts of the application the sort of work you think patient/caregiver partners should be doing ?	(*Use a 7 point scale*) (1) Never --- (7) Definitely
	Comments	_____

DEVELOPING THE PROJECT

43	Did you use a Planning Guideline tool to discuss the elements of the project with the patient/caregiver partners?	Y/N
	Comments	_____
44	How involved were the patient/caregiver partners in discussing the project with you?	(*Use a 7 point scale*) (1) Not involved --- (7) Highly involved
	Provide details	_____
45	During the planning of the research, did the patient/caregiver partners participate and contribute to the following: (*Pick all that apply*)	• Designing the methodology • The way patients, caregivers or patient data are to be handled • Planning the approach to patient engagement • Planning the approach to recruiting patients/ caregiver as <u>panelists</u> to advise the research team • Planning the approach to recruiting of patients/caregivers as <u>subjects</u> of the research • Planning for how the results of the research will become known

		• Deciding who are the key people who should get these results (KT) • Planning for the preparation of materials for either panelists or for patients or caregivers who were subjects of the research • Writing parts of the application beyond merely providing feedback on the drafts provided by you
46	To what degree were the patient/caregiver partners involved in any discussions around the outcomes expected from this research?	(*Use a 7 point scale*) (1) Not involved --- (7) Highly involved
	Is this work you think patient/caregiver partners should do?	(*Use a 7 point scale*) (1) Never --- (7) Definitely
47	Did your research team require the following from the patient/caregiver partners: *(Pick all that apply)*	• Letter of Support from the organization that put them forward as a patient partner candidate • Testimonial personally
48	Did you require them to provide a CIHR CCV? *(This is a specialized CV or bio entered into the CIHR - Canadian Institutes of Health Research - website.)*	Y/N
	If yes, did the team provide help to the patient/caregiver partner? *(Select one)*	• Created CCV for the patient/caregiver partner • Provided help in creating the CCV
	Comments	_____
49	Were the patients/caregivers required to complete an ethics course and/or provide ethics certification? *(example: TCPS-2 the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans series of modules)*	Y/N
	Comments	_____

50	If your application was not funded, was the patient engagement strategy cited as a reason for this?	Y/N/NA
	If yes, what were the limitations of the patient engagement strategy that were identified?	_____

GETTING STARTED ON THE FUNDED PROJECT

Once the funding was granted:

51	Was there enough time for patient/caregiver partners to learn about the project prior to starting the project?	Y/N
	Comments	_____
52	Was there enough time for patient/caregiver partners to get to know the team and vice versa prior to starting the project?	Y/N
	Comments	_____
53	Did you provide the patient/caregiver partners with the final, accepted funding application?	Y/N

SUPPORTING PATIENT/CAREGIVER PARTNERS

54	Were the meetings scheduled with consideration to the schedule and timeframes of the patient/caregiver partners?	Y/N
55	Do you work with the patient/caregiver partner(s) to accommodate for their challenges and ensure that it is easy for them to participate? *(Example: Some patients and caregivers have challenges getting around because of fatigue, difficulty walking or seeing to find their way, or they use a mobility device like a wheelchair. Some need help providing transport or help with caring for a loved one.)*	Y/N
	Comments	_____
56	Did you invite patient/caregiver partners to attend in-person meetings when they are held out of town?	Y/N
57	If yes, does the team handle and pay all hotel and transportation arrangements for patient/caregiver partners? *(Example: Book and pay for the hotel and travel in advance)*	Y/N
	Comments	_____

COMPENSATION (NOT EXPENSES)

58	Have you budgeted for patient/caregiver compensation?	Y/N
59	Has the team and/or the PI discussed compensation with the patient/caregiver partners?	Y/N
60	What sort of compensation has been offered? *(Select one)*	• Gift card • Honoraria or one time payment • Regular salary or regular payments for the duration of the project • Other _____
61	Have you provided compensation to your patient/caregiver partners yet?	Y/N
	Comments	_____

HANDLING EXPENSES

62	In your opinion, is administering the expenses an issue for your patient/caregiver partners?	Y/N
	Comments	_____
63	What expenses does the team cover for patient/caregiver partners? *(Select all that apply)*	• Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children • Assistance to care for patient if the partner is a caregiver
	Comments	_____
64	How quickly are expenses repaid?	• On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____

65	Are you providing administrative help to patient/caregiver partners in managing the expense form and submitting it?	Y/N

YOUR OVERALL ASSESSMENT

Please let us know what you think of the involvement of patient/caregiver partners on this project to date.

66	In your opinion, have the insights and comments of the patient/caregiver partners impacted the decisions of the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
67	Have the patient/caregiver partners shared their personal experience as a patient or caregiver?	Y/N
68	Did sharing your experience have a positive impact on the work of the research team?	
	Comments	_____
69	Do you feel you and your team are well prepared to work with patient/caregiver partners on this research team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
70	What 3 things did you learn from the experience of partnering with patients/caregivers?	* _____ * _____ * _____
71	What 3 things could the research team have done to improve the experience?	* _____ * _____ * _____
72	Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
73	Do you feel your patient/caregiver partners are equipped to contribute to your research project?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____

A BIT ABOUT YOURSELF

Please tell us a bit about who you are and why you wanted to be involved in research.

74	Where are you in your career as a researcher? *(Select one)*	• Junior • Mid-career • Senior researcher
75	What is your background? *(Select one)*	• Clinician • Researcher • Clinician/researcher • Other _____
76	Have you ever been: *(Pick all that apply)*	• a patient • a caregiver
77	What was the primary reason to have patient/caregiver partners? *(Select one)*	• Required by funder • Felt patients and caregivers would add value • Not my decision • Other
	Comments	_____

Mid Project Survey

Questions for Researchers Partnering with Patients

Help us to understand your experience of partnering with patients and caregivers on a research team so we can learn what partners could use for support in future. This is the second of 3 surveys we are asking you to complete: An initial one early in the research project, one during the middle of the project and one near the end when the results are done and being sent out.

[Option: Pre-populate form with answers from the first survey based on the unique identifier provided and ask to verify.]

PATIENT/CAREGIVER PARTNERS

Please verify or update your answers from the previous survey.

1	What is the project or topic name?	_____
2	How many patient/caregiver partners are on your research team at this time?	_____
3	When your patient/caregiver partners started with the team, at what stage was the project? (*Select one*)	• Working on the LOI (Letter of Intent) or EOI (Expression of Intent) • Working on the application • Funding received and project in process

UNDERSTANDING ROLES

Please verify or update your answers from the previous survey.

4	Did you have a discussion with the patient/caregiver partners about their role on the team?	Y/N
5	In your opinion, do the patient/caregiver partners understand the roles of the other member of the team?	Y/N
	Comments	_____
6	Has the patient/caregiver partner role changed from how it was defined initially?	Y/N/Not initially defined
	If so, how?	_____

PARTICIPATING ON THE PROJECT TEAM

Please verify or update your answers from the previous survey.

7	Do you think the patient/caregiver partners are comfortable with their understanding of the project at this time?	(*Use a 7 point scale*) (1) Very uncomfortable --- (7) Very comfortable
8	On which of the following did the patient/caregiver partners participate? (*Pick all that apply*)	• Steering committee • Executive committee • Recruitment committee • Operations committee • Main team • Patient engagement committee • Other _____ • Don't know
9	Did the patient/caregiver partners attend every meeting they were invited to up to now?	Y/N/Don't know
	Comments	_____
10	Did the patient/caregiver partners speak up and contribute at most meetings?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	If not, in your opinion, why not?	_____
11	Did you feel you and the team listened to and absorbed the input from the patient/caregiver partners to date?	(*Use a 7 point scale*) (1) Not at all ---(7) Definitely
	Comments	_____
12	Did any of the researchers on the team have problems dealing with patient/caregiver partners to date?	Y/N
	What was the nature of the problem?	_____
13	If there were problems, how was this handled by the PI?	_____
14	If there were problems, how was this handled by the patient/caregiver partners?	_____
15	Did the patient/caregiver partners express any concerns about how they were being treated by other members of the team to date?	Y/N
	If so, please describe	_____

PATIENT/CAREGIVER PANEL

16	Did your project use a patient/caregiver advisory panel?	Y/N
	Comments	_____

If you answered "No" to question 16, skip the following questions and go to question 20.

17	Did or will the patient/caregiver partners help create materials for panelists?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	*(Use a 7 point scale)* (1) Not at all ---(7) Definitely
18	Are the patient/caregiver partners helping to recruit patients/caregivers for a panel?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	*(Use a 7 point scale)* (1) Not at all ---(7) Definitely
19	Did or will the patient/caregiver partners help screen the panelists and/or orient them to the project?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	*(Use a 7 point scale)* (1) Not at all ---(7) Definitely

PATIENT PARTNER CONTRIBUTION TO THE PHASES OF THE RESEARCH

20	Did your project use patients or caregivers as subjects? *(NOTE: Some research relies on administrative data only and does not use patients or caregivers as subjects)*	Y/N
	Comments	_____

If you answered "No" to question 20, skip the following questions and go to question 23.

21	Did the patient/caregiver partners discuss and help decide how patient/caregiver subjects will be communicated with?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	*(Use a 7 point scale)* (1) Not at all ---(7) Definitely

22	Did or will the patient/caregiver partners help create materials for patients or caregivers who were subjects of the research?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	(*Use a 7 point scale*) (1) Not at all ---(7) Definitely

SUPPORTING PATIENT/CAREGIVER PARTNERS

Please verify or update your answers from the previous survey.

23	Were the meetings scheduled with consideration to the schedule and timeframes of the patient/caregiver partners?	Y/N
24	Do you work with the patient/caregiver partner(s) to accommodate for their challenges and ensure that it is easy for them to participate? *(Example: Some patients and caregivers have challenges getting around because of fatigue, difficulty walking or seeing to find their way, or they use a mobility device like a wheelchair. Some need help providing transport or help with caring for a loved one.)*	Y/N
	Comments	_____
25	Did you invite patient/caregiver partners to attend in-person meetings when they are held out of town?	Y/N
26	If yes, does the team handle and pay all hotel and transportation arrangements for patient/caregiver partners? *(Example: Book and pay for the hotel and travel in advance)*	Y/N
	Comments	_____

HANDLING EXPENSES

Please verify or update your answers from the previous survey.

27	In your opinion, is administering the expenses an issue for your patient/caregiver partners?	Y/N
	Comments	_____
28	What expenses does the team cover for patient/caregiver partners? *(Select all that apply)*	• Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children

		• Assistance to care for patient if the partner is a caregiver
	Comments	_____
29	How quickly are expenses repaid?	• On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____
30	Are you providing administrative help to patient/caregiver partners in managing the expense form and submitting it?	Y/N

YOUR OVERALL ASSESSMENT

Please let us know what you think of the involvement of patient/caregiver partners on this project to date.

31	In your opinion, have the insights and comments of the patient/caregiver partners impacted the decisions of the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
32	Have the patient/caregiver partners shared their personal experience as a patient or caregiver?	Y/N
33	Did sharing your experience have a positive impact on the work of the research team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
34	Do you feel you and your team were well prepared to work with patient/caregiver partners on this research team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
35	What 3 things did you learn so far from the experience of partnering with patients/caregivers?	* _____ * _____ * _____

36	What 3 things could the research team have done to improve the experience?	* _____ *_____ *_____
37	Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project to date?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
38	Do you feel your patient/caregiver partners are equipped to contribute to your research project?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____

End Project Survey

Questions for Researchers Partnering with Patients and Caregivers

Help us to understand your experience of partnering with patients and caregivers on a research team so we can learn what partners could use for support in future. This is the third of 3 surveys we are asking you to complete: An initial one early in the research project, one during the middle of the project and one near the end when the results are done and being sent out.

[Option: Pre-populate form with answers from the first survey and ask to verify.]

PATIENT/CAREGIVER PARTNERS

Please verify or update your answers from the previous survey.

1	What is the project or topic name?	_____
2	How many patient/caregiver partners are on your research team at this time? *(Do not include patients/caregivers on an advisory panel)*	_____
3	When your patient/caregiver partners started with the team, at what stage was the project? (Select one)	• Working on the LOI (Letter of Intent) or EOI (Expression of Intent) • Working on the application • Funding received and project in process

UNDERSTANDING ROLES

Please verify or update your answers from the previous survey.

4	Did you have a discussion with the patient/caregiver partners about their role on the team?	Y/N
5	In your opinion, do the patient/caregiver partners understand the roles of the other members of the team?	Y/N
	Comments	_____
6	Has the patient/caregiver partner role changed from how it was defined initially?	Y/N/Not initially defined
	If so, how?	_____

PARTICIPATING ON THE PROJECT TEAM

Please verify or update your answers from the previous survey.

7	Do you think the patient/caregiver partners are comfortable with their understanding of the project at this time?	Y/N/Don't know
8	On which of the following were the patient/caregiver partners? *(Pick all that apply)*	• Steering committee • Executive committee • Recruitment committee • Operations committee • Main team • Patient engagement committee • Other _____ • Don't know
	Comments	_____
9	Did the patient/caregiver partners attend every meeting they were invited to up to now?	Y/N/Don't know
	Explain	_____
10	Did the patient/caregiver partners speak up and contribute at most meetings?	*(Use a 7 point scale)* (1) Not at all --- (7) Definitely
	If not, in your opinion, why not?	_____
11	Did you feel you and the team listened to and absorbed the input from the patient/caregiver partners?	*(Use a 7 point scale)* (1) Not at all --- (7) Definitely
	Comments	_____
12	Did any of the researchers on the team have problems dealing with patient/caregiver partners to date?	Y/N
	What was the nature of the problem?	_____
13	If there were problems, how was this handled by the PI?	_____
14	If there were problems, how was this handled by the patient/caregiver partners?	_____
15	Did the patient/caregiver partners express any concerns about how they were being treated by other members of the team to date?	Y/N
	If so, please describe	_____

PATIENT PARTNER CONTRIBUTION TO THE PHASES OF THE RESEARCH

16	Did the patient/caregiver partners review and discuss the findings of the research prior to the final report?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely

If you answered "No" to question 15, skip the following questions and go to question 17.

17	Did the patient/caregiver partners' comments affect the final outcome of report?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely

SPREADING THE KNOWLEDGE

18	Did or will the patient/caregiver partners co-present the results of the research, or their perspective on the research, by being on panels and speaking at conferences?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
19	Did or will the patient/caregiver partners co-author a "lay" report about the research?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
20	Were the patient/caregiver partners asked to use their contacts to send the results of the research to a wider audience?	Y/N
	Is this work you think they should be doing as a patient/caregiver partner on the team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
21	Describe any other activity that the patient/caregiver partners participated in?	_____

SUPPORTING PATIENT/CAREGIVER PARTNERS

Please verify or update your answers from the previous survey.

22	Were the meetings scheduled with consideration to the schedule and timeframes of the patient/caregiver partners?	Y/N
23	Do you work with the patient/caregiver partner(s) to accommodate for their challenges and ensure that it is easy for them to participate? *(Example: Some patients and caregivers have challenges getting around because of fatigue, difficulty walking or seeing to find their way, or they use a mobility device like a wheelchair. Some need help providing transport or help with caring for a loved one.)*	Y/N
	Comments	_____
24	Did you invite patient/caregiver partners to attend in-person meetings when they are held out of town?	Y/N
25	If yes, does the team handle and pay all hotel and transportation arrangements for patient/caregiver partners? *(Example: Book and pay for the hotel and travel in advance)*	Y/N
	Comments	_____

HANDLING EXPENSES

Please verify or update your answers from the previous survey.

26	Is administering the expenses an issue for your patient/caregiver partners?	Y/N
	Comments	_____
27	What expenses does the team cover for patient/caregiver partners? *(Select all that apply)*	• Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children • Assistance to care for patient if the partner is a caregiver
	Comments	_____

28	How quickly are expenses repaid?	• On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____
29	Are you providing administrative help to patient/caregiver partners in managing the expense form and submitting it?	Y/N

YOUR OVERALL ASSESSMENT

Please let us know what you think of the involvement of patient/caregiver partners on this project to date.

30	In your opinion, have the insights and comments of the patient/caregiver partners impacted the decisions of the team?	Y/N
	Comments	_____
31	Have the patient/caregiver partners shared their personal experience as a patient or caregiver?	Y/N
32	Did sharing your experience have a positive impact on the work of the research team?	(*Use a 7 point scale*) (1) Not at all --- (7) Definitely
	Comments	_____
33	Do you feel you and your team were well prepared to work with patient/caregiver partners on this research team?	(*Use a 7 point scale*) *(1) Not at all --- (7) Definitely*
	Comments	_____
34	What 3 things did you learn from the experience of partnering with patients/caregivers?	* _____ *_____ *_____
35	What 3 things could the research team have done to improve the experience?	* _____ *_____ *_____

36	Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project?	(*Use a 7 point scale*) (*1) Not at all --- (7) Definitely*
	Comments	_____
37	Do you feel your patient/caregiver partners are equipped to contribute to your research project?	(*Use a 7 point scale*) (*1) Not at all --- (7) Definitely*
	Comments	_____
38	Where do you think their involvement mattered the most?	_____
39	Do you have any concerns about partnering with patients and/or caregivers at this point?	Y/N
	If so, what are they?	_____
	Comments	_____